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Original Papers

Viewpoint

Original Paper

Internet Cognitive Behavioral Therapy for Women With Postnatal Depression: A Randomized Controlled Trial of MumMoodBooster

Jeannette Milgrom[1,2,3], PhD; Brian G Danaher[4], PhD; Alan W Gemmill[1], PhD; Charlene Holt[1], DClinPsy; Christopher J Holt[1], PhD; John R Seeley[4], PhD; Milagra S Tyler[4], MA; Jessica Ross[1], DPsych; Jennifer Ericksen[1], MPsych

[1]Parent-Infant Research Institute, Melbourne, Australia

[2]University of Melbourne, Melbourne School of Psychological Sciences, Melbourne, Australia

[3]Austin Health, Department of Clinical and Health Psychology, Melbourne, Australia

[4]Oregon Research Institute, Eugene, OR, United States

Corresponding Author:
Alan W Gemmill, PhD
Parent-Infant Research Institute
Department of Clinical & Health Psychology, Heidelberg Repatriation Hospital Austin Health 330 Waterdale Road Heidelberg Heights
Melbourne, 3081
Australia
Phone: 61 03 9496 ext 4468
Fax: 61 03 9496 4148
Email: alan.gemmill@austin.org.au

Abstract

Background: There are few published controlled trials examining the efficacy of Internet-based treatment for postnatal depression (PND) and none that assess diagnostic status (clinical remission) as the primary outcome. This is despite the need to improve treatment uptake and accessibility because fewer than 50% of postnatally depressed women seek help, even when identified as depressed.

Objective: In a randomized controlled trial (RCT), we aimed to test the efficacy of a 6-session Internet intervention (the MumMoodBooster program, previously evaluated in a feasibility trial) in a sample of postnatal women with a clinical diagnosis of depression. The MumMoodBooster program is a cognitive behavioral therapy (CBT) intervention, is highly interactive, includes a partner website, and was supported by low-intensity telephone coaching.

Methods: This was a parallel 2-group RCT (N=43) comparing the Internet CBT treatment (n=21) to treatment as usual (n=22). At baseline and at 12 weeks after enrollment, women's diagnostic status was assessed by telephone with the Standardized Clinical Interview for DSM-IV (SCID-IV) and symptom severity with the Beck Depression Inventory (BDI-II). Depression symptoms were measured repeatedly throughout the study period with the Patient Health Questionnaire (PHQ-9).

Results: At the end of the study, 79% (15/19) of women who received the Internet CBT treatment no longer met diagnostic criteria for depression on the SCID-IV (these outcome data were missing for 2 intervention participants). This contrasted with only 18% (4/22) remission in the treatment as usual condition. Depression scores on the BDI-II showed a large effect favoring the intervention group (d=.83, 95% CI 0.20-1.45). Small to medium effects were found on the PHQ-9 and on measures of anxiety and stress. Adherence to the program was very good with 86% (18/21) of users completing all sessions; satisfaction with the program was rated 3.1 out of 4 on average.

Conclusions: Our results suggest that our Internet CBT program, MumMoodBooster, is an effective treatment option for women clinically diagnosed with PND. This is one of only two controlled evaluations of specialized online psychological treatment among women clinically diagnosed with PND. MumMoodBooster appears to be a feasible, effective treatment option, which is potentially accessible to large numbers of women in metropolitan, rural, and remote areas. Future work might be focused profitably on establishing comparability with face-to-face treatments and purely self-guided delivery. We have commenced a larger RCT comparing MumMoodBooster with face-to-face CBT.

Trial Registration: Australian and New Zealand Clinical Trials Registry (ANZCTR): ACTRN12613000113752; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=363561 (Archived by WebCite® at http://www.webcitation.org/6f64kuyLf).

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KEYWORDS

postnatal depression; postpartum depression; cognitive behavioral therapy; Internet-based intervention; randomized controlled trial

Introduction

Approximately 13% of women suffer postnatal depression (PND) by the time their baby is 3 months old [1]. PND, defined as an episode of major or minor depression beginning in the first year postbirth, lies between "baby blues" and postpartum psychosis in severity and prevalence. Left untreated, PND has significant deleterious effects on the mother (her mental health, her relationship with her infant, her potentially suicidal behavior), her family (interrupted employment, partner's mental health, relationship problems), and her child's development [2-4]. Yet despite the existence of effective treatments for depression, fewer than 50% of postnatal women seek or accept help, even when identified as depressed [5,6]. Barriers to help seeking and treatment uptake include perceived stigma, fear of being judged a "bad mother," lowered motivation toward help seeking due to symptoms (eg, fatigue, feelings of hopelessness), concerns about medication while breastfeeding, unequal availability of clinic-based services in remote and rural areas, and logistical difficulties in attending face-to-face clinic counseling with a young infant [7-9]. Further, for most postnatal women, psychotherapy is preferred to pharmacotherapy in the treatment of mental health difficulties often due to concerns over breastfeeding [10]. As pointed out in previous work [11-13], the rapid growth of eHealth offers a psychological treatment model that can potentially reduce or obviate many of these barriers for postnatal women.

Internet Interventions for Postnatal Depression

Encouraging results of online intervention for problems including panic disorder, anxiety, posttraumatic stress [14-17], and depression have been reported [14,18,19] and such treatments can have similar efficacy to face-to-face therapy [19-23]. Reviews of the evidence report that although self-guided interventions for depression have benefit to users [14,18,19], even low-intensity guided support from coaches or therapists helps to increase adherence to online mental health treatments [24,25]. Typically, therapeutic effects can be achieved by online interventions that offer low-intensity guidance of less than 3 contact hours in a 6-week program. Guided support can also provide a secondary "safety net" for individuals whose symptoms deteriorate during online treatment.

We developed a PND intervention (MumMoodBooster) with low-intensity guided support based on cognitive behavioral therapy (CBT), which is an established treatment of choice for depressive disorders with its efficacy supported by much research [26,27]. MumMoodBooster was adapted from our Getting Ahead of Postnatal Depression program, which is specifically adapted for the needs of postnatal women (eg, presenting behavioral strategies before cognitive content. Postnatally depressed women, overwhelmed by the demands of infant care, are often not ready to engage in cognitive tasks prior to some behavior change [28]). Previously, we have reported fully on the formative development and systematic usability testing of the MumMoodBooster program [11]. The program developmental process followed an iterative staged approach [29] recommended for development and testing of behavioral interventions [30,31]. We have also demonstrated clinical efficacy in an uncontrolled feasibility trial [13], which showed excellent adherence and acceptability. Of all users, 87% completed all six program sessions; of those women meeting diagnostic criteria for depression at baseline, 90% no longer met criteria after treatment [13].

MumMoodBooster is now one of two evaluated Internet interventions for PND. O'Mahen and colleagues have also developed and tested Netmums, a guided online behavioral activation (BA) treatment [12,32]. MumMoodBooster is a briefer intervention, (6 sessions vs 12 in Netmums) and includes cognitive therapy as well as BA, but both programs include regular telephone support. This is accomplished by a low-intensity, nontherapeutic coaching role in the case of MumMoodBooster and more frequent calls by mental health workers trained in a "high-intensity perinatal-specific BA approach" in the case of Netmums. In the antenatal period, a recently pilot-tested computerized CBT intervention for depression among pregnant women has also shown significant improvements on self-report psychometric measures [33].

Here we report on the efficacy of the MumMoodBooster intervention delivered with low-intensity guided telephone support in a randomized controlled trial (RCT) compared to a treatment as usual (TAU) condition. We included a sample of women diagnosed with a depressive disorder and reassessed diagnostic status 12 weeks after enrollment. We hypothesized that MumMoodBooster would lead to a reduction in depressive symptomatology and an increased rate of remission from the diagnosed depressive episode compared to TAU. Current evidence points to similar potential for efficacy between online and face-to-face CBT for depression in general. Our study sought first to establish whether a PND-specific online CBT program is clinically effective compared to TAU care practices.

Methods

Design

This was a parallel 2-group RCT comparing MumMoodBooster to TAU. The main outcomes were remission from the depressive episode and severity of symptoms of depression at 12 weeks postenrollment. See Multimedia Appendix 1 for the study's CONSORT-EHEALTH checklist [68].

Ethics

The study was approved by the Austin Health Human Research Ethics Committee (approval number H2012/04682) and informed consent was obtained from all participants.

Recruitment

Recruitment occurred between March 2013 and July 2014. Participants were women resident in Australia aged 18 years and older with a child aged less than 1 year. A stepped process was used to recruit eligible participants: initial screening, clinical assessment, baseline data acquisition, and randomization. The research project was available to women across Australia, in both rural and metropolitan areas. Marketing focused on Internet campaigns using Google AdWords, Facebook, and Twitter. The project was also advertised to Maternal and Child Health Centres in Melbourne who were encouraged to direct clients to the project. Messages prompted interested individuals to obtain more information and to begin a screening process by visiting the secure project recruitment website or to call project staff directly.

Screening

Screening criteria were determined online as follows: Australian residency, 18 years of age or older, English speaking, less than 1 year postpartum, Internet access with regular email use, an Edinburgh Postnatal Depression Scale (EPDS) [34,35] score of 11 to 23, no current treatment for depression (medication or psychotherapy), and a score of less than 3 on item #10 of the EPDS (indicating frequent thoughts of self-harm).

Individuals who satisfied screening criteria were emailed a participant information and consent form to complete and return by email. Consenting women were subsequently telephoned by a psychologist/psychology trainee to explain the study and to schedule a clinical assessment. At this stage, women who scored 1 to 2 on item #10 of the EPDS were asked a series of questions following the risk assessment protocol of Simon and colleagues [36] to determine intent, lethality, access to means, and history of suicide attempts. Those deemed to be at risk for suicide were excluded and referred to receive immediate crisis attention.

Clinical Assessment and Inclusion/Exclusion Criteria

Following initial telephone contact, eligible consenting women were assessed by telephone by a clinical psychologist/psychology trainee using the Structured Clinical Interview for *DSM-IV* (SCID-IV) [37,38]. Inclusion criteria based on the SCID-IV assessment were (1) meeting criteria for a major depressive disorder or (2) meeting criteria for a minor depressive disorder. Exclusion criteria were (1) current substance abuse, (2) current and past manic/hypomanic symptoms, (3) posttraumatic stress disorder, (4) alcohol abuse or dependence, (5) depression with psychotic features, (6) risk of suicide as per risk protocol, and (7) current active treatment for depression (medication or psychotherapy). All assessed women were asked to nominate a contact health professional (eg, a general practitioner) to whom the project could send notification of her diagnosis.

Baseline

Women satisfying all eligibility criteria were told verbally about the unique log-in they could use to complete the baseline (prerandomization) questionnaires.

Randomization

Women who completed the baseline assessment questionnaires were randomized immediately online to either MumMoodBooster or to TAU. The randomization procedure used a 1:1 allocation ratio and a pregenerated permuted blocks allocation schedule with the sequence concealed from the researchers consistent with CONSORT standards [39]. Treatment allocation to condition was revealed in a phone call. Women allocated to MumMoodBooster were told verbally about how to begin accessing the program. Given the nature of the intervention, participants could not be blinded to treatment beyond the point of allocation.

Treatment Conditions

MumMoodBooster

The structure and content of the MumMoodBooster intervention and its associated websites (partner's website, coach's website, administrative website) have been described in detail elsewhere [13]. Figure 1 shows the structure of the MumMoodBooster program.

Treatment consisted of six interactive sessions that were sequentially accessed and designed to encourage optimal engagement and behavior change. For illustration, Multimedia Appendix 2 contains a selection of screenshots from the program. Each session began with an autoplay video introducing session goals and content. Each session presented content using text, animations, video introductions and case vignettes, and audio and video tutorials. The program encouraged participants to personalize their program content, for example by typing in personal lists of pleasant activities, typing in personal goals, and uploading their own photos to be displayed on program webpages. Users could view online and print out a personal workbook summarizing their personalized content. For example, the "my workbook" function gave users feedback on specific strategies that they themselves had identified as helpful together with reminders of how to bring them into play at the earliest warning signs. Self-monitoring tools required participants to enter their own mood and activity data and enabled daily tracking and online charting of both mood and pleasant activities (Figure 2).

Initial steps of the program provided explicit direction, whereas later steps encouraged participants to assume greater responsibility for managing their own plan for change. Later sessions commenced by reviewing previous material before presenting new content and concepts. The program's charting function was used to help participants see the functional relation of mood and activity levels. Information from past sessions was used to reinforce gains made, to tailor subsequent program content, and to provide ipsative feedback. Although participants were allowed to set their own pace, of particular importance because women with PND are often overwhelmed by the demands of infant care, the program encouraged the completion of all six sessions at a rate of one session per week. A printable summary was used to describe key content covered in each session and provided a tailored list of recommended home practice activities. Participants were also granted unrestricted access to browse additional "library" articles on relevant topics ranging from relaxation, to problem solving, to parenting support resources. Participants also had unrestricted access to a monitored peer-based Web forum on which they could post, read, and comment on messages from other program participants. Additionally, in recognition of the role of women's partners [40], participants received access to a library article on "You and Your Partner" and were able to send an invitation to their partner to access the related partner support website (separate log-in process for partners) with information on PND.

Participants in MumMoodBooster received guided support from a telephone coach to assist and encourage them in their use and practice of particular strategies (coaches were instructed to spend a maximum of 30 minutes per week per participant). There were 7 coaches (3 graduate psychology trainees, 3 clinical psychologists, and 1 health psychologist) who were supported and supervised by 2 senior psychologists. Training for the coaching role involved working through the program (as if they were a participant), reading the coach manual, observing other coaches' complete calls, and a verbal explanation from a senior psychologist about the role and the tasks involved. Content of coaching calls adhered to a manualized script with the defined and limited aims of reinforcing progress; encouraging engagement, practice of strategies, and completion of tasks; and introducing the themes of upcoming sessions. The role of the coaches was only to support mothers in using the program and they were instructed to refrain from giving clinical guidance, but rather to point participants to relevant program content that may address their questions (similar to the "technician" role described by Titov and colleagues [41]). Telephone coaches accessed a secure administrative website to view status reports of participant's program usage to make support and encouragement consistent with progress. Women were also sent automated email prompts as reminders to complete the 12-week online assessment and to encourage visits to the program.

Figure 1. Diagrammatic structure of the MumMoodBooster postnatal depression program.

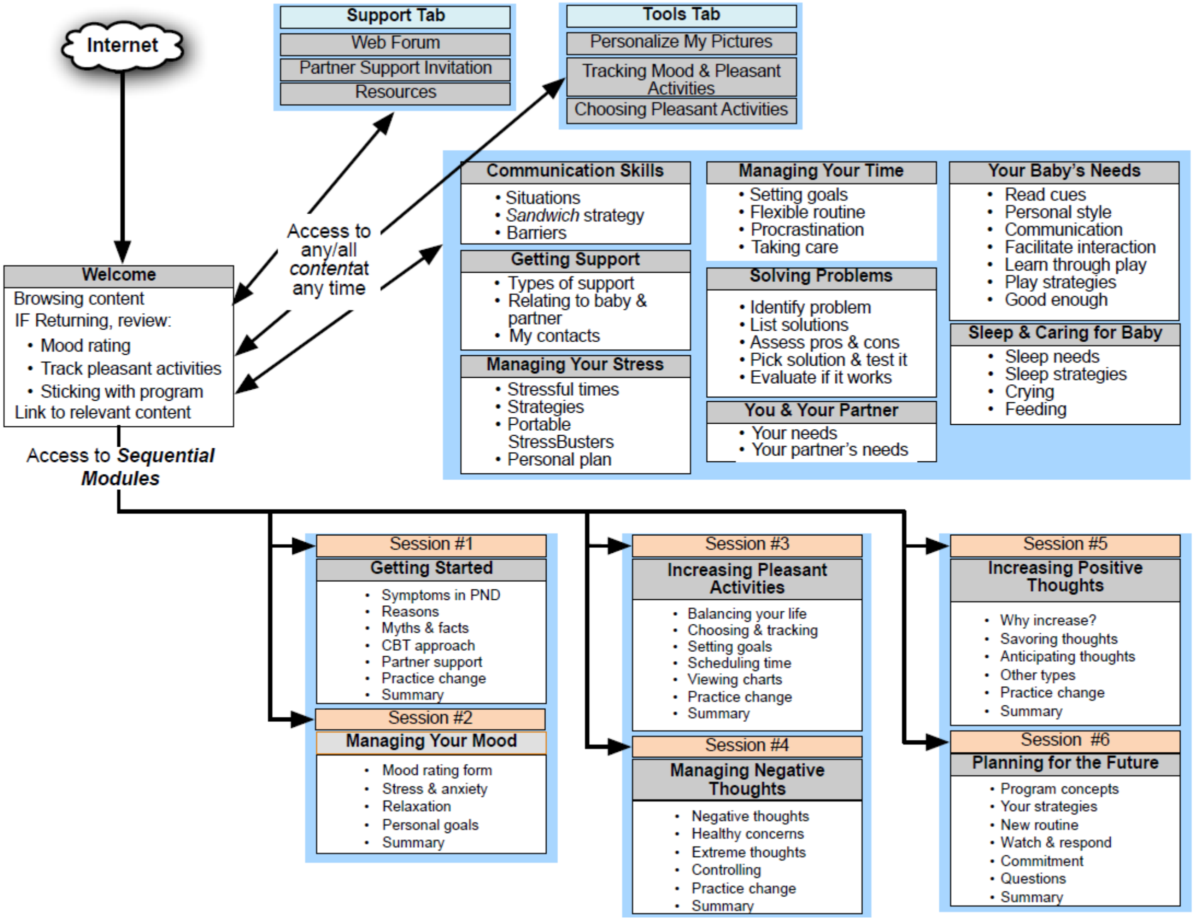
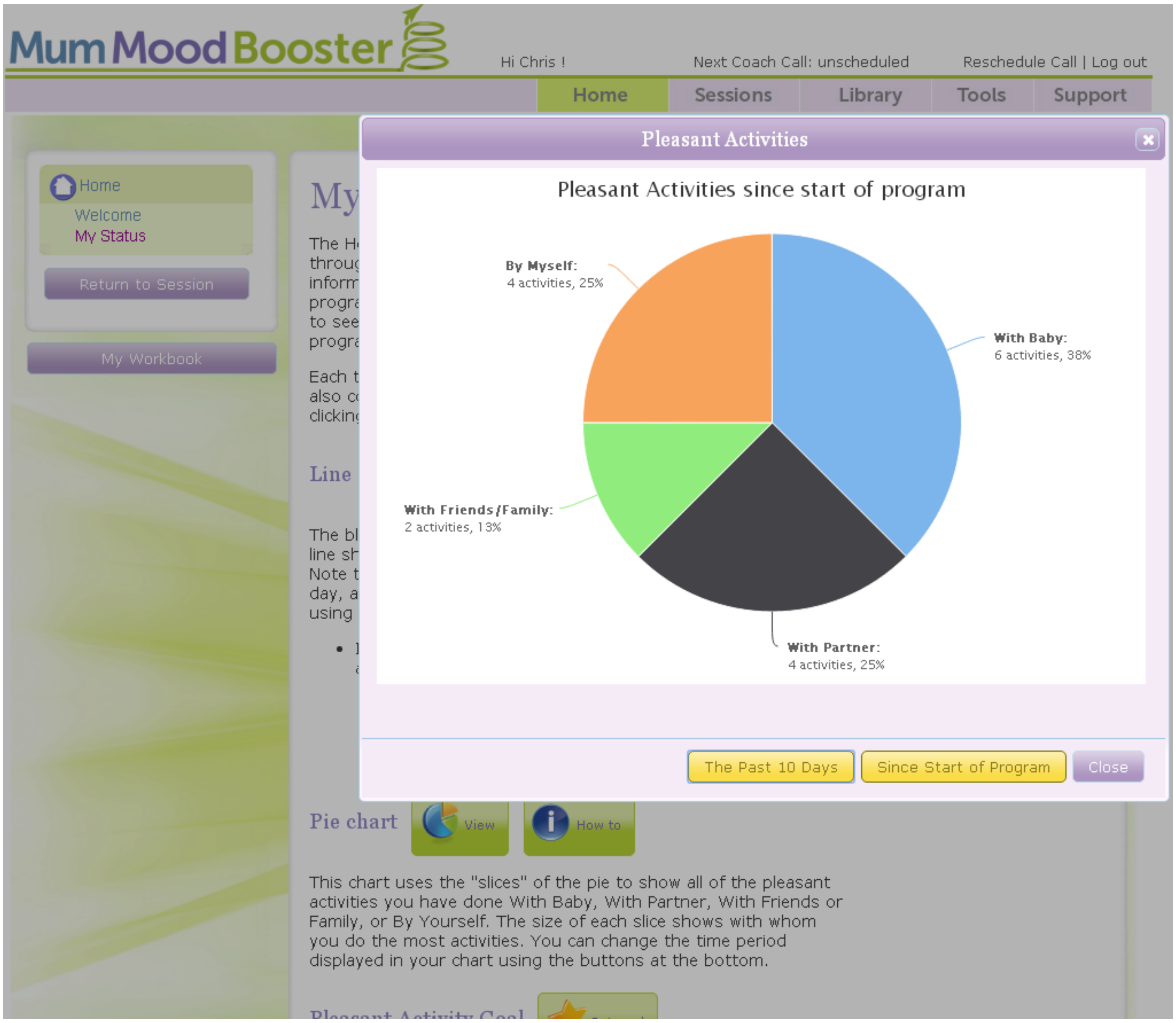


Figure 2. The charting function on a user’s “My Status” page displaying a breakdown of pleasant activities since starting the program.



This chart uses the "slices" of the pie to show all of the pleasant activities you have done With Baby, With Partner, With Friends or Family, or By Yourself. The size of each slice shows with whom you do the most activities. You can change the time period displayed in your chart using the buttons at the bottom.

Treatment as Usual

Participants in the TAU condition received the same clinical assessment as those in the MumMoodBooster condition. In this condition (as for those in the MumMoodBooster condition), women’s nominated health professional received a written notification of the depressive diagnosis that encouraged them to consult with their patient regarding mental health care needs and to form a collaborative care plan with the patient’s other relevant health care practitioners. In most cases, women nominated their Maternal and Child Health Nurse (MCHN) or general practitioner (GP) who were then free to treat or to refer to other services/agencies as they judged appropriate, as would normally happen where specialized programs are not available. Therefore, in practice, TAU varied at the discretion of each participant’s nominated health professional and was expected to include a heterogeneous mix of interventions/supports. TAU participants were also provided with links to general Internet resources on mental health. They also received the email prompts to complete online assessments.

Safety Monitoring

Safety monitoring was used to provide crisis intervention and referrals to mental health specialty care if needed and a reminder of the emergency contacts provided at baseline assessment. For women in the MumMoodBooster condition, these were carried out by the allocated telephone coach. For women in TAU, a separate safety monitor was allocated (from the same pool of staff as the telephone coaches). All study participants were monitored via safety calls on five occasions: at baseline and at weeks 3, 5, and 9 (immediately posttreatment) and at 12 weeks postenrollment. We used the protocol of Simon et al [36] to check for depressive symptoms and adverse events. If women scored 5 points above their baseline PHQ-9 score at any time, or if they responded positively to the PHQ-9 item on thoughts of self-harm, then a risk assessment was conducted. This included asking about suicidal thoughts/thoughts of self-harm, frequency of thoughts, triggers, plans, means, lethality, intention, protective factors, and history of suicide attempts/self-harm behavior.

Measures

Measures were administered via online questionnaire or by telephone. Demographic data (eg, age, parity, education, income) were gathered both during telephone assessment and in the online battery of baseline questionnaires. The key depression measures (described subsequently) are well validated and their psychometric properties are well described in general populations. The performance and psychometric properties of both generic and perinatal-specific depression measures used in the context of perinatal populations have been recently reviewed and were the subject of a full health technology report in 2009 [42,43].

Primary Depression Outcomes

Before completion of baseline questionnaires and at 12 weeks postenrollment, trained diagnostic interviewers conducted the SCID-IV [38] by telephone to determine a *DSM-IV* diagnosis of major depression or minor depression [44]. Diagnostic interviewers were blinded to treatment allocation at the 12-week time point.

At baseline and at 12 weeks postenrollment, severity of depressive symptoms was measured online using the revised Beck Depression Inventory (BDI-II) [45]. The BDI-II is a widely used, well-validated, 21-item clinical instrument that measures cognitive, affective, and physiological factors to assess severity of depression. The BDI-II has been used in many studies of perinatal depression [46-50] and has been validated against gold-standard diagnostic criteria in perinatal populations [47].

Secondary Outcomes

Depressive Symptom Trajectory

Participants completed the 9-item PHQ-9 [51,52] at enrollment and at weeks 3, 5, 9, and 12 postenrollment. The PHQ-9 was administered over the telephone during the routinely scheduled safety monitoring calls.

Anxiety and Stress Symptom Severity

Participants' anxiety and stress symptom severity were measured at baseline and at weeks 9 and 12 using the anxiety and stress scales of the Depression, Anxiety and Stress Scales—Short Form (DASS-21) [53]. The DASS-21 is a 21-item, 4-point Likert-type scale. The anxiety and stress scales each have a maximum score of 42 [53]. The DASS manual [53] provides recommended cut-offs for rating the severity of scores as normal, mild, moderate, severe, or extremely severe.

Negative Thinking

At baseline and at 12 weeks postenrollment, participants were asked to indicate how frequently over the previous week they had negative thoughts using the 30-item Automatic Thoughts Questionnaire (ATQ) [54]. The ATQ asks respondents to rate their agreement with a series of statements (eg, "My life is a mess") using a scale from 1 to 5 (1=not at all; 5=all of the time). Maximum score is 150.

Behavioral Activation

To measure changes in behavior patterns, at baseline and at 12 weeks postenrollment, women completed the 25-item Behavioral Activation for Depression Scale (BADS) [55]. Respondents rate their agreement with a series of statements (eg, "I stayed in bed for too long even though I had things to do") on a scale from 0 to 6 with a maximum total score for the scale of 150.

Relationship With Partner

Women's relationships with their partners were assessed using the abbreviated 7-item version of the Dyadic Adjustment Scale (DAS-7) [56] at baseline and at 12 weeks postenrollment. The general satisfaction score was calculated as the sum of all items. Maximum score is 36.

Self-Efficacy in Parenting Role

At baseline and at 12 weeks postenrollment, we used the Parenting Sense of Competence Scale (PSOC) [57] that asks respondents to rate the extent of their agreement with 7 items designed to assess self-perception of knowledge and competence in the mothering role. Statements (eg, "I honestly believe I have all the skills necessary to be a good mother to my baby") are rated from 1 to 6 (1=strongly disagree; 6=strongly agree). Maximum score is 42.

Engagement in MumMoodBooster Program

Website analytic tools and database flags allowed us to measure MumMoodBooster program usage in an unobtrusive manner, generating records of number and duration of visits to the website and number of program sessions attended.

Treatment Satisfaction and Helpfulness

Satisfaction with the MumMoodBooster program was assessed using a 4-point Likert scale (1=not at all satisfied; 4=very satisfied). Helpfulness of phone coach calls was similarly assessed using a 4-point Likert scale (1=not at all helpful; 4=very helpful).

Use of Other Supports/Treatments

Participants were also asked to provide details of access to other support services and treatments during the study interval.

Statistical Analysis

The primary outcomes were changes in depressive diagnostic status (assessed by the SCID-IV) and depression symptom severity (BDI-II). The categorical outcome (ie, diagnostic status) was analyzed using a contingency table and chi-square test. The continuous outcome (ie, BDI-II) was analyzed in general linear models, which accounted for baseline values as a covariate. Continuous repeated measures data (PHQ-9) were analyzed in mixed-effects growth models using restricted maximum likelihood. Log-likelihood ratio and Akaike information criterion were used to assess model fit.

Consistent with CONSORT standards [58,59], all primary analyses involved planned contrasts of the MumMoodBooster condition versus the TAU control condition with all randomized participants analyzed in their allocated treatment condition. For anxiety and stress symptom severity (DASS-21 Anxiety scale and DASS-21 Stress scale), because transformation failed to improve normality, the nonparametric Mann-Whitney *U* test was used for between-group comparison. Effect sizes were expressed as Cohen's *d* [60] with 95% confidence intervals.

There was some missing data (<5%) on the primary outcomes. Little’s missing completely at random (MCAR) test [61] revealed that these data were missing completely at random (χ^2_{335}=303.56, P=.89). Given the minimal and random nature of missing data, the highly conservative “worst-case” imputation method [41] was used for intention-to-treat analysis. This method replaces missing outcome values in the intervention and control conditions with the least favorable and most favorable scores observed within those respective conditions [41], thus providing a sensitivity analysis of the robustness of the observed treatment effect to type I error [62]. Results are presented on the basis of the intention-to-treat analyses. Computations were executed using IBM SPSS Statistics version 22 (IBM Corp, Armonk, NY, USA).

Power and Sample Size

For the outcome measure of depressive symptom severity (BDI-II), data from a previous trial of CBT [28] for PND provided relevant estimates of variability in baseline scores (mean 23, SD 8.1 points). On this basis, a difference of 6.5 points would be necessary to move mean scores from the “moderately severe” to the “minimal” category of depressive symptoms specified by Beck and colleagues [63] (cut-off between these categories=17 points). We considered this to be the minimum clinically important difference in continuous scores of depression severity [28]. With a power of 0.8 at α=.05, the required $n=15.7(8.09/6.5)^2=24.3$, which rounds to 25 per group. Thus, we aimed for a total sample size of N=50 to achieve sufficient power to detect a clinically important difference in the primary measure of depressive symptom severity.

Results

Sample

A total of 178 women began the study registration process (see Figure 3). By the end of the recruitment period, 43 mothers were randomized (24.2% of registrants) to either the MumMoodBooster condition (n=21) or the TAU condition (n=22). Figure 3 details the reasons for attrition between registration and randomization. Twelve weeks following enrollment, two women in the MumMoodBooster condition failed to complete online assessment questionnaires and telephone diagnostic interviews (all women in TAU completed the 12-week assessments).

Women in the two conditions appeared comparable in terms of baseline characteristics (Table 1). As recommended by the CONSORT Statement [58], no significance tests of between-group differences were conducted on baseline data.

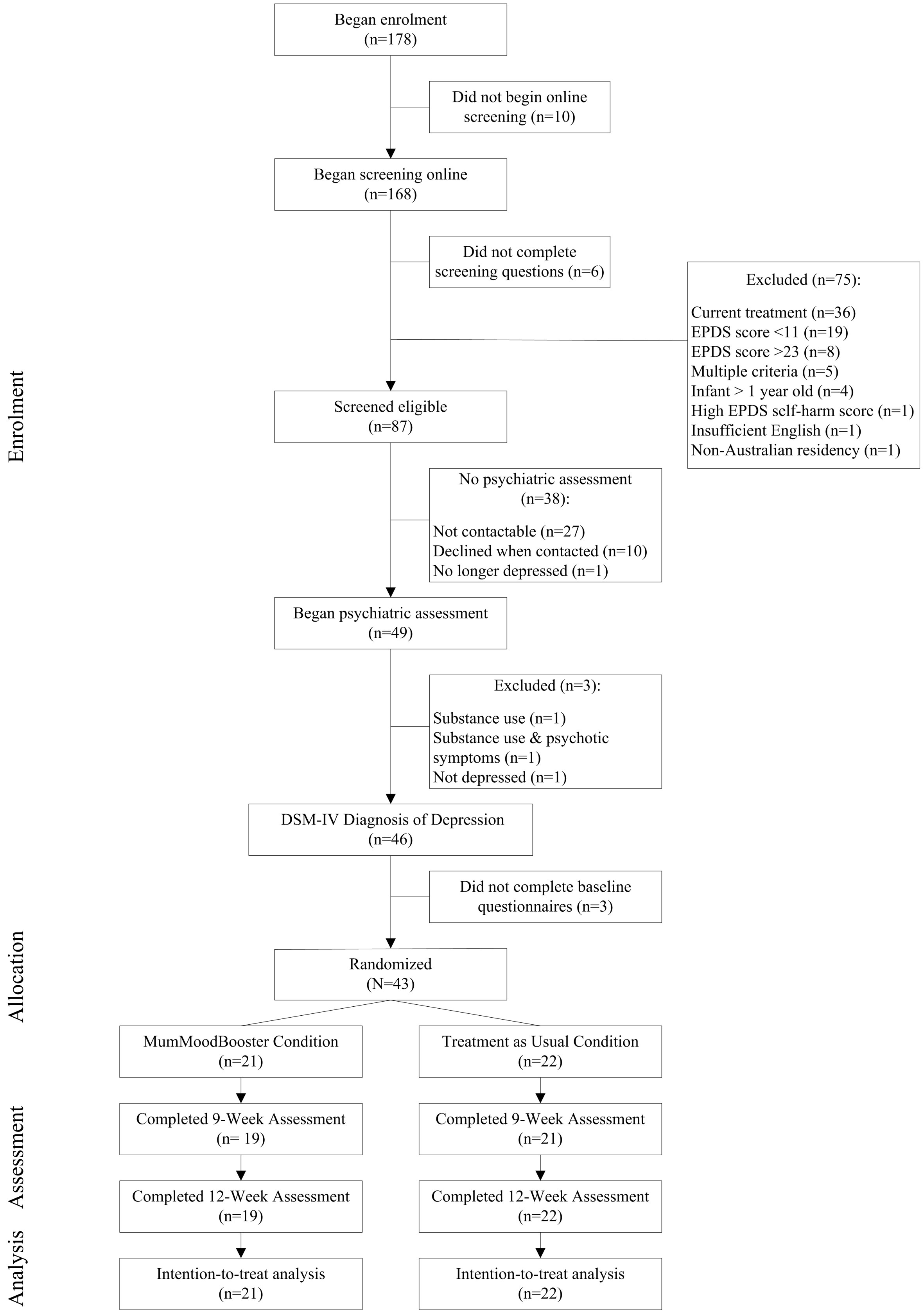
Table 1. Baseline characteristics of participants (N=43).

Characteristic	MumMoodBooster (n=21)	TAU (n=22)
Mother’s age (years), mean (SD)	31.7 (4.6)	31.5 (4.3)
Baby’s age (months), mean (SD)	6.52 (2.8)	6.15 (3.1)
EPDS at screening, mean (SD)	16.6 (3.1)	15.8 (2.8)
Born in Australia, n (%)	18 (86)	21 (96)
Current major depression, n (%)	20 (95)	20 (91)
Current minor depression, n (%)	1 (5)	2 (9)
Past major depression, n (%)	14 (67)	15 (68)
Relationship status, n (%)		
Married/Living with partner	18 (86)	20 (91)
Single	3 (14)	2 (9)
Education, n (%)		
Did not finish school	0 (0.0)	1 (5)
High school only	2 (9)	3 (14)
Certificate level	4 (19)	3 (14)
Diploma level	5 (24)	4 (18)
Undergraduate degree	6 (29)	7 (32)
Postgraduate degree	4 (19)	4 (18)
Number of children (including most recent baby), n (%)		
1	7 (33)	7 (32)
2	7 (33)	11 (50)
≥3	7 (33)	4 (18)
Family income (AUS$), n (%)		
≤$20,000	0 (0)	1 (5)
$20,001-$40,000	0 (0)	1 (5)
$40,001-$60,000	2 (10)	1 (5)
$60,001-$80,000	3 (14)	6 (27)
>$80,000	13 (62)	13 (59)
Not divulged	3 (14)	0 (0)

In the MumMoodBooster condition, 20 of 21 women (95%) were diagnosed with current major depression and 1 of 21 women (5%) with minor depression. In the TAU condition, 20 of 22 women (91%) met diagnostic criteria for current major depression and 2 of 22 women (9%) for minor depression (Table 1).

The mean age of mothers was close to the most recently available Australian national average (30 years [64]) and their infants averaged just over 6 months of age. The sample contained a higher proportion of women born in Australia than the latest national average (national average=70%) and a lower proportion of first-time mothers (national average=43%). The mean EPDS at screening was 16.2 (SD 2.9), similar to the mean observed in other Australian samples of depressed perinatal women [47]. As reported in studies of major risk factors for PND [65], 67.4% (29/43) of the cohort had experienced a past major depressive episode.

Figure 3. CONSORT diagram of participant flow through the study.



Primary Depression Outcomes

In the MumMoodBooster condition, 79% (15/19) of women no longer met *DSM-IV* criteria for depression at 12 weeks; this was 18% (4/22) in the TAU condition. In the intention-to-treat analysis, a chi-square test revealed a statistically significant between-group difference in the frequency of depressive diagnosis (major or minor depression) at 12-week follow-up (Yates corrected χ^2_1=10.3, *P*=.001). Figure 4 shows the proportions on which the intention-to-treat analysis was conducted.

Similarly, women in the MumMoodBooster condition also showed reduced severity of depression symptoms, whereas those in the TAU condition displayed little improvement (see Table 2). After controlling for baseline scores, mean depression symptoms on the BDI-II in the intervention group at 12 weeks were significantly lower than that of the TAU group (*P*=.01) and this represented a large effect size (Table 2). Results for both diagnostic status and BDI-II scores were also statistically significant in observed-case analyses before imputation.

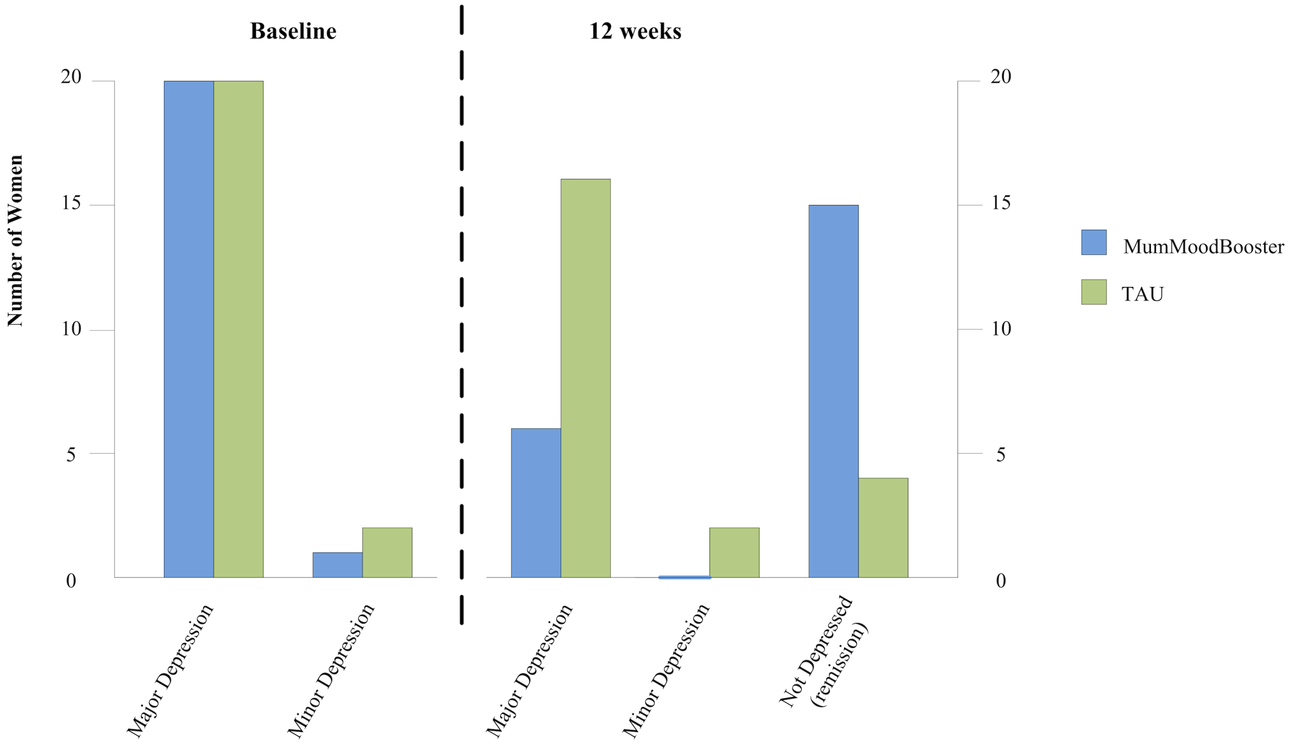
Table 2. Severity of depression, anxiety, and stress symptoms over time.[a]

Outcome measure[b]	MumMoodBooster, mean (SD) n=21	TAU, mean (SD) n=22	$F_{1,40}$	*U*	*P*	*d* (95% CI)
BDI-II						
Baseline	25.3 (6.4)	26.3 (8.6)				
12 weeks	14.5 (12.2)	23.0 (7.5)	7.4		.01	0.83 (0.20, 1.45)
DASS Anxiety						
Baseline	9.0 (7.0)	6.7 (5.3)				
9 weeks	5.0 (6.2)	5.9 (4.3)		176.0	.17	0.18 (–0.42, 0.78)
12 weeks	4.2 (5.5)	5.4 (3.0)		153.0	.05	0.27 (–0.33, 0.87)
DASS Stress						
Baseline	22.1 (8.0)	20.7 (7.2)				
9 weeks	14.2 (9.0)	18.5 (7.1)		142.5	.03	0.54 (–0.07, 1.15)
12 weeks	13.1 (8.7)	18.1 (10.2)		153.5	.06	0.53 (–0.08, 1.14)

[a] Tabled values are from intention-to-treat analyses after imputation of missing values.

[b] BDI-II: Beck Depression Inventory II; DASS: Depression, Anxiety and Stress Scales.

Figure 4. DSM-IV diagnoses at baseline and 12 weeks postenrollment.

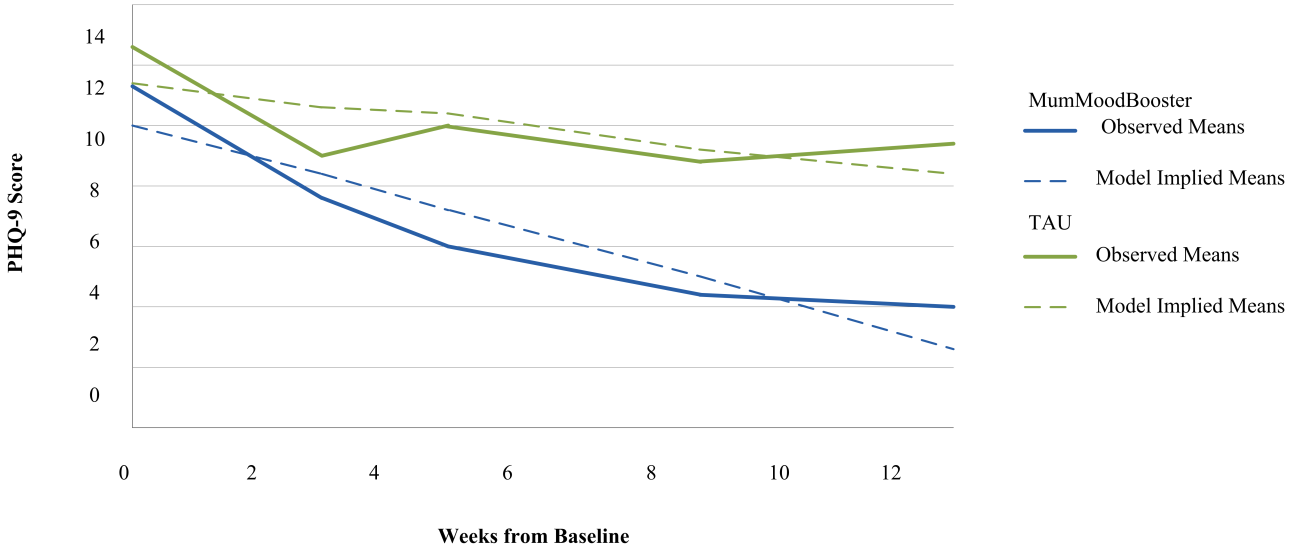


Secondary Outcomes

Trajectory of Depressive Symptoms

Figure 5 shows PHQ-9 scores across the study period for both conditions. There was no significant between-condition difference in PHQ-9 scores at baseline. A substantial reduction in PHQ-9 scores occurred from enrollment to 12 weeks in the MumMoodBooster condition (mean 7.2 point drop). However, for the TAU condition, PHQ-9 scores fluctuated slightly with only a small reduction over the same time period (mean 3.3 point drop). A mixed-effects growth model (random intercept model with a linear trajectory) revealed a significant linear decrease in PHQ-9 values for all study participants (estimate=–0.23, SE 0.08, *P*=.01, partial *r* =–.22) and a differential trajectory between conditions, with MumMoodBooster participants' scores decreasing (improving) at a greater rate (estimate=–0.34, SE 0.12, *P*=.01, partial *r*=–.23).

Figure 5. Longitudinal trajectories of Patient Health Questionnaire-9 (PHQ-9) scores from baseline to 12 weeks.



Anxiety and Stress Symptom Severity

At baseline, mean anxiety scores were within the normal-to-mild range of severity (0-9). Mean baseline stress scores fell in the moderate range of severity (19-25). At 9 weeks (immediately posttreatment) and at 12 weeks postenrollment, average symptom severity on the Anxiety scale of the DASS-21 was not significantly lower in the MumMoodBooster condition compared to the TAU condition (Table 2) and represented small effect sizes at both times (*d*=0.18 and *d*=0.27, respectively; see Table 2). Mean symptom severity on the Stress scale of the DASS-21 showed a significant between-group difference favoring the MumMoodBooster condition at 9 weeks, but not at 12 weeks. These differences represented medium effect sizes at both times (see Table 2; *d*=0.54 and *d*=0.53, respectively).

Negative Thinking and Behavioral Activation

Mean scores for measures of both negative thinking (ATQ) and behavioral activation (BADS) showed some improvement in both the MumMoodBooster and TAU conditions (see Table 3), with medium to large effect sizes favoring the MumMoodBooster condition at 12 weeks postenrollment.

Table 3. Secondary outcomes at baseline and 12 weeks.[a]

Outcome measure[b]	MumMoodBooster, mean (SD) *n*=21	TAU, mean (SD) *n*=22	$F_{1,40}$	*P*	*d* (95% CI)
ATQ [c]					
Baseline	70.19 (16.49)	80.55 (22.89)			
12 weeks	56.33 (26.73)	72.05 (20.78)	3.71	.06	0.61 (–0.01, 1.22)
BADS [d]					
Baseline	79.86 (15.76)	78.27 (15.08)			
12 weeks	103.24 (24.49)	84.77 (17.07)	7.96	.01	0.86 (0.23, 1.48)
DAS-7 [d]					
Baseline	21.10 (6.95)	19.41 (7.92)			
12 weeks	22.67 (6.43)	21.23 (6.36)	0.10	.75	0.10 (–0.50, 0.70)
PSOC [d]					
Baseline	27.52 (7.50)	21.23 (7.37)			
12 weeks	30.19 (7.53)	23.36 (7.85)	2.54	.12	0.53 (–0.08, 1.13)

[a] Tabled values are from intention-to-treat analyses after imputation of missing values.

[b] ATQ: Automatic Thoughts Questionnaire; BADS: Behavioral Activation for Depression Scale; DAS-7: Dyadic Adjustment Scale: PSOC: Parenting Sense of Competence.

[c] Lower score is superior.

[d] Higher score is superior.

Relationship With Partner and Parenting Self-Efficacy

The intervention had no statistically significant effect on partner relationships (DAS-7 scores), although its impact on the parenting self-efficacy measure (PSOC) constituted a medium effect size (Table 3).

Engagement in MumMoodBooster Program

All women offered the MumMoodBooster intervention (21/21) completed four or more sessions and 86% (18/21) completed all six sessions. Women visited the program on a mean of 20.5 occasions (SD 10.6) and the mean number of sessions attended was 5.7 (SD 0.7). The total time spent using the online program averaged 370 minutes (range 120-1076). Content on the Web forum was viewed, to varying degrees, by all participants and 57% (12/21) posted their own comments to the forum. The mean number of library articles accessed was 4 out of a possible 8. Of the six scheduled coach calls, participants completed a mean 4.3 calls (SD 2.2, range 0-6). A total of 76% (16/21) of participant partners accessed the partner support website.

Treatment Satisfaction and Helpfulness

Of the 21 women in the MumMoodBooster condition, 90% (19/21) provided ratings of the program's satisfaction and the helpfulness of coaching calls. Mean satisfaction ratings were in the moderately satisfied range (mean 3.1, SD 0.60, range 2-4) on a 4-point scale. Similarly, mean ratings of the helpfulness of telephone coach calls were in the moderately helpful range (mean 3.2, SD 0.89, range 1-4) on a 4-point scale.

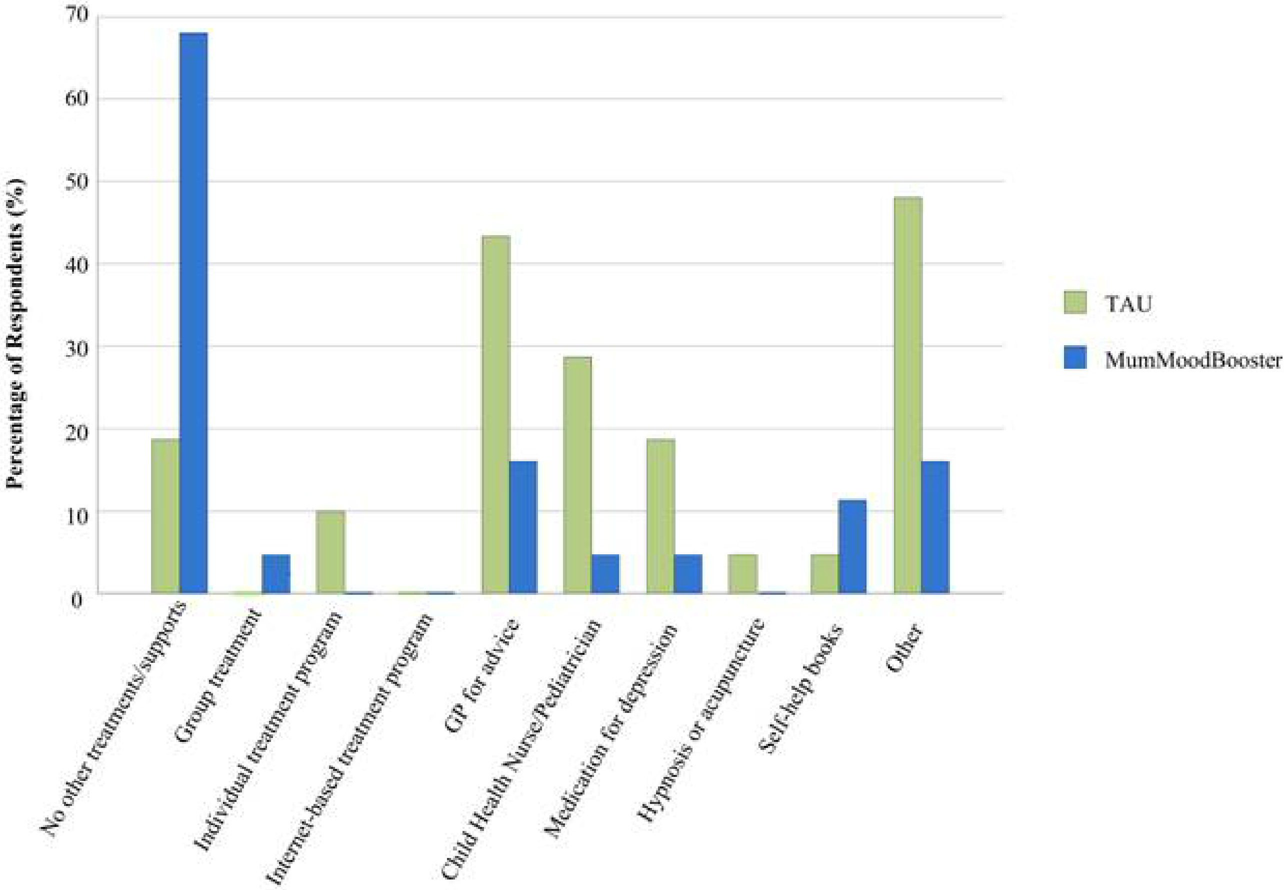
Use of Other Supports/Treatments

At the 12-week assessment, all study participants were asked: "Since you enrolled in the study, which of the following products or programs have you used to manage your mood? (choose all that apply)." A checklist was presented and participants checked the items relevant to their usage. The possible items were (1) I participated in a group treatment program, (2) I participated in an individual treatment program, (3) I participated in another Internet-based treatment program, (4) I saw my doctor who gave me advice, (5) I saw my Maternal & Child Health Nurse/Pediatrician who gave me advice, (6) I took medication for depression, (7) I used hypnosis or acupuncture, (8) I read self-help books, and (9) other (please specify). Of the respondents in the MumMoodBooster condition, 32% (6/19) reported that they had accessed one or more sources of support, whereas 81% (17/21) of those in TAU reported using one or more supports while enrolled in the trial; this was a statistically significant difference (continuity corrected χ^2_1=10.3, *P*=.002). Figure 6 shows the types of supports accessed in both groups.

Of note, individual psychological treatment was reported only by TAU participants, whereas one respondent (5%) in the MumMoodBooster condition reported commencing the use of antidepressant medication compared to 4 (19%) in TAU. More respondents in the TAU group reported having accessed their GP, child health nurse, or pediatrician. Various supports reported by participants, categorized collectively as "other," included Internet research, meditation, telephone helplines, and talking to friends/other mothers. More respondents in the TAU group

(10/21, 48%) accessed these “other” supports compared to the MumMoodBooster condition (3/19, 16%).

Figure 6. Other supports and treatments accessed during the trial (n=6 women in the MumMoodBooster condition and n=17 in the TAU condition reported accessing other supports).



Discussion

Postnatal depression is prevalent, with enormous negative effects on maternal and infant well-being, yet postnatally depressed women receive adequate treatment in less than 10% of cases [66]. Internet interventions offer promise in overcoming some of the main barriers to treatment access and allow women more direct control over their own treatment schedule. By mitigating the difficulty of attending a clinic with a young infant and by reducing barriers such as perceived stigma, these treatments hold the potential to empower depressed perinatal women to take effective steps to overcome their emotional health difficulties.

This RCT demonstrates that the MumMoodBooster intervention results in very good participant engagement with the program, increased rates of remission from diagnosed depression, as well as a significantly more rapid reduction in severity of depressive symptoms. This improvement was evidenced in a sample with baseline depression severity in the moderately severe range and with the vast majority of participants diagnosed with major depression. The intervention produced a 4-fold improvement in the rate of depression remission compared to the TAU condition—even when worst-case results were imputed for the few missing data values.

These results are an encouraging replication of the findings of our previous uncontrolled feasibility study of MumMoodBooster with postnatally depressed women in both Australia and the United States [13]. For example, the observed trajectories of depressive symptoms measured on the PHQ-9 are closely similar in both shape and values, showing rapid initial gains followed by decelerating but continued improvement from around the fifth or sixth week of treatment. Further, treatment adherence, as reflected in the mean number of website visits and CBT sessions viewed, were almost identical in the two studies. Again, similar to the feasibility results, the current RCT found that improvements in automatic thinking and behavioral activation represented medium to large treatment effects favoring the MumMoodBooster intervention, a result in accordance with theoretical expectations regarding the mechanism of action associated with CBT. In both this trial and our earlier feasibility study, we found no evidence of any improvement in women’s relationships with their partners over the study period (as measured by the DAS-7).

This RCT also evaluated changes in symptoms of anxiety and stress, commonly comorbid with depression, and found medium effects favoring the intervention in terms of stress but not anxiety. In interpreting this result, it is worth noting that, at baseline, the mean DASS-21 Anxiety score for participants already fell inside the normal range for anxious symptoms. Although comorbid anxiety symptoms are commonly reported among women with PND, in this sample there may have been little potential gain to make in terms of reducing anxiety scores.

The study has some limitations. First, the RCT was based on a relatively small sample size meaning that some caution is required in trying to generalize our results to the wider perinatal population. Second, women allocated to TAU reported high levels of alternative help seeking and this may have made the detection of true treatment effects relative to TAU more difficult. Conceivably, the comprehensive psychological assessment process for trial inclusion (which is not a consistent feature of TAU in real-world practice) may itself have affected rates of alternative help seeking. It was not unexpected to see the considerable variation in treatments and supports accessed in TAU, as has been discussed in a recent review of what constitutes TAU in the context of RCTs of psychological interventions [67]. However, the possible influence of access to alternative supports and treatments in both groups should be borne in mind when interpreting our results. Last, the follow-up period was short (12 weeks postenrollment) and precluded assessment of the endurance of the treatment effect beyond this time.

Despite these limitations, the robustness of the intention-to-treat analysis tends to uphold the reliability of the results for the primary outcomes. Finally, a major strength of the study is that the efficacy of the MumMoodBooster intervention in treating PND was evaluated against *DSM-IV* diagnostic criteria. This is the first such result using a diagnostic outcome measure in this field of research.

In summary, this RCT confirms and adds to existing evidence for the efficacy of online treatment for PND [12,13]. Apparent strengths of the MumMoodBooster program are its observed ability to rapidly improve symptoms in women with severe diagnosed depression and that it appears highly acceptable. It also appears to help change underlying negative cognitions as well as create behavioral change. As with the study by O'Mahen and colleagues [12], the version of MumMoodBooster evaluated in this RCT included telephone support, but to a lesser degree, and women found this coaching component to be helpful. Online psychological treatment may be particularly relevant for women with PND. It can be accessed in a flexible manner that may better fit a woman's own time-management needs in caring for her infant. It can be delivered with greater privacy, which may help to address the reluctance of many women to seek traditional forms of treatment due to perceived stigma [8]. Future research might focus profitably on quantifying the value of guided support in such online perinatal interventions and on the potential efficacy of less guided versions or of purely self-guided online treatments for PND. Finally, efficacy relative to traditional, in-person clinical psychological treatment remains to be established. We are currently engaged in a large (n=210) randomized trial in Australia designed to directly compare MumMoodBooster with best-practice specialized face-to-face CBT treatment for PND and with an extended period of follow-up (trial registration number: ACTRN12613000881730).

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Conflicts of Interest

None declared

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [68].

[PDF File (Adobe PDF File), 777KB - jmir_v18i3e54_app1.pdf]

Multimedia Appendix 2

Selected Screenshots.

[PDF File (Adobe PDF File), 1MB - jmir_v18i3e54_app2.pdf]

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Abbreviations

ATQ: Automatic Thoughts Questionnaire
BA: behavioral activation
BADS: Behavioral Activation for Depression Scale
BDI-II: Beck Depression Inventory
CBT: cognitive behavioral therapy
DAS-7: Dyadic Adjustment Scale
DASS-21: Depression, Anxiety and Stress Scales—Short Form
EPDS: Edinburgh Postnatal Depression Scale
GP: general practitioner
MCHN: Maternal and Child Health Nurse
PHQ-9: Patient Health Questionnaire
PND: postnatal depression
PSOC: Parenting Sense of Competence

RCT: randomized controlled trial
TAU: treatment as usual

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Original Paper

Collective-Intelligence Recommender Systems: Advancing Computer Tailoring for Health Behavior Change Into the 21st Century

Rajani Shankar Sadasivam[1], PhD; Sarah L Cutrona[1,2,3], MPH, MD; Rebecca L Kinney[1], MPH; Benjamin M Marlin[4], PhD; Kathleen M Mazor[2], EdD; Stephenie C Lemon[5], PhD; Thomas K Houston[1,6], MPH, MD

[1]Division of Health Informatics and Implementation Science, Department of Quantitative Health Science, University of Massachusetts Medical School, Worcester, MA, United States

[2]Meyers Primary Care Institute, University of Massachusetts Medical School, Worcester, MA, United States

[3]Division of General Medicine and Primary Care, University of Massachusetts Medical School, Worcester, MA, United States

[4]College of Information and Computer Sciences, , University of Massachusetts Amherst, Amherst, MA, United States

[5]Division of Preventive and Behavioral Medicine, University of Massachusetts Medical School, Worcester, MA, United States

[6]eHealth Quality Enhancement Research Initiative (QUERI), Center for Healthcare Organization and Implementation Research (CHOIR), Veteran’s Health Administration, Bedford, MA, United States

Corresponding Author:
Rajani Shankar Sadasivam, PhD
Division of Health Informatics and Implementation Science
Department of Quantitative Health Science
University of Massachusetts Medical School
368 Plantation Street
Worcester, MA,
United States
Phone: 1 5088568924
Fax: 1 5088568924
Email: rajani.sadasivam@umassmed.edu

Abstract

Background: What is the next frontier for computer-tailored health communication (CTHC) research? In current CTHC systems, study designers who have expertise in behavioral theory and mapping theory into CTHC systems select the variables and develop the rules that specify how the content should be tailored, based on their knowledge of the targeted population, the literature, and health behavior theories. In collective-intelligence recommender systems (hereafter recommender systems) used by Web 2.0 companies (eg, Netflix and Amazon), machine learning algorithms combine user profiles and continuous feedback ratings of content (from themselves and other users) to empirically tailor content. Augmenting current theory-based CTHC with empirical recommender systems could be evaluated as the next frontier for CTHC.

Objective: The objective of our study was to uncover barriers and challenges to using recommender systems in health promotion.

Methods: We conducted a focused literature review, interviewed subject experts (n=8), and synthesized the results.

Results: We describe (1) limitations of current CTHC systems, (2) advantages of incorporating recommender systems to move CTHC forward, and (3) challenges to incorporating recommender systems into CTHC. Based on the evidence presented, we propose a future research agenda for CTHC systems.

Conclusions: We promote discussion of ways to move CTHC into the 21st century by incorporation of recommender systems.

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KEYWORDS

computer-tailored health communication; machine learning; recommender systems

Introduction

> *Are there aspects of the Web 2.0 phenomenon that can be marshaled by public health practitioners to improve community and individual health or advance scientific goals?* [[1]]

Theory-based, computer-tailored health communication (CTHC) is a tool that is frequently used to support behavior change [2]. It builds on the concepts of personal relevance, relatedness, and cultural similarity, which are constructs of multiple behavioral theories including the transtheoretical model, the theory of reasoned action, social cognitive theory, and self-determination theory [3-5]. Current CTHC systems use selected variables from patients’ baseline profile and if-then rules to send tailored messages to specific subsets of patients [2,6-10]. Study designers who have expertise in behavioral theory and mapping theory into CTHC systems select the variables and develop the rules that specify how the content should be tailored (what messages need to be sent to that patient subset) based on their knowledge of the targeted population, the literature, and health behavior theories. Textbox 1 provides an illustrative example of how a current CTHC system might tailor a message as part of a smoking cessation intervention. Over 30 years of research testing CTHC approaches have provided convincing evidence of the effectiveness of tailored messages [6,7,11-16]. Technological advances have enabled CTHC to be delivered on multiple platforms (eg, websites, email, and mobile) and to reach large populations. However, as CTHC systems are currently implemented, we may have reached the natural limits of their ability to tailor communications.

Textbox 1. Computer-tailored health communication (CTHC): a simple example of a tailored message addressing weight gain on a Web-assisted tobacco intervention.

John Smith, a 38-year-old smoker, has been smoking for 15 years. He has made multiple quit attempts in the past, but during each attempt he gained between 10 and 20 pounds. Fear of weight gain is a significant barrier to another quit attempt.

John is trying to quit again and registers on the Decide2Quit.org Web-assisted tobacco intervention. For 8 weeks, the system sends 2 tailored emails per week to John to help him quit.

Current CTHC

- In this approach, tailoring is based on information that John provides when he registers. For this example, we focus on 1 characteristic only: gender.
- Since women are typically more concerned about weight gain after quitting [17-21], the developers of Decide2Quit.org have specified that half of the emails sent to women should contain information related to weight gain, but only a quarter of the emails sent to men should be focused on weight gain.
- After registering on Decide2Quit.org, John receives the first email that targets weight loss in the second week (third message) of the intervention. John likes the message and finds the tips it offers useful. He looks forward to receiving similar messages. However, the next 5 messages he receives focus on other topics. The next message with information on weight gain arrives only in week 5.
- John does not think the system helped and fails in his attempt to quit.

Recommender CTHC

- In this approach, the message is selected based on the collective-intelligence data, not on preset rules.
- After registering on Decide2Quit.org, John visits the weight loss page on the website (implicit data). The system uses these data and selects 1 of the messages targeting weight loss and sends it to John in week 2 (third message). John likes the messages and rates the message highly (explicit data). The system then notes both of these items of implicit and explicit feedback and regularly sends messages targeting weight gain to John. The system also repeats the message that John rates highly.
- Because the intervention targeted his needs more specifically, John finds these messages useful and succeeds in his attempt to quit.
- We have kept the example simple to be easily understandable. We have not included in this example how the group’s feedback can help John.

New approaches to tailoring based on collective intelligence may be able to build on the successes and lessons learned from past tailoring efforts, and may overcome the limitations inherent in current CTHC systems. Many people already encounter collective-intelligence tailoring as they interact with companies like Netflix and Amazon. These companies have developed a special class of machine learning algorithms (recommender systems) to tailor content. These systems tailor content based on collective-intelligence data (ie, data derived from the behavior of users as they interact with the system) in addition to user profiles [22-24].

Collective-intelligence data include implicit and explicit user feedback. Implicit data are derived from user actions (eg, the website view patterns of each individual accessing the system). Explicit data consist of self-reported item ratings (eg, ratings provided by users for items such as books or movies, often on a 5-star scale). However, in the health-promotion arena, patients could be asked to rate relevance, influence, or other properties of a message or product. Using these data, along with user demographic characteristics, the algorithms underlying the system generate personalized item recommendations for each user. As these systems learn more about the user, they can continually adapt to improve the recommendations.

Recommender systems can be implemented using 3 approaches: a content-based approach [25], a collaborative filtering approach [26], or a hybrid approach [27]. The distinction between a content-based approach and a collaborative filtering approach lies in the type of data used to generate a recommendation, as we discuss in further detail in the Results section. Hybrid approaches merge content and collaborative filtering [27]. By combining theory-based CTHC with the empirical approach of recommender systems, the hybrid approach is a potentially powerful combination.

The lower portion of Textbox 1 provides an example of how a recommender system could be implemented to provide tailoring as part of a smoking cessation intervention. It shows how applying a recommender approach to health promotion could potentially improve the tailoring provided by current rule-based CTHC approaches. The primary difference between current CTHC and recommender systems is how the content would be tailored. In current CTHC, study designers select the variables and develop the rules that specify how the content will be tailored. In recommender systems, machine learning algorithms use the data (patient profiles, and implicit and explicit feedback ratings) to select the variables and generate the rules that specify how the content will be tailored. As new data about the users are collected, these recommender systems have the ability to refine the variables and tailoring rules. Can we augment the performance of CTHC by using recommender systems?

We present information gained through a focused literature review and through interviews with subject experts. We begin with a description of the limitations of current CTHC systems. We then describe the potential advantages and challenges of using a recommender systems approach. Based on the evidence presented, we propose a future research agenda. Our goal is to promote discussion of techniques to improve current CTHC through use of recommender systems.

Methods

Study Design

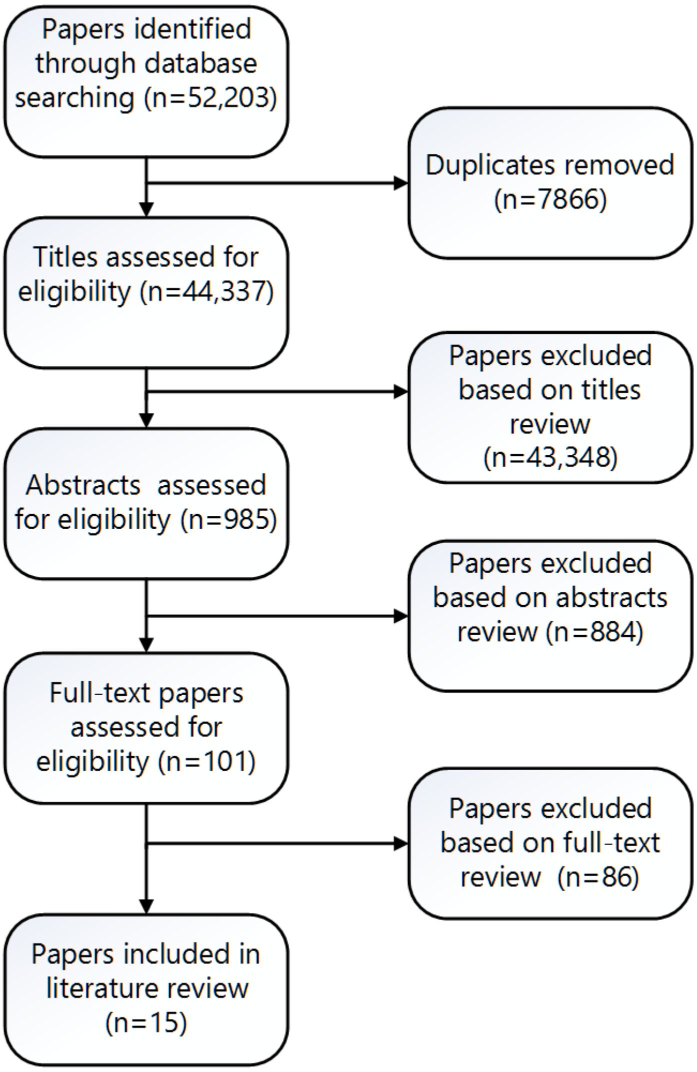
We conducted a focused literature review and interviewed experts to explore whether and how recommender systems might enhance CTHC approaches. This study was conducted between October 2012 and September 2015.

Data Collection

Literature Review

We conducted a focused literature review to identify white papers, conceptual papers, and peer-reviewed papers describing both current CTHC systems and recommender systems, as well as information for the following categories: limitations of current CTHC systems, advantages of recommender systems over rule-based systems, and challenges of implementing recommender systems for health promotion. We excluded papers that only described a specific intervention or a specific method for implementing these systems. Papers published in peer-reviewed journals and conferences between 1985 and 2015 from several disciplines, including clinical, health promotion, behavioral medicine, computer engineering, and recommender systems, were considered for the secondary literature review that was conducted from August 2015 through October 2015. The following databases were searched: PubMed, ACM Digital Library, and IEEE Xplore. Search terms for the Boolean search techniques were computer tailoring, health message tailoring, recommender systems, content-based, collaborative filtering, hybrid systems, and their combinations with health, overview, challenges, and barriers. Additionally, we reviewed the reference lists of all of the identified papers for additional relevant papers (Figure 1). Titles of the identified papers were reviewed by 1 reviewer (Kinney) under the supervision of Sadasivam. The number of papers identified in the initial search and included in the abstract review was vastly inflated due to variations in meaning of the search term (ie, hybrid systems referring to topics in electrical engineering). Papers that were excluded in the full-text review included those that were too speculative and opinion based, discussed only a specific trial or study, or were too similar to a paper that was already selected (eg, papers by the same authors). The team then synthesized the literature search results. Two authors (Sadasivam and Kinney) reviewed and summarized the information presented in the 15 papers under 3 overarching categories (limitations of current CTHC systems, advantages of recommender systems over rule-based systems, and challenges of implementing recommender systems for health promotion). These findings were presented to the coauthors for review and, as a group, we refined the points in each category.

Figure 1. Literature review study flow diagram.



Expert Interviews

We interviewed a purposive sample of experts in academia and at the National Institutes of Health (NIH) (n=8). We chose a sample size of 8 to assure representation in the 2 domains of interest (4 each): (1) computer engineering and recommender systems, and (2) health behavioral change, health communication, and computer tailoring. Interviewees were recruited through personal contacts and personal outreach at conferences, such as the Society of Behavioral Medicine, American Medical Informatics Association, and recommender systems annual conferences. We conducted individual interviews and used an open-ended interview format structured around the 3 themes: the limitations of current CTHC systems, potential advantages of recommender systems over rule-based systems, and challenges of implementing recommender systems for health promotion. In the beginning of the interview, the interviewer described the 2 types of systems (current CTHC and recommender systems) to promote discussion. Our literature findings organized around the 3 categories (limitations of current CTHC systems, advantages of recommender systems over rule-based systems, and challenges of implementing recommender systems for health promotion) were presented to the experts. We then used open-ended questions designed to solicit feedback from the experts around the 3 categories. Example questions were (1) Thinking about your last CTHC study, tell us how current CTHC systems limited your efforts in your study? (2) Thinking about your last CTHC study, tell us how you think recommender CTHC systems would have addressed current CTHC limitations? (3) What do you think are the challenges for using recommender systems in health interventions? Prompts were used when necessary. Example prompts were (1) Were you able to implement all the tailoring rules in your current CTHC study? (2) Do you think we have sufficient data to implement recommender systems? Detailed notes of each interview were taken. We used a process similar to the literature synthesis to summarize and extract information from the interviews. Specifically, the same 2 authors summarized key points and issues that were raised during the interviews (also organized into limitations of CTHC, potential advantages of recommender systems, and challenges) and presented these to the group for further synthesis.

Results

We present the results of our data synthesis below.

Limitations of Current CTHC

Source: Literature Review

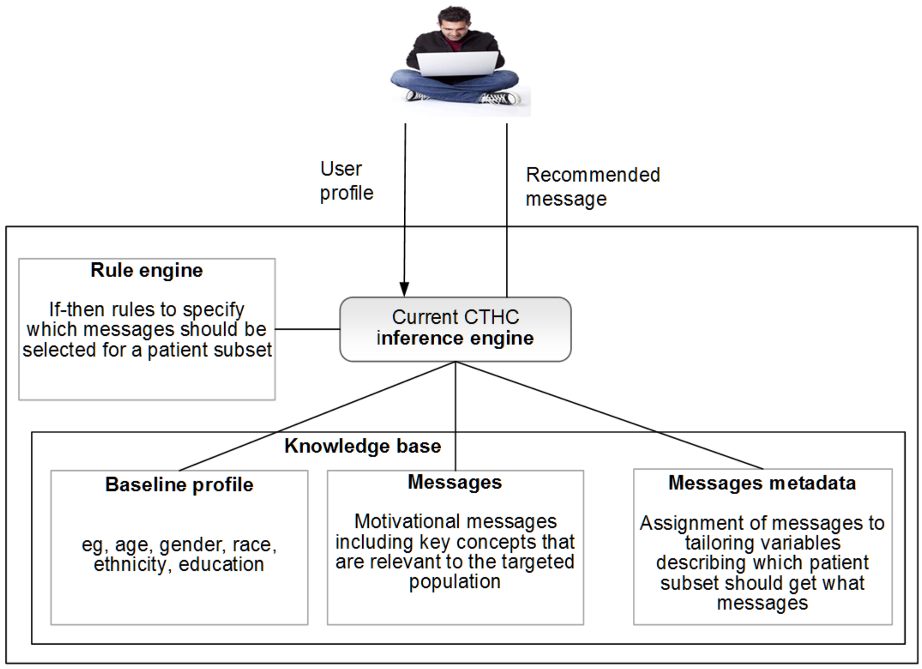
Current CTHC frameworks use theory-driven, rule-based systems to provide different messages to patient subsets [2,6,9,10,28-30]. Rule-based systems are one of the first and simplest forms of artificial intelligence, allowing automation of decisions in a manner consistent with rules provided by a human expert [31,32]. For example, rule-based systems are used as clinical decision-support systems to help providers choose the correct diagnosis. Conceptually, a rule-based system has 3 components: (1) a knowledge base that stores all facts from which the choice needs to be made, (2) rules that provide conditional statements that link the given conditions to facts, and (3) an inference engine that combines the rules and the knowledge base to suggest the optimal choices [31,32]. In developing these components (Figure 2), study designers must consider several questions [33-35]: (1) message writing: what are the important concepts for the targeted population? (2) tailoring variables: how should the target population be segmented? (3) rules: how should messages be selected for different segments of the targeted population?

In the Textbox 1 example, the tailoring variable was gender (male and female smokers), a key concept was addressing weight gain, and a rule was that half of the emails sent to women should contain information related to weight gain, but only a quarter of the emails sent to men should be focused on weight gain.

Once these questions are addressed and the messages written, study designers use metadata to describe and categorize the messages. This step allows the CTHC system to select appropriate messages for a patient subset. Metadata is defined as data about data; it describes the structure or content of a particular resource, object, or entity [36]. Previously applied to card catalogue systems within libraries, this concept is applied similarly in the electronic realm to discover concepts or resources. In a CTHC system, metadata are used to flag messages to help the inference engine identify which group of messages should be sent for a particular tailoring condition. In Textbox 1, examples of metadata include flagging for weight gain messages, and a gender flag to indicate whether the message should be sent to a man or woman, or there should be a common message for both genders. Thus, for John, the CTHC system would use the weight gain flag and the gender flag to select an appropriate message.

As study designers address the above questions and develop the intervention, they also have to balance several factors, including time and cost. This study designer-driven, rule-based approach may lead to 3 important limitations, detailed in the expert interviews.

Figure 2. Structure of a current rule-based computer-tailored health communication (CTHC) system.



Source: Expert Interviews

Tailoring on Multiple Variables is Challenging With a Rule-Based Approach

Leaders in the field of CTHC have demonstrated that high tailoring (tailoring on many variables) is better than low tailoring (using fewer variables) [37]. The use of rule-based expert systems may limit the complexity of CTHC systems in terms of the number of tailoring variables that can be included [2,6,9,10]. As noted, typically these rules are programmed using if-then statements [30,32,38]. The number of rules that can actually be implemented is dependent on several factors, including the programming team, the project’s budget, and the timeline. For example, if a smoking cessation CTHC system is tailored for gender (male, female) only, 2 if-then statements are required. By adding age (eg, 19-34, 35-44, ≥45 years) as a tailoring variable, the number of if-then statements required becomes 6. A third condition (smoking status: contemplation, preparation, and action) increases the number of if-then statements necessary to 18. In general, the number of patient segments increases exponentially as the number of tailoring variables increases. Thus, tailoring on many variables quickly becomes difficult to implement and very resource intensive.

A Theory-Based, Designer-Written Rules Approach May Limit Individual Relevance

While theory provides important guidance to CTHC investigators, current theories may underrepresent the complexity of factors that influence health behaviors [39,40]. This disconnect may be especially problematic when trying to reach diverse populations. Unique sociocultural dimensions, such as interconnectedness, level of health socialization, and ecological and health care system factors, influence personal perspectives and may affect the success of an outreach effort [28]. Testing of CTHC interventions in pilot studies may help to improve the interventions, but such pilots have limited effectiveness. Budgetary and time constraints often drive researchers to focus on improving messages for a few key concepts rather than capturing a broad perspective. In such situations, generalizability is limited and the risk of missing influential variables persists. The previously noted limitation on the number of rules that can easily be implemented also increases the possibility of key concepts being excluded.

Rule-Based CTHC Systems Often Have Limited Ability to Adapt in Real Time

A user’s personal preferences and behaviors can change over the duration of the intervention. An optimal CTHC system needs to have the capabilities to adapt in order to remain relevant and engaging. While the ability of current systems to collect real-time behavior has improved (eg, ecological momentary assessment and use of sensors), current CTHC rule-based approaches are limited in how they can adapt to this information. CTHC rule-based systems typically adapt only to anticipated and predicted changes in behavior (ie, how the study designers think users will behave). For example, current CTHC systems can be easily programmed to adapt to changes in a smoker’s motivation to quit. However, to adapt to all the behavioral patterns of the individual and the group, existing rules would need to be modified or new rules added. This approach quickly becomes resource intensive and often infeasible.

Using the Textbox 1 example, because the study designers did not choose weight gain as a tailoring variable and did not write rules for it, the rule-based CTHC was not able to personalize the intervention to John’s needs by sending him additional emails targeting weight gain. However, the recommender CTHC system was able to note John’s viewing of the weight gain page on the website (ie, implicit data) and then to send a message targeting weight gain to John early on in the intervention. Based on John’s ratings, the recommender system was able to further adapt and send additional messages targeting weight gain to him. Thus, John’s experience of the intervention was further enhanced because of the additional tailoring provided by the recommender system.

Advantages of Incorporating Recommender Systems to Advance CTHC

Source: Literature Review

The use of complex algorithms to generate the tailoring recommendations based on collective-intelligence data allows tailoring based on the “observed behavior” of the users—how the users are responding to the intervention collected through user feedback, rather than how the study designers predict the users are going to respond. User feedback data can be in the form of explicit or implicit data. As noted, recommender systems can be implemented using 3 approaches: a content-based approach [25], a collaborative filtering approach [26], or a hybrid approach [27]. Content-based recommender systems use the description of the items (metadata) and the preferences of the user to make user-specific recommendations. Given a sample of rating data, content-based recommender systems learn a function to match users to items by taking the user profile information (eg, age, gender) and the metadata of the items as input. While content-based recommender systems conceptually work similarly to current CTHC systems, the main difference between them is that the matching function is specified by study designers in existing CTHC systems in the form of tailoring rules, while the matching function is optimized based on rating data in the case of content-based recommender systems. Since the matching function is learned from data and not specified by hand, it is feasible to consider many more demographic and tailoring variables.

In contrast to content-based recommender systems, collaborative filtering recommender systems match users to items by directly leveraging feedback ratings data (implicit or explicit) of the item (ie, messages in the case of CTHC). The simplest examples of this approach are nearest-neighbor methods [26]. These methods match a target user with other users who have given similar feedback ratings data regarding the items the users have rated in common. The set of users matched to the target user are referred to as the target user’s nearest neighbors. The method then recommends items to the target user that their neighboring users have rated highly. The assumption behind these methods is that if 2 users are observed to have close agreement on the feedback ratings of a sufficiently large number of items, they will likely agree closely on the ratings for the remainder of the items.

Hybrid recommender systems merge the strengths of content-based and collaborative filtering recommender systems [27]. These systems recommend items by merging information about user demographics and explicit item characteristics with information about how similar users rate items. This approach would technologically be the most challenging to develop, requiring an integrated framework that links together the different types of information into a unified model. Hybrid models can potentially bridge the world of theory-based approaches with empirical recommender systems-based approaches. For example, in the CTHC case it may become possible to first segment users according to a study designer-specified top-level tailoring variable such as smoking status, then using the recommender system algorithm to automatically and significantly refine the tailoring within each top-level segment based on all available information sources.

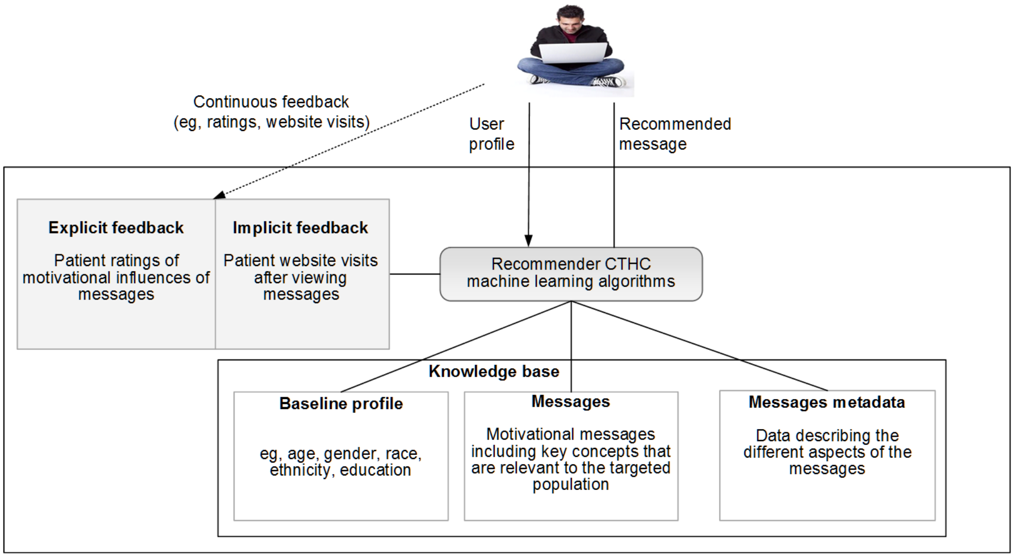
Source: Expert Interviews

When seeking to develop recommender system-based CTHC, study designers must face the following questions (see also Figure 3): (1) message writing: what are the important concepts for the targeted population? (2) tailoring variables: how do we collect the collective-intelligence data and what do we collect (including implicit and explicit data), and what data and variables can be made available for the algorithm in order to generate recommendations?

In the aforementioned smoking cessation example (Textbox 1), John's rating of messages is explicit data, and his visiting a webpage on the website is implicit data. Along with John's demographic characteristics, the recommender system was able to further personalize John's experience on the intervention using these data.

As in current CTHC, in the recommender system study designers will have to develop metadata describing message characteristics that will be used for message selection. Study designers do not typically have to consider the selection of the tailoring variables and the rules, as these will be derived from the data collected by the algorithms underlying the recommender systems. This data-driven approach has the potential to provide several advantages. These are as follows.

Figure 3. Components of recommender systems for computer tailoring. The primary differences between the 2 systems depicted in Figure 2 and 3 are shaded in gray. They represent the continuous feedback data that the recommender systems are able to use. CTHC: computer-tailored health communication.



Tailoring is Based on a Near-Infinite Number of Variables

Sophisticated machine learning algorithms are potentially able to consider all of the available user variables and to tailor based on these variables. As noted above, rule-based systems are limited in the number of variables that can be used. The recommender system approach potentially reduces the possibility of any key variable being excluded and allows for tailoring on more variables. The number of variables that can be effectively incorporated or is meaningful to the participant has to be empirically tested. Systems also have to be designed to collect all potential user data to take advantage of this ability of the recommender systems.

Tailoring is Not Limited to Theory or Study Designers' Knowledge

A recommender systems approach would be an ideal complement to theory-based approaches because it would identify important variables from user data and behavior. The machine learning algorithms of recommender systems recommend messages based on the data and are not limited to the study designer-written rules. Textbox 1 provides an example of how recommender systems can augment theory-based approaches. By incorporating the smoker's (John) feedback, the system was able to augment the tailoring provided by the system, sending additional messages targeting weight gain to the smoker.

Algorithms Can Adapt to Real-Time Feedback

In contrast to rule-based approaches, the machine learning algorithms of the recommender system can more easily adapt to unpredicted changes in individual as well as group user behavior. As noted in the Textbox 1 example, the system was able to note John's browsing of a webpage on the site, as well as his ratings of the message, and used this information to further tailor the intervention. Thus, these systems can adapt to continuous feedback provided by the users of the intervention. Similar to the systems used by Netflix and Amazon, the system continually learns. As more users contribute data, more sophisticated message tailoring is possible.

Table 1 summarizes our above discussion on the differences between current CTHC and recommender systems, including how recommender systems can augment current CTHC. The next sections will describe potential challenges to incorporating collective-intelligence data and recommender systems in CTHC. In addition, we highlight important research questions.

Table 1. Rule-based computer-tailored health communication (CTHC) versus recommender systems.

Feature	Rule-based CTHC	Recommender systems
Intervention development questions	(1) Message writing: What are the important concepts for the targeted population?	(2) Message writing: What are the important concepts for the targeted population?
	(2) Tailoring variables: How should the target population be segmented?	(2) Tailoring variables: What collective-intelligence data (implicit and explicit data) should be collected and how?
	(3) Rules: How should messages for the participant patient segment be selected?	
Message selection	Rules-driven: Study designers develop rules based on the literature and theory. These rules link user profiles to the metadata of the messages, selecting messages for a patient subset.	Data-driven: Sophisticated machine learning algorithms derive the tailoring rules from the collective-intelligence data of the individual, as well as the group.
Complexity (number of variables)	The number of variables incorporated can become quickly unmanageable. It is limited by the sophistication of the study designers in the team, project's timeline, and budget.	Sophisticated algorithms can potentially consider all the variables collected in the intervention.
Use of theory	Tailoring is limited to theoretical constructs.	Theory is augmented by deriving recommendations from the user data.
Adaptation	System is limited to predicted changes in behavior.	System can continuously adapt, potentially improving with each message delivered. Responds to the user's behavior and to the group's behavior over time.

Challenges to Incorporating Recommender Systems in CTHC

Source: Expert Interviews

The potential is there, but can recommender systems be adapted to CTHC systems? There are several challenges or potential barriers to widespread adoption of this approach including.

Limited Availability of Collective-Intelligence Data at the Start of the Intervention

When companies such as Netflix and Amazon deployed their recommender systems, they had already collected collective-intelligence data on several thousands of users. In contrast, most CTHC interventions do not have access to such data sets, such as prior ratings of motivational messages, use and effectiveness data of an intervention, or sensor data from physiological measures of recipients' reactions. The lack of such collective-intelligence data at the start affects the ability to reach and maintain sufficient momentum in the early stages of an intervention.

Limited Sample Size and Intervention Study Time

The sample size and study timeline of a typical behavioral health intervention impose additional challenges to a recommender system. In 2012, Amazon.com reported having a client base of over 100 million customers worldwide, while Netflix boasted 29.4 million users in that same year. In contrast, CTHC research settings draw on much smaller initial populations, often with limited user interaction. CTHC interventions have shorter timeframes, often due to the dictates of limited research funding. Small study populations and limited data collection may threaten both the generalizability of the messages and the precision of the algorithms.

Steep Rate of Intervention Attrition

Attrition rates tend to be very high in technology-assisted health interventions [41-46]. Typically, most users engage with the interventions only once or twice during the study. Combined with the limited sample size issue discussed above, this can significantly limit the availability of implicit feedback. Moreover, the users who engage more frequently may also be different from those users who are less engaged, and their feedback may not reflect the feedback of the less-engaged users [37,46].

Potential Unintended Consequence

There are potential unintended consequences of using a data-driven approach to tailor messages for users. Web 2.0 companies have developed over the years a sophisticated approach to collecting feedback data and channeling these data into their recommender systems. Explicit ratings in the form of "like" functions and implicit ratings, such as user webpage visits or purchase of a product, provide detailed ongoing feedback that informs subsequent messages sent to customers. While effectiveness of a message promoting online merchandise may be measured by users' purchasing decisions, assessing the effectiveness of behavioral health messages is more complex. For example, users' preferences could possibly tend toward information that reinforces the behavior that is being targeted for reduction. In other words, a user liking a message may not mean that the message will influence behavior change in the desired direction.

For example, triggers for smoking can vary among smokers [47]. In a hypothetical case, listening to music might be a useful relaxation technique for some participants, helping to reduce stress and to remove a trigger for smoking. However, for other smokers, listening to music might act as a trigger. A purely recommender system-based approach might not be able to distinguish between music as a relaxation device and music as a trigger. Avoiding unintended consequences of this type of situation would be challenging. Methods for monitoring the tailoring or for collecting data in ways that allow the system to make these distinctions would be important. Such approaches would need to be empirically tested.

Discussion

Proposed Research Agenda

Source: Expert Interviews

We propose the following research agenda to respond to the above challenges and to advance the field of CTHC using recommender systems approaches.

Research to Understand What Collective-Intelligence Data to Collect for Health Interventions and How

As noted, complicating the generation of collective-intelligence data is the lack of clarity of what constitutes appropriate feedback for health behavioral messages. Studies are needed to evaluate the research questions associated with this issue. We need to understand whether message feedback ratings on a single question (or dimension) are sufficient, or whether we need ratings on multiple questions. For example, a study designed to address this question could be to recruit users to rate messages on multiple dimensions (Textbox 2) and to assess whether these dimensions provide the same or different information. Because time and order of the questions could also be a factor in the ratings, the survey should be designed to present these questions in a random order. If the ratings of the messages are highly correlated, then having a single question might be sufficient. However, if they are not correlated, having additional questions might be useful. Researchers must balance the need for additional information with the burden of asking their users to rate multiple questions.

Textbox 2. Example dimensions of collective-intelligence data collection (further research might expand this list to include additional items).

Motivational influence

This message influences me to change my behavior. (yes/no)

Emotional engagement

This message affected me emotionally. (positive and negative emotions)

Relevance

This message was personally relevant to me.

Preference

I would like more messages like this one.

Second, as noted above, using the wrong feedback data might lead to unintended consequences (see Results). Assessing whether a message might lead to unintended consequences could be challenging. One approach is to use technological advancements in data collection (eg, ecological momentary assessment or sensors) to assess the user’s behavior after receiving a message. For example, in a smoking cessation study, smokers who are attempting to quit could be provided with a mobile app to record any smoking and the reasons for smoking during the intervention. This information could then be compared with the messages that were sent immediately preceding the smoking event to assess whether that particular message was correlated with the smoking.

There are also a few strategies that can be studied to overcome the limited availability of collective-intelligence data. For example, the preintervention stage of a study can be used for explicit data collection. Research is necessary to determine the minimum amount of explicit data needed to develop a reasonably functioning CTHC algorithm**.** Research is also needed on how to continue gathering explicit data throughout the intervention. This could be in the form of a question at the end of every message sent to the participants. Research is also warranted on how to incorporate implicit data into the algorithm as the intervention participants engage with the system (eg, visits to a website).

Technological advances can also be used to generate additional collective-intelligence data. The considerable data warehouse technologies can be used to aggregate collective-intelligence data from multiple interventions. A new investigator can then use these data collected by other investigators to initiate this CTHC intervention. Another interesting development in recent years is the development of large social networks around health issues. For example, BecomeAnEx and QuitNet are social networks focused on helping smokers [48,49]. In these networks, users are continuously interacting with and supporting each other in their efforts to adopt health behaviors, while generating large quantities of untapped collective-intelligence data. One way to use these collective-intelligence data for CTHC would be to write natural language-processing tools to identify messages similar to an investigator’s health messages, and then mine the collective-intelligence data on these similar messages, such as the number of views of these messages and follow-up posts. This information could then be used to initialize a recommender system for a new intervention. Research is needed to examine whether these approaches are feasible and develop appropriate natural language-processing tools to extract information from existing social networks. Research is also needed to examine whether adding external data to the algorithms would be an improvement over cold starting [50] these systems without any data (ie, using rules to select the first set of messages and then personalize them based on user feedback) or with minimal data. A study could randomly assign participants to receive messages tailored either by a collective-intelligence system that is cold started or by a recommender system augmented by using data from other social networks. Users in the study could then be asked to rate each message that they receive. A comparison of the user's ratings by time might provide insights into whether the collective-intelligence data enhanced the intervention. Questions include the following. Did the augmented collective-intelligence system receive higher ratings in the initial time periods as compared with the cold-started recommender system? Did this trend continue, or did the effect of augmenting with external data disappear after some time in the intervention?

Research to Understand Appropriate Selection of the Recommender Approach

As noted, recommender systems can be implemented using 3 approaches: content based, collaborative, or hybrid. Each of these has distinct advantages. While content-based systems are similar to rule-based approaches, content-based systems can use the rich metadata that can be developed for a particular message. While metadata is primarily used for flagging the messages to a particular tailoring condition, use of metadata in content-based systems can be more powerful. CTHC messaging can be described in several ways, including its relevance to particular concepts in a behavioral theory (eg, self-efficacy), the message polarity (positive, negative, or neutral sentiment), and the topical content of the message (eg, mentioning weight loss or cravings). In theory, a content-based system can use all this information in developing a matching function. However, in practice the cost of explicitly specifying large amounts of metadata for each message can be prohibitively expensive.

Collaborative filtering methods can bypass the need to match users to items based on explicitly defined metadata and instead derive recommendations based directly on items that similar users have rated highly. As a result, collaborative filtering recommender systems have been successful in domains such as book and movie recommendation, where enumerating all relevant characteristics of the users and items is difficult, if not impossible. However, there are certain disadvantages to using a purely collaborative filtering approach. This approach would imply that the tailoring is purely data driven and may lead to unintended consequences (see Results).

Hybrid systems can bridge theory-based, rule-based tailoring with the recommender empirical tailoring. While this might appear to be the best fit, it might not be feasible to develop hybrid models for all projects, given the limitations of time, content, and available collective-intelligence data. Thus, research is needed to identify the best recommender approach for an intervention and what approach would provide an advance over current rule-based approaches, make the intervention most engaging within the project constraints, and most influence the targeted behavior.

Studies are needed to compare the performance of all 3 approaches. For example, a study could directly compare the performance of all 3 approaches by randomly assigning participants to receive messages tailored by either a content-based, a collaborative, or a hybrid recommender system. Such a study could be evaluated in terms of several different outcomes. In a pilot study, the outcome could simply be a comparison of the ratings provided by participants for a period of time (eg, 30 days) or of the use of the intervention functions. Ratings could be in the form of explicit ratings (eg, Textbox 2 dimensions) or implicit ratings (eg, user webpage visits or setting a goal). In a long-term effectiveness study, the outcome could be desirable changes in the behavior (eg, quitting smoking). Investigators must also factor in the cost of developing these systems in their evaluations.

Research to Understand the Impact of Using Collective-Intelligence Data for CTHC

Will recommender systems be better than current CTHC? There is no evidence regarding the use of recommender systems in CTHC. Research is needed to understand the benefit of incorporating recommender approaches into CTHC, in terms of increased engagement as well as behavior change. Comparative effectiveness studies are needed to evaluate the relative impact of rule-based tailoring versus recommender systems tailoring across different health behavior targets. The outcome of such a study would be assessing the behavior change of interest, as well as increased engagement and satisfaction with the intervention.

To achieve these agenda, we may need changes in our training and funding models with an increased focus on supporting interdisciplinary research bridging behavioral science and computing. As with any interdisciplinary teams, researchers must be conscious of differences between disciplines in terms of terminology to ensure clear communication across team members. More fundamentally, researchers also need to be conscious of differences between disciplines in terms of where research challenges lie. For example, behavioral scientists may not be familiar with the challenges of developing, implementing, and deploying new algorithms and systems. On the other hand, computer scientists may not be familiar with the challenges involved in conducting behavior change intervention research, such as the time and effort needed to recruit subjects and ensure adequate levels of adherence to study protocols.

While this divide between disciplines has decreased with the increasing number of collaborations, additional training would speed up this merging. A model similar to the US National Science Foundation (NSF)/NIH mHealth Summer Institute training model might be a suitable approach to address some of these issues [51]. In the mHealth Summer Institute, behavioral scientists and mHealth researchers are brought together and exposed to the methodology and challenges faced by each respective field. Proposal development offers its own challenges. Investigators would benefit from attending conferences in the fields of those with whom they wish to collaborate, and the development of joint meetings may be beneficial in order to lay the groundwork for future proposal development.

As mentioned above, modifying existing funding models should also be considered. Developing recommender systems will require considerable time, which the typical NIH funding model does not facilitate. Substantial preintervention work will be needed to develop these systems, including collective-intelligence data collection through pilot surveys, recommendation algorithm development and validation, Web system design, message creation, and metadata creation. A joint NSF/NIH model similar to the Big Data Request for Applications that provides an additional development cycle and also stresses collaboration across disciplines might be a potential funding model for advancing the research agenda of using recommender systems in CTHC [52].

Limitations

The views presented in this paper are limited. Research on the incorporation of recommender systems is in its infancy. Therefore, few papers relevant to this work have been published. We wrote this paper hoping it would start the conversation. Our hope is that the research community will consider the points presented in this paper and respond with additional issues that we have not yet considered.

Conclusions

Recent technological advances and the widespread use of recommender systems outside health care present an incredible opportunity to improve on an already effective CTHC approach, and to reach and affect billions of users through Web and mobile technologies. Multiple challenges must be addressed to adapt recommender systems for CTHC. In this paper, we have attempted to start a discussion that we hope will help to move CTHC into the 21st century of these recommender systems.

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Conflicts of Interest

None declared.

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Abbreviations

CTHC: computer-tailored health communication
NIH: National Institutes of Health
NSF: National Science Foundation

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Original Paper

Web-Based Interventions Targeting Cardiovascular Risk Factors in Middle-Aged and Older People: A Systematic Review and Meta-Analysis

Cathrien RL Beishuizen[1], MSc, MD; Blossom CM Stephan[2], PhD; Willem A van Gool[1], MD, PhD; Carol Brayne[3], MD; Ron JG Peters[4], MD, PhD; Sandrine Andrieu[5], MD, PhD; Miia Kivipelto[6], MD, PhD; Hilkka Soininen[7], MD, PhD; Wim B Busschers[8], MSc; Eric P Moll van Charante[8], MD, PhD; Edo Richard[1,9], MD, PhD

[1]Academic Medical Center, Department of Neurology, University of Amsterdam, Amsterdam, Netherlands
[2]Institute of Health and Society, Newcastle University Institute for Ageing, Newcastle University, Newcastle upon Tyne, United Kingdom
[3]Cambridge Institute of Public Health, Department of Public Health and Primary Care, University of Cambridge, Cambridge, United Kingdom
[4]Academic Medical Center, Department of Cardiology, University of Amsterdam, Amsterdam, Netherlands
[5]Inserm U1027, Department of Epidemiology and Public Health, Toulouse University Hospital, Toulouse, France
[6]Aging Research Center, Alzheimer Disease Research Center, Karolinska Institutet, Stockholm, Sweden
[7]Department of Neurology, University of Eastern Finland and Kuopio University Hospital, Kuopio, Finland
[8]Academic Medical Center, Department of General Practice, University of Amsterdam, Amsterdam, Netherlands
[9]Department of Neurology, Radboud University Medical Center, Nijmegen, Netherlands

Corresponding Author:
Edo Richard, MD, PhD
Academic Medical Center
Department of Neurology
University of Amsterdam
PO Box 22660
Amsterdam, 1100 DD
Netherlands
Phone: 31 20 5663446
Fax: 31 20 5669290
Email: e.richard@amc.uva.nl

Abstract

Background: Web-based interventions can improve single cardiovascular risk factors in adult populations. In view of global aging and the associated increasing burden of cardiovascular disease, older people form an important target population as well.

Objective: In this systematic review and meta-analysis, we evaluated whether Web-based interventions for cardiovascular risk factor management reduce the risk of cardiovascular disease in older people.

Methods: Embase, Medline, Cochrane and CINAHL were systematically searched from January 1995 to November 2014. Search terms included cardiovascular risk factors and diseases (specified), Web-based interventions (and synonyms) and randomized controlled trial. Two authors independently performed study selection, data-extraction and risk of bias assessment. In a meta-analysis, outcomes regarding treatment effects on cardiovascular risk factors (blood pressure, glycated hemoglobin A1c (HbA1C), low-density lipoprotein (LDL) cholesterol, smoking status, weight and physical inactivity) and incident cardiovascular disease were pooled with random effects models.

Results: A total of 57 studies (N=19,862) fulfilled eligibility criteria and 47 studies contributed to the meta-analysis. A significant reduction in systolic blood pressure (mean difference –2.66 mmHg, 95% CI –3.81 to –1.52), diastolic blood pressure (mean difference –1.26 mmHg, 95% CI –1.92 to –0.60), HbA1c level (mean difference –0.13%, 95% CI –0.22 to –0.05), LDL cholesterol level (mean difference –2.18 mg/dL, 95% CI –3.96 to –0.41), weight (mean difference –1.34 kg, 95% CI –1.91 to –0.77), and an increase of physical activity (standardized mean difference 0.25, 95% CI 0.10-0.39) in the Web-based intervention group was found. The observed effects were more pronounced in studies with short (<12 months) follow-up and studies that combined the Internet application with human support (blended care). No difference in incident cardiovascular disease was found between groups (6 studies).

Conclusions: Web-based interventions have the potential to improve the cardiovascular risk profile of older people, but the effects are modest and decline with time. Currently, there is insufficient evidence for an effect on incident cardiovascular disease. A focus on long-term effects, clinical endpoints, and strategies to increase sustainability of treatment effects is recommended for future studies.

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KEYWORDS

eHealth; cardiovascular disease; prevention; older people; aging; systematic review; meta-analysis

Introduction

The field of eHealth is expanding the potential of contemporary medicine [1]. Global aging and its associated burden of cardiovascular disease may expand the scope for innovative Internet interventions [2,3]. Current cardiovascular risk management programs in primary care will become too expensive and, although they are highly effective in research settings [4-6], their effectiveness is markedly lower in daily life [7]. This evidence-practice gap has several causes [8]. Adherence to life-long lifestyle and medication regimens is a serious challenge, illustrated by long-term adherence rates in chronic diseases that average as low as 50% [9,10]. Web-based interventions are cheap, have a wide reach, and they enable self-management [11]. This renders Web-based interventions potentially powerful and scalable tools to enhance sustained adherence in cardiovascular risk management [12].

Older people form an important target population because cardiovascular risk reduction appears effective until old age [13-16]. In 2012, 42% of European people aged between 55 and 74 years used the Internet and this number is increasing [17]. Meta-analyses showed that Web-based interventions targeting single cardiovascular risk factors can induce improvements in adult populations [18-21]. However, optimal cardiovascular prevention and risk management practice, as affirmed by the European Society of Cardiology [22] and the American Heart Association [23], requires targeting the complete cardiovascular risk profile. This is particularly applicable for older people, who often have multiple risk factors or already suffered a cardiovascular event. A comprehensive approach would increase the value of Web-based interventions for daily practice. Currently, little is known about the effectiveness of Web-based interventions in older people.

In this systematic review and meta-analysis, we aim to answer the question whether Web-based interventions for cardiovascular risk factor management reduce cardiovascular risk and disease in older people.

Methods

Search Strategy and Selection of Eligible Studies

We performed a systematic literature search for randomized controlled trials (RCT) on Web-based interventions in older people targeting one or more cardiovascular risk factors and/or disease. Methods were predefined in a research protocol using the PRISMA checklist and the Systematic Reviews Guidelines of the Center of Reviews and Dissemination (Multimedia Appendix 1). We defined Web-based interventions as Web-based participant-centered treatment or prevention programs delivered via the Internet and interacting with the participant in a tailored fashion [24,25]. Internet had to be the main medium through which the intervention was delivered, but other media (phone, face-to-face) could be included too. We excluded the following eHealth interventions: telemonitoring, telemedicine, and mobile phone-mediated interventions. The target of the intervention had to be one or more cardiovascular risk factors and/or cardiovascular disease. Thus, we included interventions for both primary and secondary prevention of cardiovascular disease [22]. The target population had to have a mean age of 50 years or older and could have a mixed level of cardiovascular risk (one or more cardiovascular risk factors or established cardiovascular disease).

Main outcomes of interest were incident cardiovascular disease (myocardial infarction, angina pectoris, heart failure, stroke or transient ischemic attack, and peripheral arterial disease), cardiovascular mortality and overall mortality, and changes in cardiovascular risk factors including blood pressure (BP), glycated hemoglobin A_{1c} (HbA_{1c}), low-density lipoprotein (LDL) cholesterol, smoking status, weight, level of physical exercise, or a composite cardiovascular risk score.

We performed a comprehensive literature search in the EMBASE, Medline, CINAHL, and Cochrane databases from 1995 onward (because the Internet was not widely available before then). Key search terms were cardiovascular risk factors and diseases (separate diseases and risk factors specified), terms related to aspects of cardiovascular risk management (eg, diet, exercise, BP control), Web-based interventions (including all definitions and synonyms), and RCT/review/meta-analysis. The search was last updated on November 3, 2014 by CRB. The comprehensive search strategy is provided in Multimedia Appendix 2. Studies were included if (1) they were on Web-based interventions targeting cardiovascular risk factors and/or disease, (2) study design was a RCT, (3) at least 50 patients were included, (4) mean age was at least 50 years, (5) the duration of the intervention was 4 or more weeks and follow-up was 3 or more months, (6) at least one of the outcomes of our interest was reported, and (7) language was English. Study selection was performed by two independent researchers (CRB and BS) by means of screening of titles and abstracts, and thereafter reading full texts on the basis of the inclusion criteria. If two publications described the same trial, the paper that reported the primary outcomes of the trial was included. Disagreements were resolved by discussion or by a third investigator (ER). We assessed reviews and meta-analyses encountered with our search strategy to check for additional relevant articles.

Data Extraction

Two reviewers (BS and CRB) extracted data using a predefined data extraction form (Multimedia Appendix 3) for half of the included articles and checked each other's results. Extracted information included study characteristics, patient baseline characteristics, characteristics of the intervention and control conditions, and available data on clinical and intermediate outcomes. For BP, glucose control, weight, lipids, and physical activity level, we extracted all baseline and follow-up levels, change scores or mean differences. Corresponding authors were contacted if needed. We used an adapted Cochrane Risk of Bias Tool to evaluate randomization procedures, representativeness of study populations, blinding of outcome assessors (blinding of participants was usually not possible due to study design), completeness of outcome data, and completeness of reporting.

Meta-Analysis

For categorical variables, we calculated odds ratios with 95% confidence intervals. We estimated pooled odds ratios with Mantel-Haenszel random-effects models. For continuous outcomes, mean differences or standardized mean differences (Hedges' *g* effect sizes) with 95% confidence intervals were calculated. We estimated pooled effects with DerSimonian and Laird random-effects models. All HbA_{1c} values were converted to percentages. All LDL cholesterol values were converted to mg/dL. All weight values were converted to kg. For level of physical activity, which was assessed with various instruments, we calculated standardized mean differences and 95% confidence intervals. If mean differences or standardized mean differences were reported, we included them directly in the pooled analyses. If not, we calculated change scores (difference between baseline and follow-up within group) or values assessed at follow-up. If values were measured at multiple time points, we used the values recorded at the last follow-up contact.

For studies with multiple arms, we included only one intervention arm in the meta-analysis in order not to create "unit-of-analysis" error by double counting the control group. Where possible, we selected the Internet-only intervention arm. No data were imputed.

We estimated pooled effects for all single cardiovascular risk factors. To address the overall question of efficacy of Web-based interventions for cardiovascular risk factor management, we evaluated the effect on cardiovascular composite scores, clinical outcomes (cardiovascular morbidity and mortality), and pooled the standardized primary outcomes of all studies. We used the primary outcomes as defined by the authors of the studies.

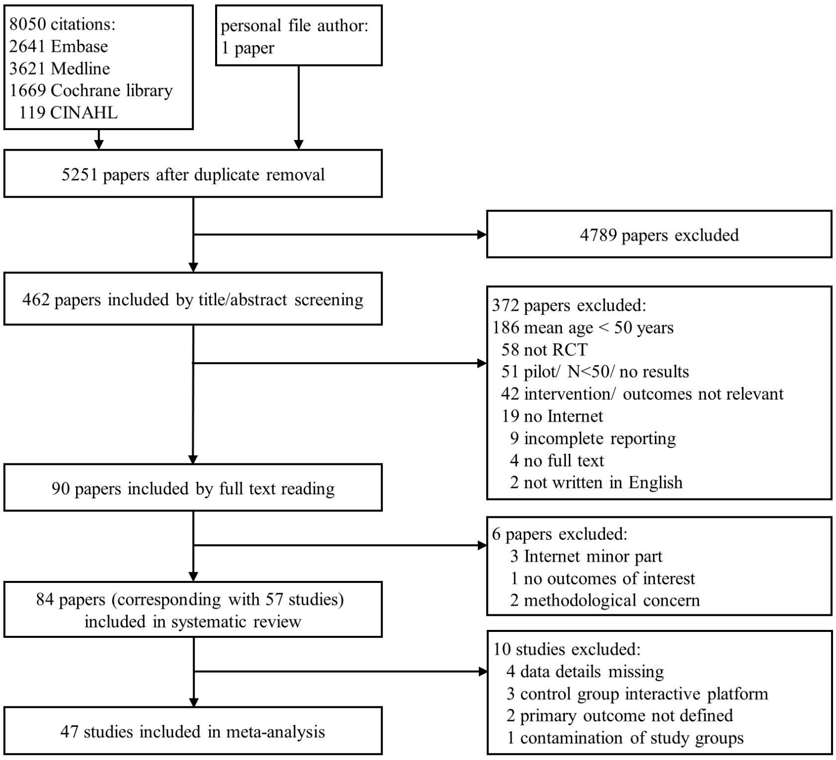
Funnel plots were inspected to assess for potential publication bias. Statistical heterogeneity was assessed using Q and I^2 tests. We explored reasons for heterogeneity by jackknife analysis and subgroup analyses. We assessed the following factors in subgroup analyses: study duration (predefined, short term [<12 months] versus long term [≥12 months]), type of cardiovascular prevention (primary versus secondary) [22], and type of intervention (Internet only or "blended" [Internet application combined with human support]). Subgroup analyses were performed on the studies used for the analysis on primary outcomes only. The latter subgroup analysis (on type of intervention) consisted of two separate analyses, one to evaluate the Internet-only interventions versus the control conditions and one to evaluate the blended interventions versus control conditions. In case a study tested both types of interventions with a multiple-arm design, the appropriate arm was included for each analysis. In addition, we performed a mixed effects meta-regression using the unrestricted maximum likelihood method to explore the association between study duration and effect size (standardized primary outcome). Last, we performed sensitivity analyses for the different domains of the risk-of-bias assessment by repeating the analysis on standardized primary outcomes in subgroups of studies with low risk of bias versus studies with an unclear or high risk of bias. For this analysis, we wanted to include all studies that contributed to one of the meta-analyses. Therefore, we complemented the sample of studies with defined primary outcomes that were cardiovascular risk factors of interest with studies that had not defined their primary outcome. If there was no defined primary outcome, we used the cardiovascular risk factor that was targeted most directly in the intervention studied. We used Review Manager 5.2 to draw the risk-of-bias assessment figure and to calculate standard deviations or 95% confidence intervals in cases where only standard errors were available in the original data. We used Microsoft Office Excel version 10, SPSS version 20, and Comprehensive Meta Analysis version 2.2.064 for the statistical analyses.

Results

Study Selection

The search yielded 5251 papers after removal of duplicates. We did not identify additional studies by searching reference lists. After screening of titles and abstracts, 462 papers remained. Review of these full texts resulted in 57 RCTs (corresponding with 84 papers) that fulfilled the selection criteria and were included in the systematic review. We contacted 16 authors to request additional data: nine authors responded and three authors complied with our request. Out of this final selection, 47 studies could be included in the meta-analysis (see Figure 1 for PRISMA flowchart).

Figure 1. Prisma flowchart illustrating literature search.



Study Characteristics

The 57 RCTs included 19,862 individuals (Tables 1-5). Study sample size ranged from 61 to 2140 participants. Median study duration was 9 months (interquartile range [IQR] 6, range 3-60 months). The mean dropout rate was 15% (range 0%-62%). The mean age of the study populations ranged from 50 to 71 years. In only 7 studies were all participants older than 50 years of age. All participants had an increased risk of cardiovascular disease: 46 studies conducted primary prevention (control of cardiovascular risk factors or diabetes) and 11 studies conducted secondary prevention. In 41 studies, the intervention targeted a single cardiovascular risk factor; in 16 studies, multiple risk factors were addressed. We found no studies on interventions for smoking cessation meeting our inclusion criteria. In most studies, the primary outcome was change in a specific cardiovascular risk factor targeted by the intervention. Sixteen studies reported on clinical outcomes including new cardiovascular events [26-31] and mortality rates [29-41] as a part of adverse event monitoring. All interventions included lifestyle education and were participant-centered. Forty-four studies stimulated self-management by means of goal setting and self-monitoring. Half of interventions were stand-alone Internet platforms and the other half were “blended” (ie, the platforms were supported by a nurse or another health care professional). Intervention usage was reported by 22 studies. The median percentage of participants logging in to the intervention platform was 72% (range 33%-100%).

Quality Assessment

Methodological quality of the included studies varied (Multimedia Appendix 4). Most studies adequately described the randomization and allocation concealment procedures. Due to the nature of the interventions, none of the studies had a double-blind design. In 20 studies, outcome assessors were blinded [27,29,30,32,34-40,42,52,54,57,59,61,64,67,81], in 19 studies blinding was not mentioned or unclear [28,31,33,41,43,44,46,48,53,56,60,63,65,69,71,74,76,77,80], and in 18 studies outcome assessors were not blinded [26,45,47,49-51,55,58,62,66,68,70,72,73,75,78,79,82].

Effect of Web-Based Interventions on Single Risk Factors

Of the 57 studies included in the systemic review, 47 studies [26-32,34-42,44-53,55-60,62,64-68,70,73,74,76-79,81,82] provided sufficient information to be included in the meta-analysis. The mean age of the study populations of these 46 studies had the same range as the complete sample of 57 studies.

Systolic and Diastolic Blood Pressure

The pooled analysis showed a significant reduction in both systolic and diastolic BP favoring the intervention (26 studies; n=7720; Figures 2 and 3). For systolic BP, the weighted mean difference was –2.66 mmHg (95% CI –3.81 to –1.52; I^2=53%). For diastolic BP, the weighted mean difference was –1.26 mmHg (95% CI –1.92 to –0.60; I^2=46%).

Table 1. Characteristics of the studies included for the systematic review: interventions targeting diabetes.[a]

Study	Setting and study length	Participants	Age (years), mean (SD)	Sex (% female)	Intervention	Control	Primary; secondary outcomes
Bond 2010 [42]	2-arm RCT; USA; 6 m	62 people with DM via university/veteran clinic	67.2 (6.0)	45	Website: education, self-monitoring (glucose, exercise, weight, BP, medication), forum; nurse support (email, chat)	Standard diabetes care	HbA_{1c}, BP, weight, total cholesterol, HDL cholesterol
IDEATEL 2000-2010 [34]	2-arm RCT; USA; 60 m	1665 Medicare recipients with DM	70.9 (6.7)	63	Online home telemedicine unit: nurse support (video chat), Web portal for self-monitoring (glucose, BP), education	Standard diabetes care	HbA_{1c}, systolic BP, diastolic BP, total cholesterol, LDL cholesterol
D-net 2001 [43]	4-arm RCT; USA; 10 m	320 people with DM2, Internet, from 16 GPs	59 (9.2)	53	Website: (1) Self-management (glucose), coach support; (2) education, forum; (3) 1 and 2 combined[b]	(4) Information on medical and lifestyle aspects of diabetes	Not defined; behavioral, biological, and psychosocial outcomes
My path 2010 [44]	3-arm RCT; USA; 12 m	463 Medicare recipients with DM2, BMI ≥25 kg/m^2 or ≥1 CV risk factor, Internet	58.4 (9.2)	50	(1) Website for computer-assisted self-management(CASM): goal setting, monitoring (HbA_{1c}, BP, cholesterol), forum, education;[b,c] (2) CASM+ social support (coach, group sessions)[b,c]	(3) Computer-based health risk appraisal, no key features of CASM	Behavior changes in diet, physical activity, medication adherence
My care team 2005 [45]	2-arm RCT; USA; 12 m	104 people with DM, HbA_{1c} ≥9.0% via veteran clinic	63.5 (7.0)	0.5	Website: self-management (glucose, BP), education, reminders (phone); care manager support	DM self-management training, usual care	HbA_{1c} and BP at 3, 6, 9, and 12 m
Mobile DM 2011 [32]	4-arm cluster RCT; USA; 12 m	26 physician practices with 163 people with DM and HbA_{1c} ≥7.5%	52.8 (8.1)	50	(2) Self-management via website + mobile phone, patient informs doctor;[b] (3) 2 + doctor access to data; (4) 3 + advice from doctor[c]	(1) Care as usual	Change in HbA_{1c} over 1 year
Avdal 2011 [46]	2-arm RCT; Turkey; 6 m	122 people with DM2, Internet from clinic	51 (7.3)	51	Website: review risk profile, messaging to researcher, daily glucose monitoring	Education and usual care	HbA_{1c}, attendance rates at outpatient clinic
Cho 2006 [47]	2-arm RCT; South Korea; 30 m	80 people with DM, Internet from clinic	53 (9)	39	Website: monitoring (glucose, medication, BP, weight, lifestyle), nurse feedback, medication alterations	Conventional note-keeping record system	HbA_{1c} and HbA_{1c} fluctuation index
Lorig 2010 [48]	3-arm RCT; USA; 6 m	761 people with DM2, Internet	54.3 (9.9)	73	Self-management website with peer support: lessons, action plans, bulletin board, messaging	Care as usual	HbA_{1C} level at 6 and 18 months
Grant 2008 [49]	2-arm cluster RCT; USA; 12 m	244 people with DM, HbA_{1c} >7.0% from 11 primary clinics	56.1 (11.6)	49	Online personal health record: education, diabetes care plan, agenda, messaging, prescription refills	Access to general website Patient Gateway	Changes in HbA_{1c}, BP, and LDL cholesterol
McMahon 2012 [50]	3-arm RCT; USA; 12 m	151 people with DM, HbA_{1c}>8.5% from veteran health services	60.2 (10.8)	5	(1) Self-monitoring via phone (BP, glucose); (2) website: self-monitoring (BP, glucose), education, support by care managers[b,c]	(3) Website with links to other DM websites; usual care	Change in HbA_{1c} and BP over time

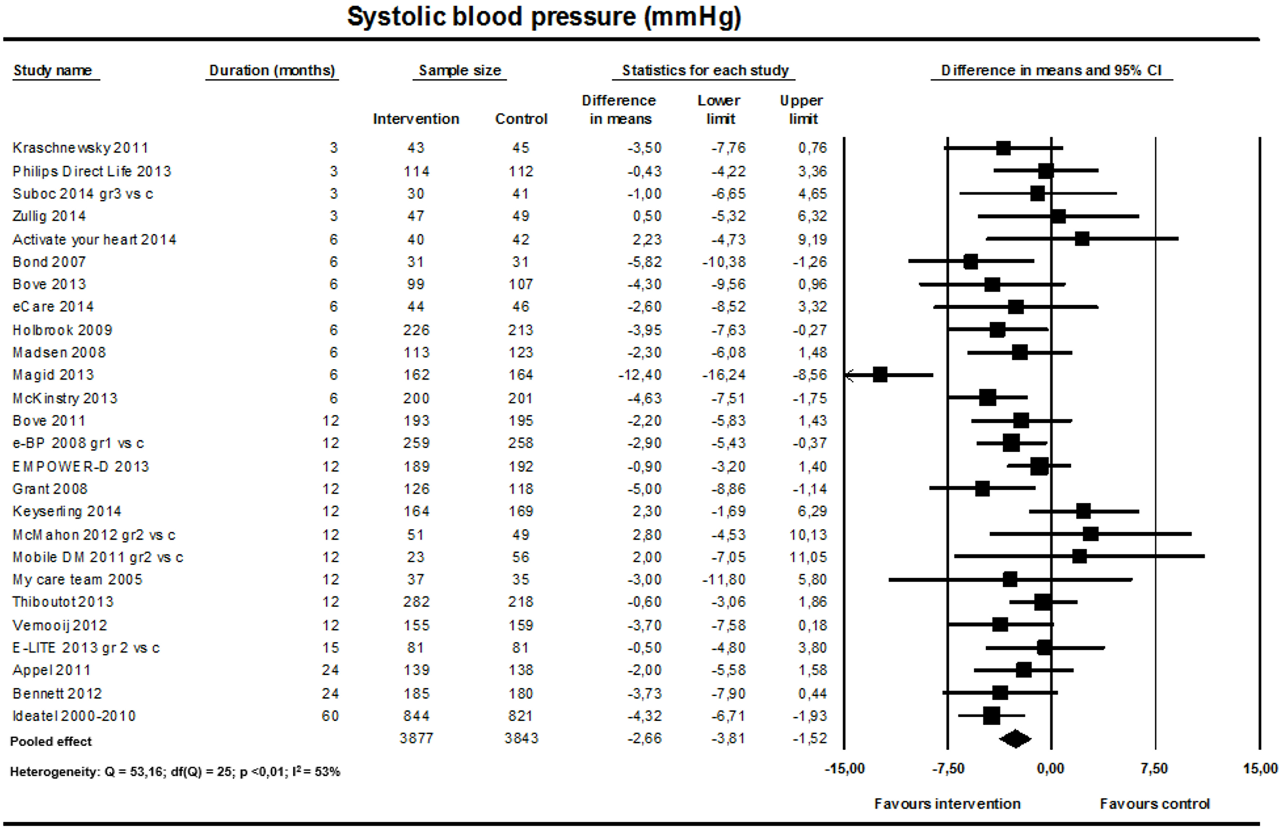
Study	Setting and study length	Participants	Age (years), mean (SD)	Sex (% female)	Intervention	Control	Primary; secondary outcomes
Ralston 2009 [51]	2-arm RCT; USA; 12 m	83 people with DM2, HbA_{1c}≥7.0% and Internet from clinic: 65% with 2 CV risk factors	57.3 (—)	52	Electronic medical record: self-monitoring (glucose, exercise, diet, medication), support by care manager, usual care visits	Usual care visits	Change in HbA_{1c}
Kwon 2004 [52]	2-arm RCT; South Korea; 3 m	110 people with DM2, Internet from clinic: 27% hypertension	54.1 (9.1)	33	Website: self-monitoring (glucose), reminders, professor/nurse/dietician-support	Monthly visit to diabetes specialist	HbA_{1c}
EMPOWER-D 2013 [39]	2-arm RCT; USA; 12 m	415 people with DM and HbA_{1c} ≥7.5% from clinic	53.7 (10.2)	40	Online health record: risk estimation, self-monitoring (glucose, diet, exercise, BP), nurse support, own doctor informed	Usual care	HbA_{1c} at 12 m
RE-DEEM 2013 [53]	3-arm RCT; USA; 12 m	392 people with DM2, Internet from community centers	56.1 (9.6)	54	(1) CASM website: goal setting; self-monitoring (HbA_{1c}, BP, cholesterol); 8 phone calls;[b] (2) Computer-assisted self-management + problem solving treatment (CASP): CASM + 8 sessions problem solving	Computer health risk appraisal, education, same phone calls as intervention	Diabetes distress; HbA_{1c}, physical activity, medication compliance

[a] Abbreviations: BP: blood pressure; CASM: computer-assisted self-management; CASP: computer-assisted self-management + problem solving treatment; CV: cardiovascular; DM: diabetes mellitus; DM2: type 2 diabetes mellitus; GP: general practitioner; HbA1c; glycated hemoglobin A1c; HDL: high-density lipoprotein; LDL: low-density lipoprotein.

[b] For studies with more than 2 arms, this arm was used for all analyses.

[c] For studies with more than 2 arms, this arm was used for the subgroup analysis on blended interventions.

Figure 2. Effect on systolic blood pressure (26 studies).



Study name	Duration (months)	Sample size: Intervention	Sample size: Control	Difference in means	Lower limit	Upper limit
Kraschnewsky 2011	3	43	45	-3,50	-7,76	0,76
Philips Direct Life 2013	3	114	112	-0,43	-4,22	3,36
Suboc 2014 gr3 vs c	3	30	41	-1,00	-6,65	4,65
Zullig 2014	3	47	49	0,50	-5,32	6,32
Activate your heart 2014	6	40	42	2,23	-4,73	9,19
Bond 2007	6	31	31	-5,82	-10,38	-1,26
Bove 2013	6	99	107	-4,30	-9,56	0,96
eCare 2014	6	44	46	-2,60	-8,52	3,32
Holbrook 2009	6	226	213	-3,95	-7,63	-0,27
Madsen 2008	6	113	123	-2,30	-6,08	1,48
Magid 2013	6	162	164	-12,40	-16,24	-8,56
McKinstry 2013	6	200	201	-4,63	-7,51	-1,75
Bove 2011	12	193	195	-2,20	-5,83	1,43
e-BP 2008 gr1 vs c	12	259	258	-2,90	-5,43	-0,37
EMPOWER-D 2013	12	189	192	-0,90	-3,20	1,40
Grant 2008	12	126	118	-5,00	-8,86	-1,14
Keyserling 2014	12	164	169	2,30	-1,69	6,29
McMahon 2012 gr2 vs c	12	51	49	2,80	-4,53	10,13
Mobile DM 2011 gr2 vs c	12	23	56	2,00	-7,05	11,05
My care team 2005	12	37	35	-3,00	-11,80	5,80
Thiboutot 2013	12	282	218	-0,60	-3,06	1,86
Vernooij 2012	12	155	159	-3,70	-7,58	0,18
E-LITE 2013 gr 2 vs c	15	81	81	-0,50	-4,80	3,80
Appel 2011	24	139	138	-2,00	-5,58	1,58
Bennett 2012	24	185	180	-3,73	-7,90	0,44
Ideatel 2000-2010	60	844	821	-4,32	-6,71	-1,93
Pooled effect		3877	3843	-2,66	-3,81	-1,52

Heterogeneity: Q = 53,16; df(Q) = 25; p <0,01; I^2 = 53%

Table 2. Characteristics of the studies included for the systematic review: interventions targeting blood pressure.[a]

Study	Setting and study length	Participants	Age (years), mean (SD)	Sex (% female)	Intervention	Control	Primary; secondary outcomes
e-BP 2008 [29]	3-arm RCT; USA; 12 m	778 people with Internet, hypertension, from GPs: 61.1% obese	59.1 (8.5)	52	(1) Website: BP self-monitoring;[b] (2) 1 + pharmacist support[c]	General website: personal medical record	Change in diastolic, systolic and mean BP
Nolan 2012 [54]	2-arm RCT; Canada; 4 m	387 people with hypertension via website: 41% obese	56.5 (7.4)	59	BP action plan website: assessing motivational readiness, advice, feedback, education	E-newsletters	Change in diastolic and systolic BP, and pulse pressure
Bove 2013 [55]	2-arm RCT; USA; 6 m	241 people with elevated BP from 2 clinics	59.6 (13.6)	65	Website + telephone system: education, self-monitoring (BP, weight, exercise), online nurse support, doctor informed	Provision of data from initial assessment, usual care	Proportion of participants with controlled BP at 6 m
Madsen 2008 [56]	2-arm RCT; Denmark; 6 m	236 people with hypertension from 10 GPs	55.9 (11.7)	50	Website: self-monitoring (BP), feedback from own doctor by email	Usual care	Change in ambulatory systolic BP -at 6 m
Magid 2013 [57]	2-arm RCT; USA; 6 m	348 people with hypertension from 10 clinics	60 (11)	40	Written educational material, website: self-monitoring (BP), pharmacist support, doctor informed, reminders	Written education material, usual care	Proportion of participants with controlled BP at 6 m
McKinstry 2013 [38]	2-arm RCT; Scotland; 6 m	401 people with hypertension from 20 GPs	60.7 (11.2)	40	Telemonitoring unit + website: self-monitoring (BP), feedback from own doctor	Usual care	Mean ambulatory BP at 6 m
Thiboutot 2013 [58]	2-arm cluster RCT; USA; 12 m	500 patients with elevated BP from 54 GPs	60.5 (11.9)	58	Website: self-monitoring (BP, medication), feedback, reminders	Different prevention website (eg, breast screening)	BP control at 12 m

[a] Abbreviations: BP: blood pressure; GP: general practitioner.

[b] For studies with more than 2 arms, this arm was used for all analyses.

[c] For studies with more than 2 arms, this arm was used for the subgroup analysis on blended interventions.

Table 3. Characteristics of the studies included for the systematic review: interventions targeting weight loss and weight loss maintenance.[a]

Study	Setting and study length	Participants	Age (years), mean (SD)	Sex (% female)	Intervention	Control	Primary; secondary outcomes
Weight loss							
Appel 2011 [35]	3-arm RCT; USA; 24 m	415 people with obesity, ≥1 CV risk factor, Internet from 6 primary clinics	54 (10.2)	64	(1) Website + mobile coach support: education, self-monitoring (weight, diet, exercise), reminders, doctor informed;[b,c] (2) 1 + in-person support	1 (or 2) meetings with coach; brochure with websites for weight loss	Change in weight from baseline to 24 m
Bennett 2012 [28]	2-arm RCT; USA; 24 m	365 obese people with hypertension from 3 clinics	54.6 (10.9)	69	Website/interactive voice response system: self-monitoring weight, setting, coach support (phone), group sessions, education	Self-help booklet	Change in weight at 24 m
Bennett 2010 [59]	2-arm RCT; USA; 3 m	101 obese people with hypertension, Internet from clinic	54.4 (8.1)	48	Website: goal setting, self-monitoring, behavioral skills education, forum, coach support (online, phone, face-to-face)	Folder on healthy weight, usual care	Change in weight at 12 weeks
Kraschnewsky 2011 [60]	2-arm RCT; USA; 3 m	100 overweight people, Internet via flyers/Internet	50.3 (10.9)	70	Website: target body weight, monitoring, behavioral tips, videos, weight loss plan, tailored feedback, reminders	Wait list, people got access to website after 12 weeks	Weight loss
Webber[d] 2008 [61]	2-arm RCT; USA; 4 m	66 women, BMI 25-40, Internet from advertisements	50.0 (9.9)	100	Website: weight loss tips, lessons, message board, self-monitoring (weight, diet), chat sessions	All features of intervention except for online chat sessions	Not defined; weight, BMI, diet, exercise
E-LITE 2013 [36]	3-arm RCT; USA; 15 m	241 people with a BMI ≥25, metabolic syndrome from 1 clinic	52.9 (10.6)	47	(1) Website + 12 lifestyle classes;[c] (2) website: self-monitoring (weight, exercise), messaging, DVD with lifestyle classes[b]	Usual care	Change in BMI from baseline to 15 m
POWER 2014 [62]	4-arm RCT; UK; 12 m	179 people with BMI ≥30 kg/m^2 or ≥28 kg/m^2 + CV risk factors from 5 GPs	51.2 (13.1)	66	(1) Website: 12 self-management sessions monitoring (weight), nurse support (email);[b,c] (2) 1 + 3 nurse contacts; (3) 1 + 7 nurse contacts	Usual care	Weight at 12 m
Weight loss maintenance							
Stop Regain 2008 [41]	3-arm RCT; USA; 18 m	314 people with 10% weight loss in 2 years, via advertisements	51 (10)	81	(1) Website: self-monitoring, email counseling, experts chat;[b] (2) face-to-face: self-monitoring via phone, weekly group sessions	(3) Newsletters	Weight gain at 18 m
WLM 2008 [40]	2-phase 3-arm RCT; USA; 30 m	1032 people with ≥4 kg previous weight loss, hypertension, Internet via university/ medicare	55.6 (8.7)	63	(1) Website: goal setting, action plans, self-monitoring (weight, PA, diet), education, bulletin board, reminders, support (email/phone);[b] (2) personal contact (phone +face-to-face)	Printed lifestyle guidelines, 1 visit with coach	Change in weight

[a] Abbreviations: BMI: body mass index; CV: cardiovascular; GP: general practitioner; PA: physical activity.

[b] For studies with more than 2 arms, this arm was used for all analyses.

[c] For studies with more than 2 arms, this arm was used for the subgroup analysis on blended interventions.

[d] Control arm consists of same interactive Internet platform as intervention arm.

Table 4. Characteristics of the studies included for the systematic review: interventions targeting physical activity and cholesterol.[a]

Study	Setting and study length	Participants	Age (years), mean (SD)	Sex (% female)	Intervention	Control	Primary; secondary outcomes
Physical activity							
Richardson[b] 2010 [63]	2-arm RCT; USA; 4 m	324 patients from clinic: 12% CHD, 20% DM2, 62% BMI >30	52.0 (11.4)	65	Website as control + online community forum	Website: pedometer, tailored feedback	Change in average daily step count, patient attrition
Reid 2011 [30]	2-arm RCT; Canada; 12 m	223 patients with a recent CHD event, Internet via 2 cardiac centers	56.4 (9.0)	16	Website: tutorials, exercise plans, self-monitoring, specialist support	Usual care, education booklet	Mean steps per day
Ferney 2009 [64]	2-arm RCT; Australia; 6 m	106 inactive residents: 58% overweight	52.0 (4.6)	72	Website: behavioral strategies, goal setting, self-monitoring, advice, bulletin board, news	Website with minimal interactivity	Not defined; physical activity, website use
Active after 55 2013 [65]	2-arm RCT; USA; 3 m	405 sedentary people with Internet via senior centers/websites	60.3 (4.9)	69	Website: education, goal setting, exercise planning, 11 online exercise lessons, self-monitoring, reminders	No access to the intervention	Not defined; physical activity, BMI
HEART 2014 [37]	2-arm RCT; New Zealand; 6 m	171 people with stable CHD, Internet from 2 hospitals	60.2 (9.2)	19	Exercise prescription, behavioral strategies, Website: videos, self-monitoring (exercise), education, reminders	Usual care	Change in peak oxygen uptake from baseline to 6 m
Philips Direct Life 2013 [66]	2-arm RCT; Netherlands; 3 m	235 inactive people with Internet through local media	64.8 (2.9)	41	Website: goal setting, self-monitoring (exercise), e-coach feedback	Waitlist control	Change in physical activity
Suboc 2014 [67]	3-arm RCT; USA; 3 m	114 sedentary people through media and Internet	63.0 (7.0)	34	(1) Pedometer; (2) website + pedometer: exercise strategies, goal setting, self-monitoring (exercise) feedback, forum[c]	No intervention	Endothelial function; vascular stiffness, step count, exercise
Peels 2013 [68]	5-arm cluster RCT; Netherlands; 12 m	2140 people from 6 municipal regions, ±50% overweight	63.2 (8.4)	51	(1) Printed feedback report; (2) 1 + local exercise tips; (3) Web-based feedback report; (4) 3 + local exercise tips[c]	Waitlist control	Physical activity
Cholesterol							
Bloch[b] 2006 [69]	3-arm RCT; USA; 6 m	171 employees with increased cholesterol, DM or CHD	54.8 (9.4)	—	(1) Website + financial reward; (2) website + 4 classes, nurse support (phone)	Website, 10-year CVD score, monitoring, goals, tailored info	LDL cholesterol change at 6 m
Live well 2013 [70]	2-arm RCT; USA; 3 m	61 people with LDL cholesterol ≥3.37 mmol/L, Internet from primary clinics	52.0 (12.8)	75	Web-based rate-your-plate assessment, written educational material, Website: goal setting, self-monitoring, reminders	Web-based rate-your-plate assessment	Not defined; cholesterol, weight, Framingham risk score

[a] Abbreviations: BMI: body mass index; CHD: coronary heart disease; CVD: cardiovascular disease; DM: diabetes mellitus; DM2: type 2 diabetes mellitus; LDL: low-density lipoprotein.

[b] Control arm consists of same interactive Internet platform as intervention arm.

[c] For studies with more than 2 arms, this arm was used for all analyses.

Table 5. Characteristics of the studies included for the systematic review: interventions targeting multiple risk factors.[a]

Study	Setting and study length	Participants	Age (years), mean (SD)	Sex (% female)	Intervention	Control	Primary; secondary outcomes
Lindsay 2008 [71]	2-arm RCT; UK; 6 m	108 heart patients living in deprived areas	62.9 (6.0)	33	eHealth portal: glossary, education, local community links, discussion forum	No access to the eHealth portal	Not defined; behavior change (exercise, smoking, diet)
Heartcare II 2010 [72]	2-arm cluster RCT; USA; 30 m	282 patients with chronic heart disease needing nursing care	64.0 (12.7)	39	Personal health record: education, monitoring, communication, goal setting, email, bulletin board	Usual care as the home care agencies use to provide	Satisfaction with nursing care
Hughes 2011 [73]	3-arm RCT; USA; 12 m	423 senior university employees with Internet, 32% overweight, 46% obese	51.0 (7.0)	82	(1) Coach for Web-based risk assessment, lifestyle plan, email, phone or in-person contact;[c] (2) website: risk profile assessment, advice, goal setting, action planning[b]	Printed list of health promotion programs	Not defined; diet, exercise, weight
Southard 2003 [26]	2-arm RCT; USA; 6 m	104 patients with CHD or heart failure from 10 hospitals, 200 GPs, adverts	62.3 (10.6)	25	Website + nurse: education, self-monitoring, discussion group, links contact (email, phone or mail), dietician	Usual care	Not defined; weight, exercise, BP, lipid profile, new CV events
Winett 2007 [74]	3-arm cluster RCT; USA; 16 m	14 churches with 1071 members: 57% overweight, 60% sedentary	51.4 (15.7)	67	(1) Website: education, goal setting, pedometer;[b] (2) 1 + pulpit support[c]	Waitlist condition	Nutrition improvement, physical activity
Vernooij 2012 [27]	2-arm RCT; Netherlands; 12 m	330 patients with CVD, 2 risk factors, Internet via 2 hospitals	59.9 (8.4)	25	Website: risk profile, self-monitoring (BP, cholesterol), treatment goal, nurse support, news, medication changes	Usual care by specialist or GP, receiving baseline risk profile	Relative change in Framingham heart risk score after 1 year
Verheijden 2004 [75]	2-arm RCT; Canada; 8 m	146 people with increased CV risk, Internet from 14 GPs	63.0 (10.5)	45	Website: tailored information, diet tool, bulletin board	Usual care	Not defined; BMI, BP, lipid profile
Ross 2004 [33]	2-arm RCT; USA; 12 m	107 patients with heart failure, Internet via clinic	56.0 (-)	23	Online medical record (clinical notes, laboratory reports, test results), education, nurse support	Usual care	Change in self-efficacy domain
Bove 2011 [76]	2-arm RCT; USA; 12 m	465 people with CVD risk >10% via community, clinics, churches	61.0 (10.0)	46	Online telemedicine system: laboratory and medication review, self-monitoring (BP, weight, pedometer), feedback, education, own doctor involved	4-months meetings with nurse: review data from logbooks	Reduction in Framingham 10-year CVD risk score
Keyserling 2014 [31]	2-arm RCT; USA; 12 m	385 people with CHD risk score ≥10% but no CVD from 5 GPs	62.0 (7.8)	48	Website: CHD risk calculator, advice, education, action planning, goal setting.	Same CHD risk calculator, but in-person and by phone	Framingham 10-year CHD risk score at 4 and 12 m
Zullig 2014 [77]	2-arm RCT; USA; 3 m	96 people with CVD or DM from primary clinics	36.1 (12.2)	67	CVD risk assessment, website: 6 modules with risk assessments, goal setting, education	Printed information on CVD	Not defined; Framingham 10-year CVD risk score, BMI, smoking status, systolic BP
Activate your Heart 2014 [78]	2-arm RCT; UK; 6 m	95 people with stable angina, Internet from 9 GPs	66.2 (9.2)	25	Website: CVD risk assessment, education, goal setting, self-monitoring, email/chat with experts	Usual care with GP	Change in step count at 6 weeks and 6 m

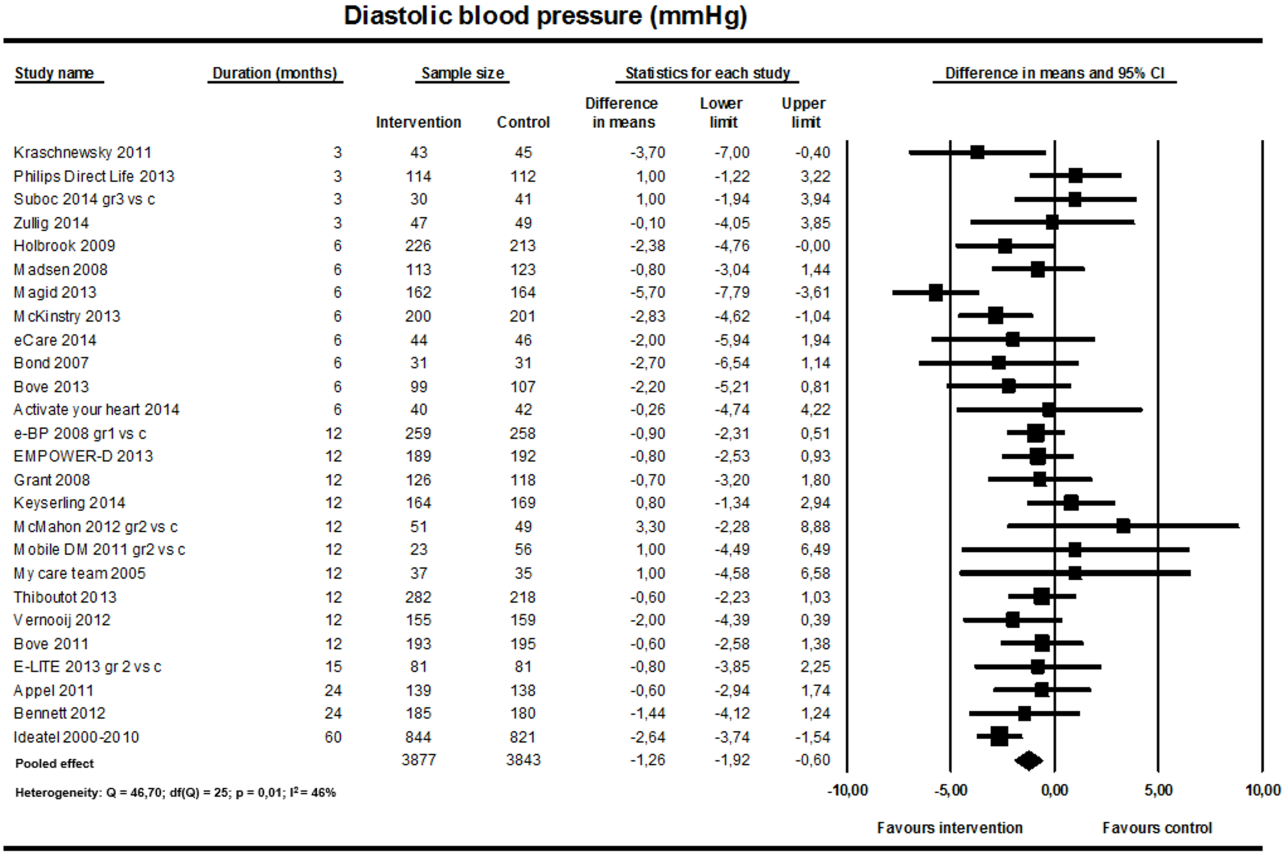
Study	Setting and study length	Participants	Age (years), mean (SD)	Sex (% female)	Intervention	Control	Primary; secondary outcomes
e-Care 2014 [79]	2-arm RCT USA 6m	101 people with BMI >26, elevated BP via electronic health records	56.9 (7.0)	42	Website + dietician: CVD risk assessment, goal setting, action planning, self-monitoring (weight, BP, physical activity, diet)	Usual care, printed report for patient and doctor	Change in systolic BP, weight and 10-year CVD risk score
Greene 2012 [80]	2-arm RCT; USA; 6 m	513 employees + families 45% overweight and 48% obese	60% older than 50 years	79	Printed lifestyle guide, website: online social network, self-monitoring (weight, exercise), goal setting, feedback	Printed lifestyle guide	Not defined; physical activity, weight, lipid profile
Holbrook 2009 [81]	2-arm cluster RCT; Canada; 12 m	46 GPs with 511 people with DM, ≥1 CV risk factor	60.7 (12.5)	49	Personal Web-based profile overview for DM/CVRM care, automated telephone reminders, summary for doctor, doctor involved	Usual care	Composite score for process of care
Diabetes in Check 2014 [82]	2-arm RCT; Australia; 9 m	436 people with DM, Internet via DM network	58.2 (10.3)	48	Website: self-monitoring (exercise) goal setting, education, discussion board	General website with home page and contacts page only	Not defined; physical activity, BMI

[a] Abbreviations: BMI: body mass index; BP: blood pressure; CHD: coronary heart disease; CV: cardiovascular; CVD: cardiovascular disease; CVRM: cardiovascular risk management; DM: diabetes mellitus; GP: general practitioner.

[b] For studies with more than 2 arms, this arm was used for all analyses.

[c] For studies with more than 2 arms, this arm was used for the subgroup analysis on blended interventions.

Figure 3. Effect on diastolic blood pressure (26 studies).



Diastolic blood pressure (mmHg)

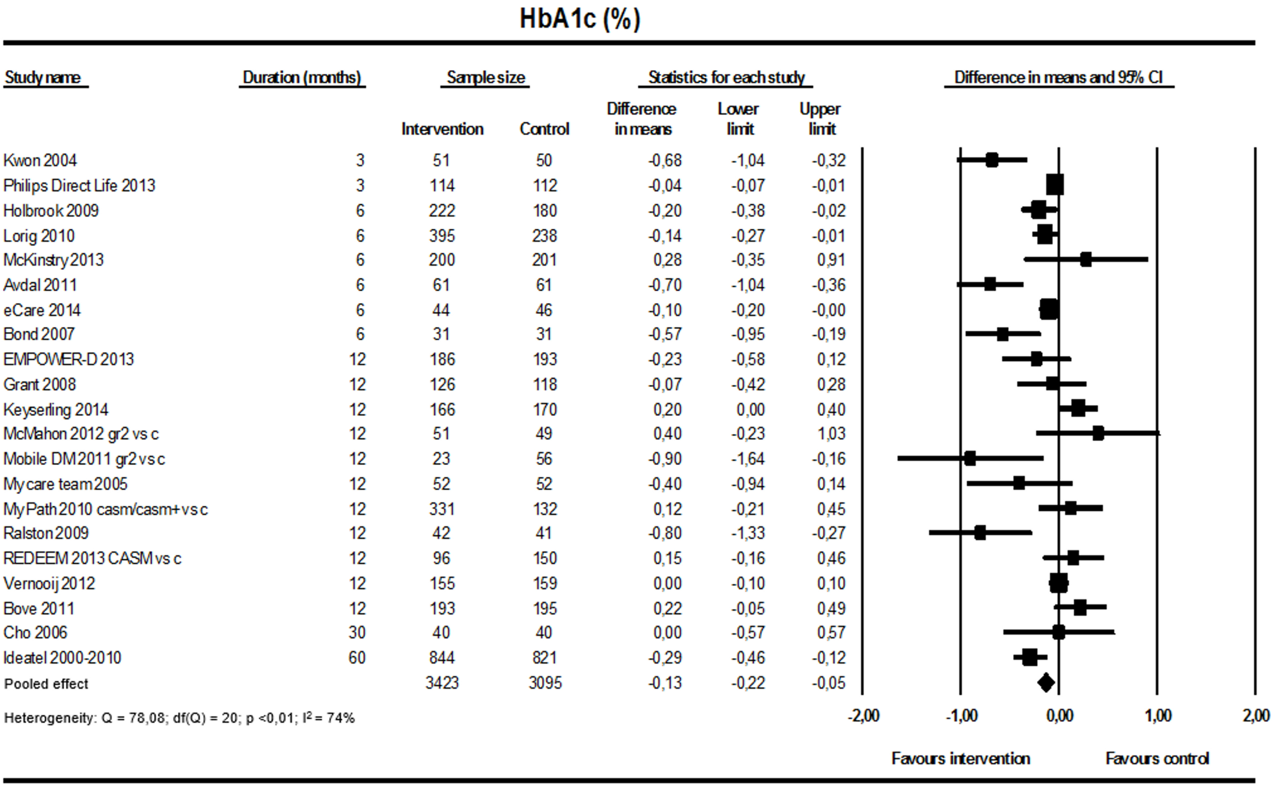
Study name	Duration (months)	Sample size: Intervention	Sample size: Control	Difference in means	Lower limit	Upper limit
Kraschnewsky 2011	3	43	45	-3,70	-7,00	-0,40
Philips Direct Life 2013	3	114	112	1,00	-1,22	3,22
Suboc 2014 gr3 vs c	3	30	41	1,00	-1,94	3,94
Zullig 2014	3	47	49	-0,10	-4,05	3,85
Holbrook 2009	6	226	213	-2,38	-4,76	-0,00
Madsen 2008	6	113	123	-0,80	-3,04	1,44
Magid 2013	6	162	164	-5,70	-7,79	-3,61
McKinstry 2013	6	200	201	-2,83	-4,62	-1,04
eCare 2014	6	44	46	-2,00	-5,94	1,94
Bond 2007	6	31	31	-2,70	-6,54	1,14
Bove 2013	6	99	107	-2,20	-5,21	0,81
Activate your heart 2014	6	40	42	-0,26	-4,74	4,22
e-BP 2008 gr1 vs c	12	259	258	-0,90	-2,31	0,51
EMPOWER-D 2013	12	189	192	-0,80	-2,53	0,93
Grant 2008	12	126	118	-0,70	-3,20	1,80
Keyserling 2014	12	164	169	0,80	-1,34	2,94
McMahon 2012 gr2 vs c	12	51	49	3,30	-2,28	8,88
Mobile DM 2011 gr2 vs c	12	23	56	1,00	-4,49	6,49
My care team 2005	12	37	35	1,00	-4,58	6,58
Thiboutot 2013	12	282	218	-0,60	-2,23	1,03
Vernooij 2012	12	155	159	-2,00	-4,39	0,39
Bove 2011	12	193	195	-0,60	-2,58	1,38
E-LITE 2013 gr 2 vs c	15	81	81	-0,80	-3,85	2,25
Appel 2011	24	139	138	-0,60	-2,94	1,74
Bennett 2012	24	185	180	-1,44	-4,12	1,24
Ideatel 2000-2010	60	844	821	-2,64	-3,74	-1,54
Pooled effect		3877	3843	-1,26	-1,92	-0,60

Heterogeneity: Q = 46,70; df(Q) = 25; p = 0,01; I^2 = 46%

Glycated Hemoglobin A1c

A significant reduction in HbA_{1c} level favoring the intervention among patients with type 2 diabetes mellitus was found (21 studies; n=6518; Figure 4). The weighted mean difference for HbA_{1c} was –0.13% (95% CI –0.22 to –0.05; I^2=74%). The jackknife procedure did not reveal one particular study responsible for high heterogeneity.

Figure 4. Effect on glycated hemoglobin (21 studies).



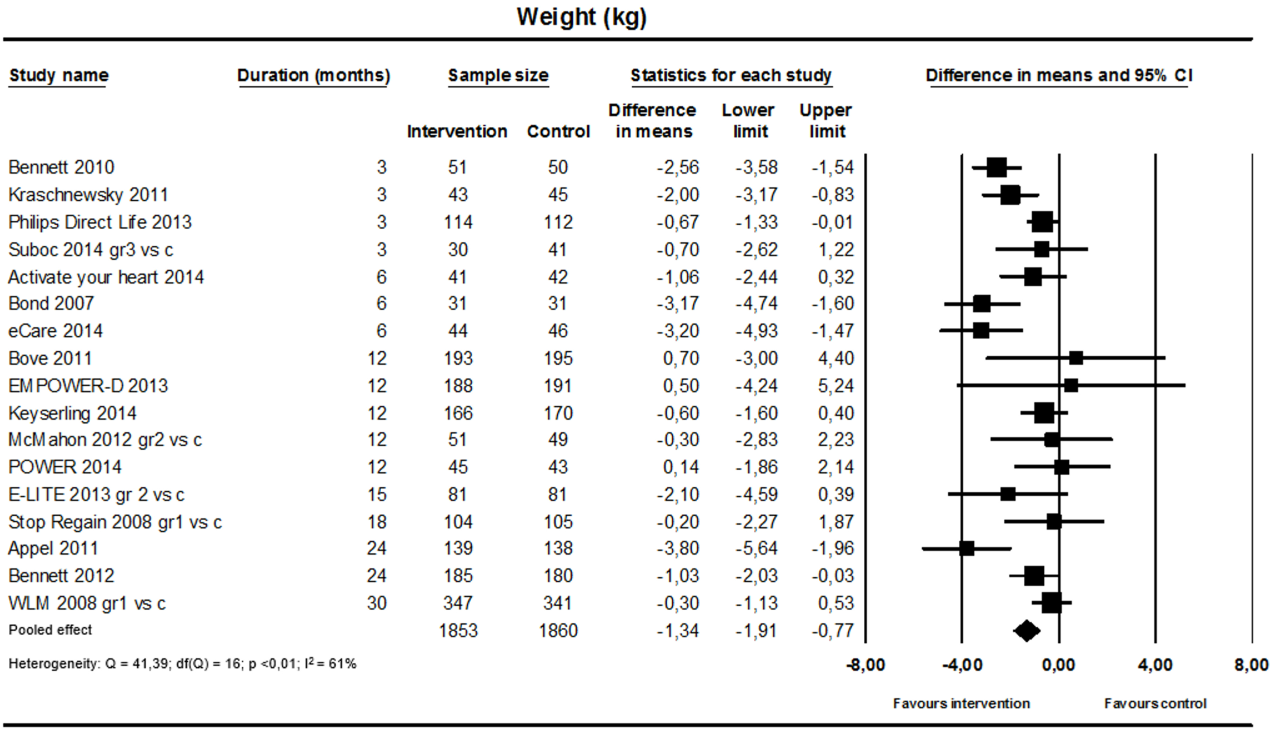
Study name	Duration (months)	Sample size: Intervention	Sample size: Control	Difference in means	Lower limit	Upper limit
Kwon 2004	3	51	50	-0,68	-1,04	-0,32
Philips Direct Life 2013	3	114	112	-0,04	-0,07	-0,01
Holbrook 2009	6	222	180	-0,20	-0,38	-0,02
Lorig 2010	6	395	238	-0,14	-0,27	-0,01
McKinstry 2013	6	200	201	0,28	-0,35	0,91
Avdal 2011	6	61	61	-0,70	-1,04	-0,36
eCare 2014	6	44	46	-0,10	-0,20	-0,00
Bond 2007	6	31	31	-0,57	-0,95	-0,19
EMPOWER-D 2013	12	186	193	-0,23	-0,58	0,12
Grant 2008	12	126	118	-0,07	-0,42	0,28
Keyserling 2014	12	166	170	0,20	0,00	0,40
McMahon 2012 gr2 vs c	12	51	49	0,40	-0,23	1,03
Mobile DM2011 gr2 vs c	12	23	56	-0,90	-1,64	-0,16
My care team 2005	12	52	52	-0,40	-0,94	0,14
MyPath 2010 casm/casm+ vs c	12	331	132	0,12	-0,21	0,45
Ralston 2009	12	42	41	-0,80	-1,33	-0,27
REDEEM 2013 CASM vs c	12	96	150	0,15	-0,16	0,46
Vernooij 2012	12	155	159	0,00	-0,10	0,10
Bove 2011	12	193	195	0,22	-0,05	0,49
Cho 2006	30	40	40	0,00	-0,57	0,57
Ideatel 2000-2010	60	844	821	-0,29	-0,46	-0,12
Pooled effect		3423	3095	-0,13	-0,22	-0,05

Heterogeneity: Q = 78,08; df(Q) = 20; p <0,01; I^2 = 74%

Weight

Fifteen studies tested interventions for weight loss and two studies tested interventions for maintenance of weight loss. The pooled analysis (17 studies; n=3713; Figure 5) showed a significant reduction in weight favoring the intervention (weighted mean difference –1.34 kg, 95% CI –1.91 to –0.77; I^2=61%). A sensitivity analysis leaving out the two studies on weight loss maintenance resulted in a similar effect size and level of heterogeneity. The jackknife procedure identified three studies contributing considerably to heterogeneity [35,42,59].

Figure 5. Effect on weight (17 studies).



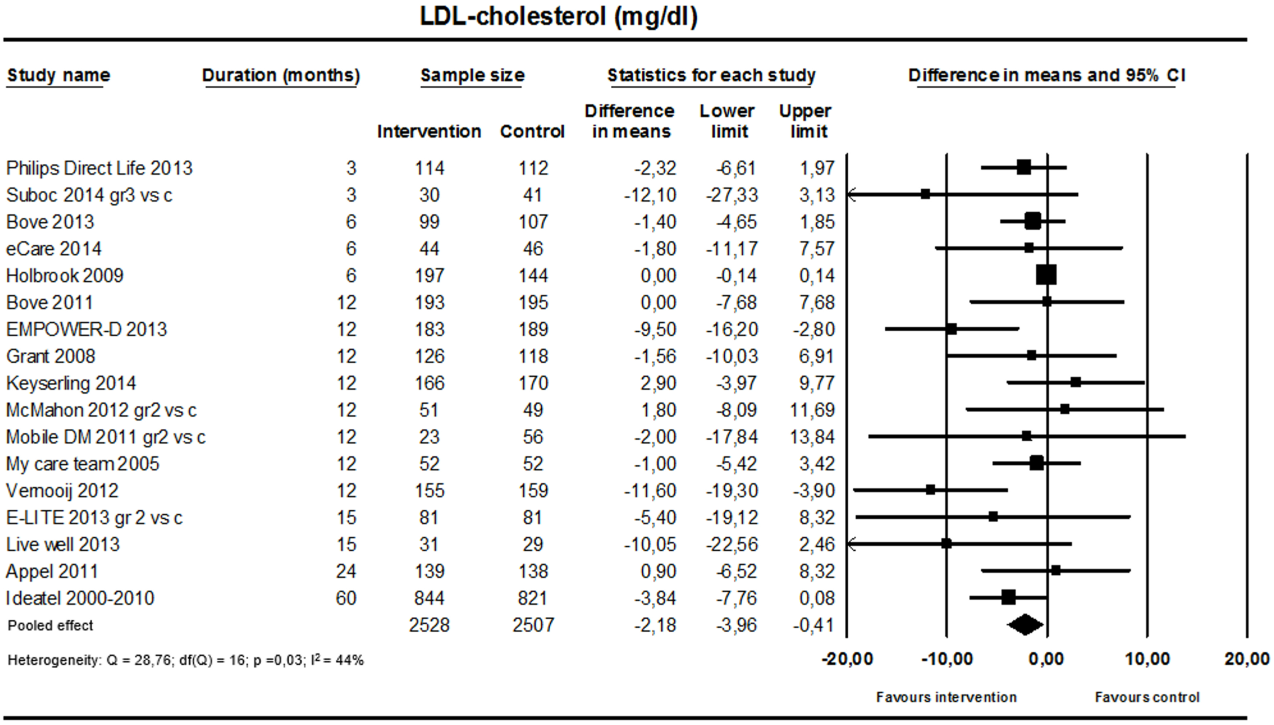
Study name	Duration (months)	Sample size: Intervention	Sample size: Control	Difference in means	Lower limit	Upper limit
Bennett 2010	3	51	50	-2,56	-3,58	-1,54
Kraschnewsky 2011	3	43	45	-2,00	-3,17	-0,83
Philips Direct Life 2013	3	114	112	-0,67	-1,33	-0,01
Suboc 2014 gr3 vs c	3	30	41	-0,70	-2,62	1,22
Activate your heart 2014	6	41	42	-1,06	-2,44	0,32
Bond 2007	6	31	31	-3,17	-4,74	-1,60
eCare 2014	6	44	46	-3,20	-4,93	-1,47
Bove 2011	12	193	195	0,70	-3,00	4,40
EMPOWER-D 2013	12	188	191	0,50	-4,24	5,24
Keyserling 2014	12	166	170	-0,60	-1,60	0,40
McMahon 2012 gr2 vs c	12	51	49	-0,30	-2,83	2,23
POWER 2014	12	45	43	0,14	-1,86	2,14
E-LITE 2013 gr 2 vs c	15	81	81	-2,10	-4,59	0,39
Stop Regain 2008 gr1 vs c	18	104	105	-0,20	-2,27	1,87
Appel 2011	24	139	138	-3,80	-5,64	-1,96
Bennett 2012	24	185	180	-1,03	-2,03	-0,03
WLM 2008 gr1 vs c	30	347	341	-0,30	-1,13	0,53
Pooled effect		1853	1860	-1,34	-1,91	-0,77

Heterogeneity: Q = 41,39; df(Q) = 16; p <0,01; I^2 = 61%

Low-Density Lipoprotein Cholesterol

A small but significant reduction in LDL cholesterol favoring the intervention was found (17 studies; n=5035; Figure 6; weighted mean difference –2.18 mg/dL, 95% CI –3.96 to –0.41; I^2=44%).

Figure 6. Effect on low-density lipoprotein cholesterol (17 studies).



LDL-cholesterol (mg/dl)

Study name	Duration (months)	Sample size: Intervention	Sample size: Control	Difference in means	Lower limit	Upper limit
Philips Direct Life 2013	3	114	112	-2,32	-6,61	1,97
Suboc 2014 gr3 vs c	3	30	41	-12,10	-27,33	3,13
Bove 2013	6	99	107	-1,40	-4,65	1,85
eCare 2014	6	44	46	-1,80	-11,17	7,57
Holbrook 2009	6	197	144	0,00	-0,14	0,14
Bove 2011	12	193	195	0,00	-7,68	7,68
EMPOWER-D 2013	12	183	189	-9,50	-16,20	-2,80
Grant 2008	12	126	118	-1,56	-10,03	6,91
Keyserling 2014	12	166	170	2,90	-3,97	9,77
McMahon 2012 gr2 vs c	12	51	49	1,80	-8,09	11,69
Mobile DM 2011 gr2 vs c	12	23	56	-2,00	-17,84	13,84
My care team 2005	12	52	52	-1,00	-5,42	3,42
Vernooij 2012	12	155	159	-11,60	-19,30	-3,90
E-LITE 2013 gr 2 vs c	15	81	81	-5,40	-19,12	8,32
Live well 2013	15	31	29	-10,05	-22,56	2,46
Appel 2011	24	139	138	0,90	-6,52	8,32
Ideatel 2000-2010	60	844	821	-3,84	-7,76	0,08
Pooled effect		2528	2507	-2,18	-3,96	-0,41

Heterogeneity: Q = 28,76; df(Q) = 16; p =0,03; I^2 = 44%

Physical Activity

Fourteen studies (n=4444; Figure 7) reported the effect on physical activity. Eight studies used self-reported physical activity levels in minutes per week, five studies used daily step counts obtained from pedometers, and one study measured physical activity with accelerometers. Because of the differences in measurement instruments, we calculated standardized mean differences. A small significant difference in increase of physical activity levels was found in favor of the intervention (weighted standardized mean difference 0.25, 95% CI 0.10-0.39; I^2=81%), but heterogeneity was high. The jackknife procedure identified one study [65] driving a substantial part of heterogeneity; without this study, I^2 was 68%.

Effect of Web-Based Interventions on Overall Cardiovascular Risk Profile, Cardiovascular Morbidity, and Mortality

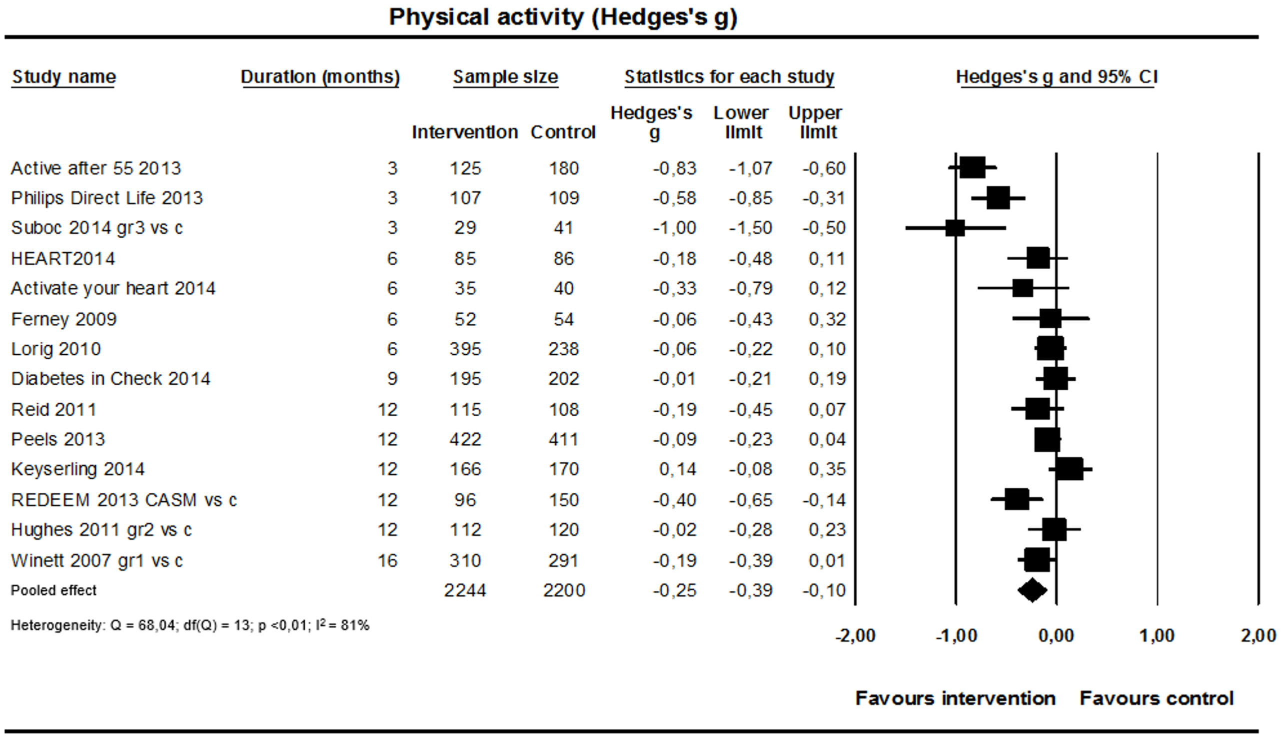
Cardiovascular Composite Scores

Nine studies (n=2321; Figure 8) reported a cardiovascular composite score. Five studies reported the Framingham 10-year cardiovascular disease risk score, three studies reported the Framingham 10-year coronary heart disease risk score, and one study reported a clinical composite score based on number of cardiovascular risk factors on target (BP, HbA_{1c}, body mass index, LDL cholesterol, physical activity, albuminuria, foot ulcers, and smoking). Because of the differences between the composite scores, we calculated standardized mean differences. A small significant improvement of the cardiovascular composite scores was found (weighted standardized mean difference –0.10, 95% CI –0.18 to –0.02; I^2=0%).

General Effect of Web-Based Interventions on Cardiovascular Risk Factors

Finally, we pooled the primary outcomes of the 37 studies (n=11,021; Figure 9) that defined a primary outcome (systolic BP: 7 studies; HbA_{1c}: 13 studies; weight: 8 studies; physical activity: 6 studies; cardiovascular composite score: 3 studies). The weighted standardized mean difference was –0.24 (95% CI –0.31 to –0.16; I^2=69%) in favor of the intervention. The jackknife procedure revealed that one study [57] somewhat influenced the heterogeneity; without this study, heterogeneity dropped to 64%. The funnel plot (Multimedia Appendix 5) indicated that small studies reporting large effects might be overrepresented. The Egger's test confirmed that the funnel plot was not symmetrical (*P*=.01).

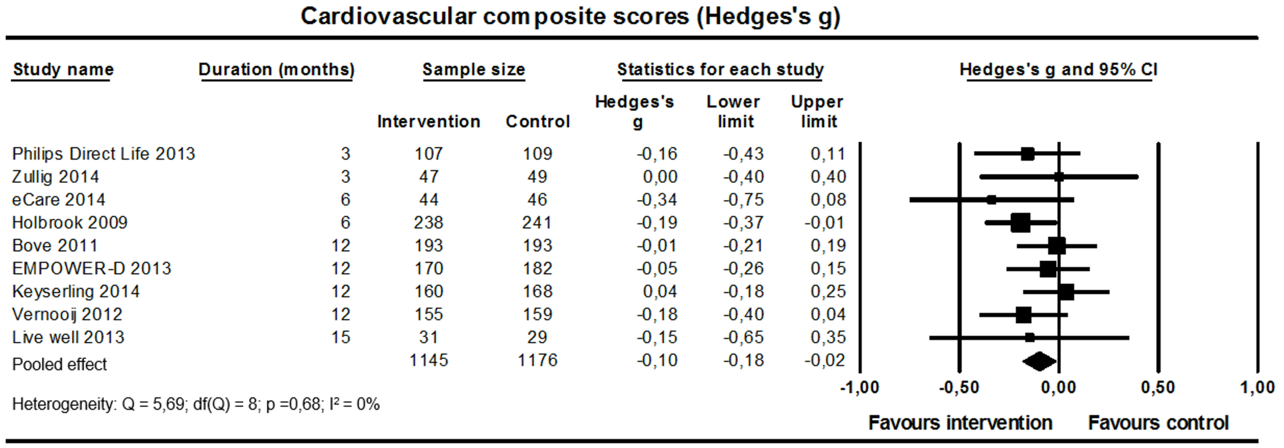
Figure 7. Effect on physical activity (14 studies).



Study name	Duration (months)	Sample size Intervention	Sample size Control	Hedges's g	Lower limit	Upper limit
Active after 55 2013	3	125	180	-0,83	-1,07	-0,60
Philips Direct Life 2013	3	107	109	-0,58	-0,85	-0,31
Suboc 2014 gr3 vs c	3	29	41	-1,00	-1,50	-0,50
HEART2014	6	85	86	-0,18	-0,48	0,11
Activate your heart 2014	6	35	40	-0,33	-0,79	0,12
Ferney 2009	6	52	54	-0,06	-0,43	0,32
Lorig 2010	6	395	238	-0,06	-0,22	0,10
Diabetes in Check 2014	9	195	202	-0,01	-0,21	0,19
Reid 2011	12	115	108	-0,19	-0,45	0,07
Peels 2013	12	422	411	-0,09	-0,23	0,04
Keyserling 2014	12	166	170	0,14	-0,08	0,35
REDEEM 2013 CASM vs c	12	96	150	-0,40	-0,65	-0,14
Hughes 2011 gr2 vs c	12	112	120	-0,02	-0,28	0,23
Winett 2007 gr1 vs c	16	310	291	-0,19	-0,39	0,01
Pooled effect		2244	2200	-0,25	-0,39	-0,10

Heterogeneity: Q = 68,04; df(Q) = 13; p <0,01; I^2 = 81%

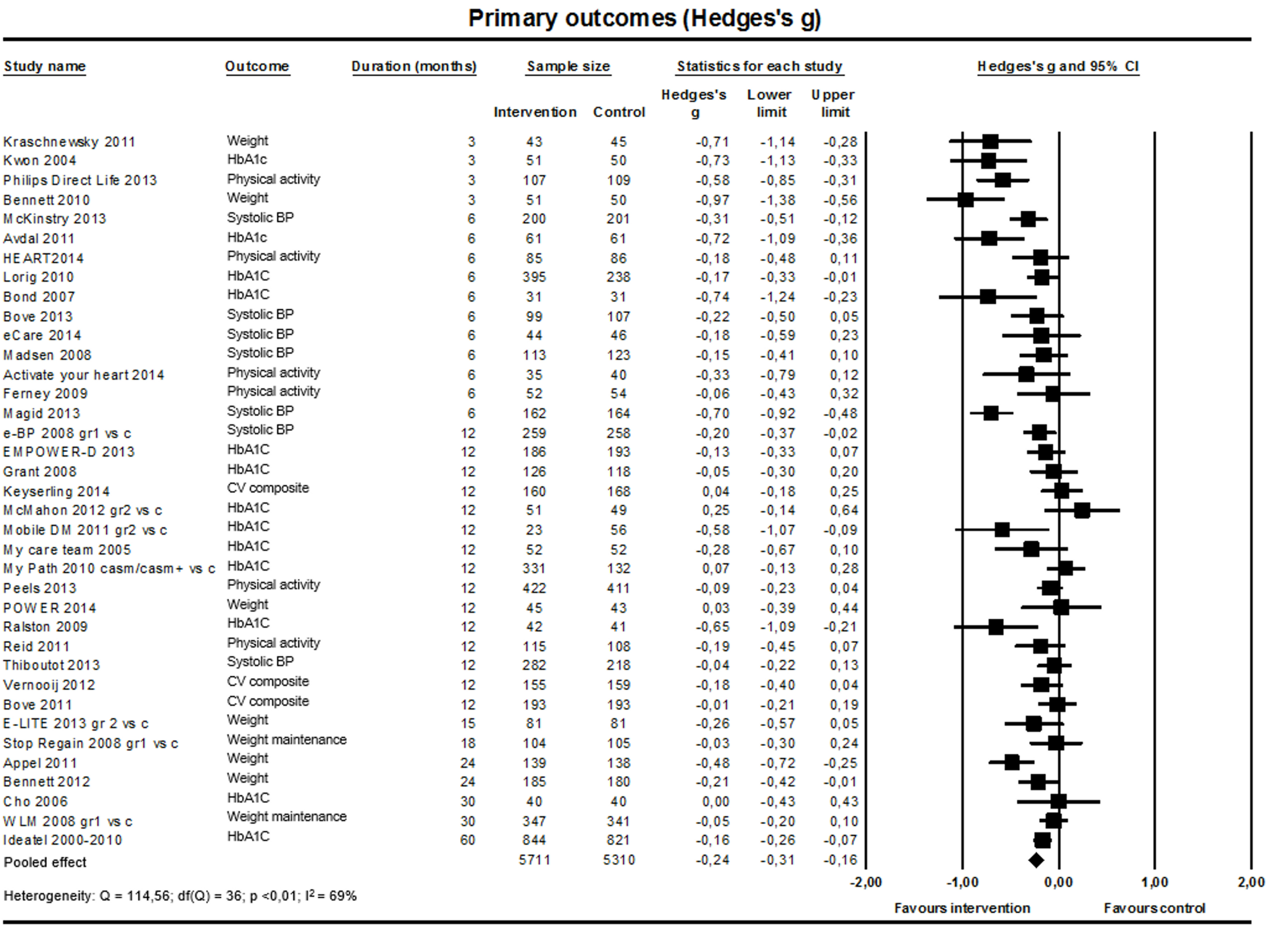
Figure 8. Effect on cardiovascular composite scores (9 studies).



Study name	Duration (months)	Sample size Intervention	Sample size Control	Hedges's g	Lower limit	Upper limit
Philips Direct Life 2013	3	107	109	-0,16	-0,43	0,11
Zullig 2014	3	47	49	0,00	-0,40	0,40
eCare 2014	6	44	46	-0,34	-0,75	0,08
Holbrook 2009	6	238	241	-0,19	-0,37	-0,01
Bove 2011	12	193	193	-0,01	-0,21	0,19
EMPOWER-D 2013	12	170	182	-0,05	-0,26	0,15
Keyserling 2014	12	160	168	0,04	-0,18	0,25
Vernooij 2012	12	155	159	-0,18	-0,40	0,04
Live well 2013	15	31	29	-0,15	-0,65	0,35
Pooled effect		1145	1176	-0,10	-0,18	-0,02

Heterogeneity: Q = 5,69; df(Q) = 8; p =0,68; I^2 = 0%

Figure 9. General effect on primary outcomes (37 studies).



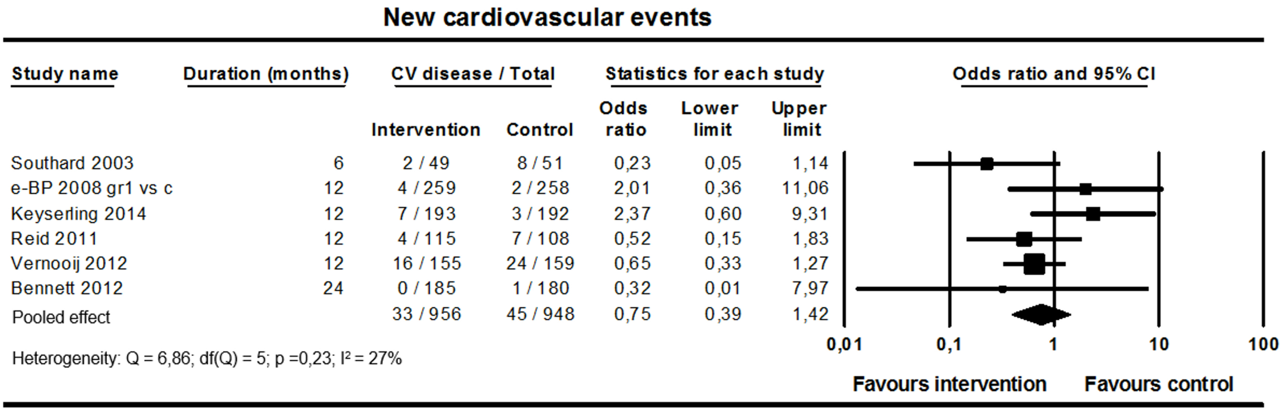
Study name	Outcome	Duration (months)	Sample size: Intervention	Sample size: Control	Hedges's g	Lower limit	Upper limit
Kraschnewsky 2011	Weight	3	43	45	-0,71	-1,14	-0,28
Kwon 2004	HbA1c	3	51	50	-0,73	-1,13	-0,33
Philips Direct Life 2013	Physical activity	3	107	109	-0,58	-0,85	-0,31
Bennett 2010	Weight	3	51	50	-0,97	-1,38	-0,56
McKinstry 2013	Systolic BP	6	200	201	-0,31	-0,51	-0,12
Avdal 2011	HbA1c	6	61	61	-0,72	-1,09	-0,36
HEART2014	Physical activity	6	85	86	-0,18	-0,48	0,11
Lorig 2010	HbA1C	6	395	238	-0,17	-0,33	-0,01
Bond 2007	HbA1C	6	31	31	-0,74	-1,24	-0,23
Bove 2013	Systolic BP	6	99	107	-0,22	-0,50	0,05
eCare 2014	Systolic BP	6	44	46	-0,18	-0,59	0,23
Madsen 2008	Systolic BP	6	113	123	-0,15	-0,41	0,10
Activate your heart 2014	Physical activity	6	35	40	-0,33	-0,79	0,12
Ferney 2009	Physical activity	6	52	54	-0,06	-0,43	0,32
Magid 2013	Systolic BP	6	162	164	-0,70	-0,92	-0,48
e-BP 2008 gr1 vs c	Systolic BP	12	259	258	-0,20	-0,37	-0,02
EMPOWER-D 2013	HbA1C	12	186	193	-0,13	-0,33	0,07
Grant 2008	HbA1C	12	126	118	-0,05	-0,30	0,20
Keyserling 2014	CV composite	12	160	168	0,04	-0,18	0,25
McMahon 2012 gr2 vs c	HbA1C	12	51	49	0,25	-0,14	0,64
Mobile DM 2011 gr2 vs c	HbA1C	12	23	56	-0,58	-1,07	-0,09
My care team 2005	HbA1C	12	52	52	-0,28	-0,67	0,10
My Path 2010 casm/casm+ vs c	HbA1C	12	331	132	0,07	-0,13	0,28
Peels 2013	Physical activity	12	422	411	-0,09	-0,23	0,04
POWER 2014	Weight	12	45	43	0,03	-0,39	0,44
Ralston 2009	HbA1C	12	42	41	-0,65	-1,09	-0,21
Reid 2011	Physical activity	12	115	108	-0,19	-0,45	0,07
Thiboutot 2013	Systolic BP	12	282	218	-0,04	-0,22	0,13
Vernooij 2012	CV composite	12	155	159	-0,18	-0,40	0,04
Bove 2011	CV composite	12	193	193	-0,01	-0,21	0,19
E-LITE 2013 gr 2 vs c	Weight	15	81	81	-0,26	-0,57	0,05
Stop Regain 2008 gr1 vs c	Weight maintenance	18	104	105	-0,03	-0,30	0,24
Appel 2011	Weight	24	139	138	-0,48	-0,72	-0,25
Bennett 2012	Weight	24	185	180	-0,21	-0,42	-0,01
Cho 2006	HbA1C	30	40	40	0,00	-0,43	0,43
WLM 2008 gr1 vs c	Weight maintenance	30	347	341	-0,05	-0,20	0,10
Ideatel 2000-2010	HbA1C	60	844	821	-0,16	-0,26	-0,07
Pooled effect			5711	5310	-0,24	-0,31	-0,16

Heterogeneity: Q = 114,56; df(Q) = 36; p <0,01; I² = 69%

Cardiovascular Morbidity and Total Mortality

Six studies (n=1904; 1 short-term and 5 long-term studies) reported on cardiovascular event rates. The mean length of the studies was 13 months (range 6-24 months). The pooled analysis showed no difference in rate between groups (pooled OR 0.75, 95% CI 0.39-1.42; I^2=27%; Figure 10). Total mortality rates were reported in 13 studies; in five studies, no deaths occurred and in the other eight studies, there were no differences between groups.

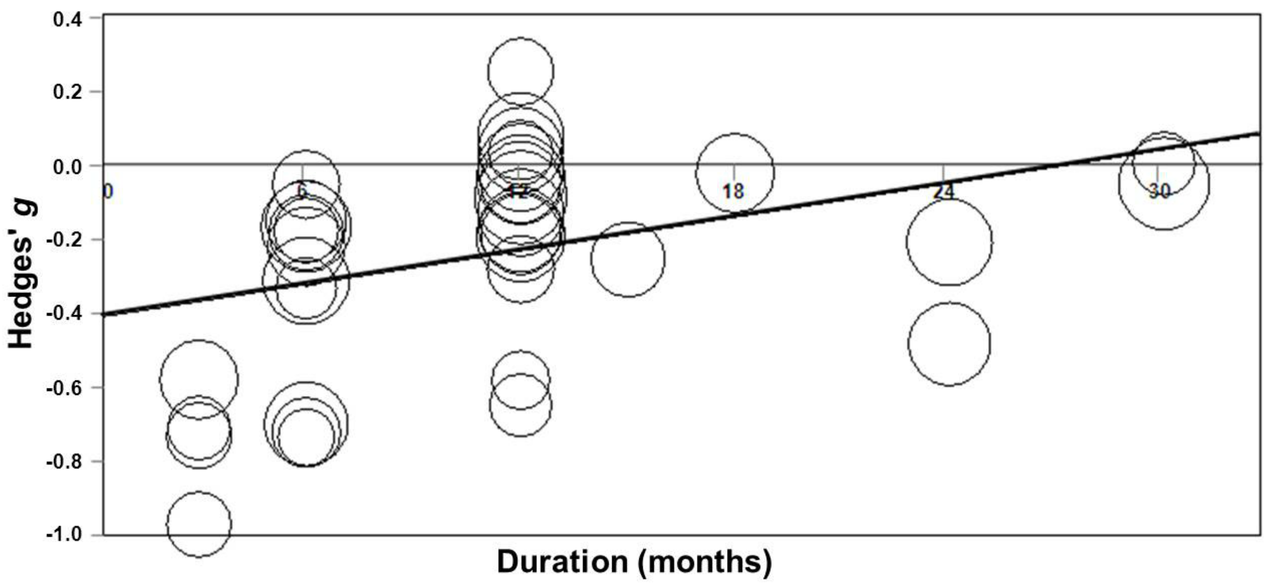
Figure 10. Effect on cardiovascular event rates (6 studies).



Study name	Duration (months)	CV disease / Total: Intervention	CV disease / Total: Control	Odds ratio	Lower limit	Upper limit
Southard 2003	6	2 / 49	8 / 51	0,23	0,05	1,14
e-BP 2008 gr1 vs c	12	4 / 259	2 / 258	2,01	0,36	11,06
Keyserling 2014	12	7 / 193	3 / 192	2,37	0,60	9,31
Reid 2011	12	4 / 115	7 / 108	0,52	0,15	1,83
Vernooij 2012	12	16 / 155	24 / 159	0,65	0,33	1,27
Bennett 2012	24	0 / 185	1 / 180	0,32	0,01	7,97
Pooled effect		33 / 956	45 / 948	0,75	0,39	1,42

Heterogeneity: Q = 6,86; df(Q) = 5; p =0,23; I² = 27%

Figure 11. Association between study duration and effect size (Hedges' g). One outlier study (Ideatel) was removed from analysis.



Subgroup Analyses

Results are summarized in Table 6. Within the analysis of pooled primary outcomes, the intervention effect was more pronounced in the short-term studies (15 studies; n=2934; standardized mean difference –0.43, 95% CI –0.57 to –0.29; I^2=69%) than in the long-term studies (22 studies; n=8087; standardized mean difference –0.12, 95% CI –0.19 to –0.06; I^2=41%). The same pattern was found for all other outcomes except for LDL cholesterol (Multimedia Appendix 6). There were no substantial differences in effect size between studies on primary prevention versus secondary prevention. To further explore the studies targeting primary prevention, we compared studies with populations of relatively low age (not all participants older than 50 years, n=29) with studies with populations of older age (all participants older than 50 years, n=4). The pooled effect size was larger for the studies with older participants (Hedges' *g*=–0.30) than for the studies with relatively younger participants (Hedges' *g*=–0.23), but the confidence intervals overlapped largely. We repeated the analysis of pooled primary outcomes on the sample of studies testing an Internet-only and a blended intervention. The intervention effect was more pronounced in the sample of blended studies (26 studies; n=7538; standardized mean difference –0.33, 95% CI –0.43 to –0.22; I^2=78%) compared to the sample of Internet-only studies (14 studies; n=4280; standardized mean difference –0.15, 95% CI –0.23 to –0.07; I^2=40%).

Table 6. Subgroup analyses within the analysis of standardized primary outcomes.

Subgroup	N of studies	Hedges' *g*	95% CI	I^2
Duration [a]				
Short (<12 months)	15	–0.43	–0.57, –0.29	69%
Long (≥12 months)	22	–0.12	–0.19, –0.06	41%
Type of prevention [a]				
Primary (including diabetes control)	33	–0.25	–0.32, –0.17	72%
Secondary	4	–0.20	–0.34, –0.06	0%
Primary prevention: age subgroups [b]				
Not all older than 50 years	29	–0.23	–0.33, –0.14	72%
All older than 50 years	4	–0.30	–0.51, –0.09	80%
Internet only vs control[c]	14	–0.15	–0.23, –0.07	40%
Blended vs control[d]	26	–0.33	–0.43, –0.22	79%

[a] Subgroup analysis performed in the sample of studies that was used for the analysis of primary outcomes.

[b] Subgroup analysis performed on the sample of studies that targeted primary prevention (including diabetes control).

[c] Subgroup analysis performed on the sample of studies that evaluated an Internet-only intervention. In case a study tested multiple arms, the appropriate arm was included in the analysis.

[d] Subgroup analysis performed on the sample of studies that evaluated a blended intervention. In case a study tested multiple arms, the appropriate arm was included in the analysis.

Meta-Regression

Because of the fairly consistent finding that treatment effects were higher in short-term studies than in long-term studies, we performed a mixed effects meta-regression to explore the association between study duration and effect size. The effect size seemed to become smaller in studies with longer follow-up, although the association was not significant (Hedges' *g*=–0.321+0.006*months; *P*=.07). After removal of one outlier study [34] that had a very long follow-up (5 years), the effect size significantly decreased over time in studies lasting 3 to 32 months (Hedges' *g*=–0.415+ 0.015*months; *P*=.008; Figure. 11).

Sensitivity Analyses for the Risk-of-Bias Assessment

We performed sensitivity analyses for each of the six domains of bias assessed with the adapted Cochrane Risk of Bias Tool by comparing the standardized primary outcomes of the studies with the low risk and unknown/high risk of bias (Multimedia Appendix 7). There were no significant differences in pooled effect sizes in any of the domains except for the domain random sequence generation, in which the pooled effect was significantly larger in the subgroup of studies with unknown/high risk of bias.

Discussion

In this systematic review and meta-analysis, we found for people with elevated cardiovascular risk, Web-based interventions lead to improvement of systolic and diastolic BP, HbA_{1c}, weight, LDL cholesterol, physical activity levels, and cardiovascular risk composite scores. Only seven studies included participants all aged 50 years or older. Therefore, our conclusions apply for the population in middle age and beyond. Effects were more pronounced over the short term (study duration <12 months) and in studies that tested a blended intervention (combination of an Internet application and human support). We found no evidence for an effect on incident cardiovascular disease.

Our findings on single cardiovascular risk factors are consistent with conclusions of other meta-analyses in younger adult populations [19-21]. We found a significant reduction in systolic BP of 2.66 mmHg. A reduction of 3 mmHg in systolic BP can lead to an 8% reduction in annual stroke mortality rate and a 5% reduction in annual coronary heart disease mortality rate [83]. We found a reduction of LDL cholesterol of 2.18 mg/dL (converted=0.06 mmol/L). A reduction of 0.5 mmol/L in LDL cholesterol for at least 2 years can lead to a reduction in coronary heart disease events of 20% [6]. Theoretically, assuming a linear relation, a reduction of 0.06 mmol/L could lead to a 2.4% reduction of coronary heart disease events. Thus, the effects on Internet interventions on BP reduction and, to a lesser extent, LDL cholesterol reduction, can be clinically relevant at the population level if reductions are maintained. In addition, we evaluated the effect on the complete cardiovascular risk profile and prevention of cardiovascular disease, which has not been performed before. One other systematic review without meta-analysis that evaluated Internet interventions for lifestyle change in older people reported that interventions with multiple components are more effective than interventions with a single component [84].

We found that the beneficial effects of Web-based interventions decline over time and effects are larger when interventions are combined with human support. Decreasing adherence over time was reported in several studies included in our meta-analysis and could be an important contributor to the decreasing effect over time. We were unable to formally test this because information on adherence and engagement was only reported by 22 studies and definitions varied widely. The identified effect moderators are not specific to Web-based interventions for cardiovascular risk factors [85,86]. Maintenance of behavioral change is notoriously complex and best achieved in longer studies with intensive interventions, more face-to-face, and more follow-up contacts. However, such interventions lead to high attrition rates, probably reflecting selection of the most motivated participants [87]. A careful balance should be sought between effectiveness and implementability when designing cardiovascular risk management interventions, whether or not an Internet-based approach is used.

Our results do not show a beneficial effect of Web-based interventions on incident cardiovascular disease. Although the declining effect over time could play a role, more likely explanations for these findings are the limited follow-up time of the studies to detect these outcomes (mean length of the studies was 13 months) and the fact that these outcomes were not the primary focus of these studies. Because of the latter, data collection may not have been systematic and adjudication of the data by an independent committee may be lacking. Therefore, we cannot draw strong conclusions from these findings.

The results of this study should be interpreted with caution because of several limitations. The methodological quality of the studies was fair, but none of the studies was double blind, rendering them prone to performance bias. Only 20 studies had a blinded outcome assessment, so detection bias may also be present. Because the sensitivity analyses for the risk-of-bias assessment did not reveal significant differences between the low risk and unknown/high risk-of-bias subgroups, except for the domain of random sequence generation, we think that our findings have not been largely affected by these potential sources of bias. Another limitation is the substantial heterogeneity in several of the meta-analyses that is, in part, explained by two effect modifiers: study duration and intervention type. Patient groups with a higher burden have a larger window of opportunity for improvement potentially resulting in larger intervention effects [88], which could also have contributed to heterogeneity. We could not draw firm conclusions on the difference between primary and secondary prevention, because only four studies on secondary prevention were included in this analysis. Last, there is a potential for publication bias and small study bias. Most of the studies with small sample sizes reported large effects and similar studies with null findings did not appear in the funnel plots (Multimedia Appendix 5).

Strengths of our study are the comprehensive search strategy, the quantitative meta-analysis, and the assessment of the effect of Web-based interventions for all cardiovascular risk factors using both intermediate and clinical outcomes. Our search strategy was comprehensive because we used a broad definition of Web-based interventions and only excluded telemedicine and mobile phone interventions. It was not always possible to set Web-based interventions apart from telemedicine and mobile phone interventions. As long as the Web-based program was the main component of the intervention, we judged the study eligible for our systematic review. By pooling the effect sizes on all different cardiovascular risk factors, we aimed to assess the overall effect of an Internet-based approach for people with increased risk of cardiovascular disease. This approach provides insight into the overall potential of Internet-based interventions in this field. Although basic computer literacy as an inclusion criterion probably led to selection of participants with a relatively high socioeconomic status, several studies included in the meta-analysis focused on people from medically underserved areas. Therefore, the external validity of the results might be acceptable and may be generalizable to middle-aged to older primary care populations with an increased risk of cardiovascular disease.

Our results show that Web-based interventions can be effective in improving the cardiovascular risk factor profile of middle-aged and older people, but effects are modest and can only have clinical relevance on the population level if sustained over time. Considering the current interest and focus on eHealth by policy makers, funding agencies, and a myriad of research and patient organizations [89,90], it is important to evaluate the actual evidence base objectively. Unrealistic expectations of the effectiveness of Web-based interventions obscure the true challenges that have to be overcome first, including testing interventions that were designed specifically for older people, improving methodological robustness of studies, and improving sustainability of effects. On the macro level, trials can assess sustainability by prolonging follow-up, recording clinical events, and measuring surrogate cardiovascular outcomes (eg, BP, cholesterol levels, and weight) at multiple time points (eg, at 6, 12, 24, and 36 months). On the micro level, adherence should be evaluated by studying intervention usage through time with standardized evaluation methods. Sustainability is of particular importance because long-term effects are required for primary and secondary prevention to truly contribute to the prevention of cardiovascular disease. Web-based interventions combined with human support are more promising than Internet-only interventions.

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Authors' Contributions

CRB had full access to all data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. ER, EMvC, WvG, CB, MK, SA, and HS conceived the study. CRB, BS, and ER wrote the study protocol and analysis plan. CRB and BS collected and extracted the data, with support from ER and EMvC. CRB performed the statistical analysis, supported by BS, ER, WB, and WvG. CRB and ER drafted the manuscript and all authors critically revised the manuscript for important intellectual content.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Research protocol.

[PDF File (Adobe PDF File), 63KB - jmir_v18i3e55_app1.pdf]

Multimedia Appendix 2

Comprehensive search strategy.

[PDF File (Adobe PDF File), 31KB - jmir_v18i3e55_app2.pdf]

Multimedia Appendix 3

Data-extraction form.

[PDF File (Adobe PDF File), 37KB - jmir_v18i3e55_app3.pdf]

Multimedia Appendix 4

Summary of the risk of bias assessment.

[PDF File (Adobe PDF File), 296KB - jmir_v18i3e55_app4.pdf]

Multimedia Appendix 5

Funnel plots.

[PDF File (Adobe PDF File), 77KB - jmir_v18i3e55_app5.pdf]

Multimedia Appendix 6

Subgroup analysis: study-duration.

[PDF File (Adobe PDF File), 55KB - jmir_v18i3e55_app6.pdf]

Multimedia Appendix 7

Risk of bias assessment: sensitivity analyses for the domains of risk of bias.

[PDF File (Adobe PDF File), 35KB - jmir_v18i3e55_app7.pdf]

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Abbreviations

BP: blood pressure
HbA1c: glycated hemoglobin A1c
IQR: interquartile range
LDL: low-density lipoprotein
PA: physical activity
RCT: randomized controlled trial

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Original Paper

Effectiveness of a Web-Based Guided Self-help Intervention for Outpatients With a Depressive Disorder: Short-term Results From a Randomized Controlled Trial

Robin Maria Francisca Kenter[1,2], MSc; Pim Cuijpers[1,2], PhD; Aartjan Beekman[2], PhD; Annemieke van Straten[1,2], PhD

[1]Faculty of Behavioural and Movement Sciences, Department of Clinical, Neuro and Developmental Psychology, Vrije Universiteit Amsterdam, Amsterdam, Netherlands

[2]EMGO Institute for Health Care and Research, VU University Medical Centre, Amsterdam, Netherlands

Corresponding Author:
Robin Maria Francisca Kenter, MSc
Faculty of Behavioural and Movement Sciences
Department of Clinical, Neuro and Developmental Psychology
Vrije Universiteit Amsterdam
Van der Boechorststraat 1
Amsterdam, 1081 BT
Netherlands
Phone: 31 20 59 88970
Fax: 31 20 59 88970
Email: robin.kenter@vu.nl

Abstract

Background: Research has convincingly demonstrated that symptoms of depression can be reduced through guided Internet-based interventions. However, most of those studies recruited people form the general population. There is insufficient evidence for the effectiveness when delivered in routine clinical practice in outpatient clinics.

Objective: The objective of this randomized controlled trial was to study patients with a depressive disorder (as defined by the Diagnostic and Statistical Manual of Disorders, fourth edition), as assessed by trained interviewers with the Composite International Diagnostic Interview, who registered for treatment at an outpatient mental health clinic. We aimed to examine the effectiveness of guided Internet-based self-help before starting face-to-face treatment.

Methods: We recruited 269 outpatients, aged between 18 and 79 years, from outpatient clinics and randomly allocated them to Internet-based problem solving therapy (n=136), with weekly student support, or to a control condition, who remained on the waitlist with a self-help booklet (control group; n=133). Participants in both conditions were allowed to take up face-to-face treatment at the outpatient clinics afterward. We measured the primary outcome, depressive symptoms, by Center for Epidemiological Studies Depression scale (CES-D). Secondary outcome measures were the Hospital Anxiety and Depression Scale Anxiety subscale (HADS-A), Insomnia Severity Index questionnaire (ISI), and EuroQol visual analog scale (EQ-5D VAS). All outcomes were assessed by telephone at posttest (8 weeks after baseline).

Results: Posttest measures were completed by 184 (68.4%) participants. We found a moderate to large within-group effect size for both the intervention (d=0.75) and the control (d=0.69) group. However, the between-group effect size was very small (d=0.07), and regression analysis on posttreatment CES-D scores revealed no significant differences between the groups (b=1.134, 95% CI –2.495 to 4.763). The per-protocol analysis (≥4 sessions completed) results were also not significant (b=1.154, 95% CI –1.978 to 7.637). Between-group differences were small and not significant for all secondary outcomes. Adherence to the intervention was low. Only 36% (49/136) received an adequate dosage of the intervention (≥4 of 5 sessions). The overall treatment satisfaction was moderate.

Conclusions: Internet-based problem solving therapy is not more effective in reducing symptoms of depression than receiving an unguided self-help book during the waitlist period at outpatient mental health clinics. The effect sizes are much smaller than those found in earlier research in the general population, and the low rates of adherence indicate that the acceptability of the intervention at this stage of treatment for depressed outpatients is low. However, taking into account that there is much evidence for the efficacy of Internet-based treatments, it is too early to draw firm conclusions about the effectiveness of these treatments in outpatient clinics as a whole.

Trial Registration: Netherlands Trial Register NTR2824; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=2824 (Archived by WebCite at http://www.webcitation/ 6g3WEuiqH)

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KEYWORDS

depression; outpatient clinics; Internet-based treatment; problem solving therapy; specialized mental health care

Introduction

Depressive disorders are highly prevalent [1]. They affect 16% of the population on a lifetime basis [2,3] and are expected to become the leading cause of disability in high-income countries by 2030 [4]. Depression substantially impairs patients' daily life and reduces quality of life to a great extent. It is therefore essential to reduce the burden of depression as much as we can. A reduction in the associated health care uptake and improved work productivity is also beneficial to society as a whole.

Given the high prevalence and demand for mental health care, it is important for mental health care providers to optimize the use of their scarce resources. Long waiting lists before the start of psychological treatment are undesirable, but not uncommon. Patients who are referred to specialized mental health care rarely receive immediate access to psychological treatments [5]. In the Netherlands, for example, the time between registration and the first treatment session is normally at least 6 weeks. This time might be used more efficiently by deploying Internet-based self-help treatments [6], which might make treatment more effective and efficient if patients require fewer or no face-to-face sessions afterward.

Previous controlled studies have demonstrated that guided self-help is clinically effective in diverse populations [7-9] and that it has effects comparable with those of face-to-face treatments [10,11]. However, most studies on Internet treatments have been conducted with self-referred participants recruited from the community through advertisements. Those patients probably would not have received any treatment if these trials had not been conducted. This population might be different from those who seek help at outpatient mental health clinics, who might have more severe symptoms and different expectations, as they expect to receive regular face-to-face treatment. This might influence the way they view and respond to Internet treatment. The current evidence base on the effectiveness of guided self-help delivered by the Internet to clinical populations who are referred to outpatient mental health clinics is small. Although some research exists on the effectiveness of Internet treatments in routine psychiatric care [12], most research has focused on self-referred participants from the general population [13,14] or in primary care settings [15].

Internet-based guided self-help interventions are not offered as a first step for patients who are waiting for outpatient mental health clinics, and no trials have specifically evaluated whether starting with Internet-based treatments is effective in those settings. It is important to examine whether the effects found in previous trials can be replicated in clinical populations in outpatient care, as guided self-help has many advantages that could be of great benefit. The advantages include improved access to treatments for patients, less waiting time, and potential costs savings, as these treatments require significantly less therapist time than do conventional treatments and put less strain on therapeutic resources. Introducing Internet-delivered self-help interventions as a start of treatment might bridge the treatment gap and can possibly speed up clinical recovery [16].

Aims and Hypotheses

We conducted this randomized controlled trial among patients with a depressive disorder (as defined by the *Diagnostic and Statistical Manual of Disorders*, fourth edition, DSM-IV) who registered for help in an outpatient mental health clinic. The aim of the study was to examine the effects of guided Internet-based self-help before starting face-to-face therapy. We expected the intervention group to report significant improvements in symptoms of depression at posttest, relative to the control group.

Methods

Ethics Statement and Trial Registration

The trial was approved by the Medical Ethics Committee of the VU Medical Centre Amsterdam (registration number 2011.223) and has been registered with the Netherlands Trial Register (NTR2824). We collected written informed consent from all participants.

Design and Sample Size

Our study was a randomized clinical trial examining the effects of an Internet-based problem solving therapy with scheduled email guidance before starting face-to-face therapy in outpatient clinics. The control group stayed on the waiting list and received a self-help book but without any form of guidance. The reason for sending this self-help book was to motivate people to participate in the trial.

The full study design can be found elsewhere [17]. We made changes to the protocol by not using analysis of covariance for data analysis, but instead using regression analysis. Moreover, we managed to recruit 269 patients instead of the 248 participants as outlined in the protocol.

Recruitment

We recruited patients directly after registration for regular face-to-face treatments at the participating outpatient clinics. From December 2011 to August 2013. a total of 828 patients consented to share their contact details with the research team.

We screened patients presenting with symptoms of a mood disorder by telephone using the Composite International Diagnostic Interview for presence of a major depressive disorder. Subsequently, we checked other inclusion and exclusion criteria. Baseline measures were administered by phone to eligible patients (N=269). After each inclusion an independent researcher allocated patients to either the intervention group (n=136) or the control group (n=133) using a random allocation sequence stratified by location in blocks of 6, 8, and 10 generated by the independent researcher in the program Random Allocation Software version 2.0 (Informer Technologies, Inc).

Inclusion and Exclusion Criteria

To be eligible for this study, participants had to (1) be aged ≥18 years, (2) be waiting for face-to-face treatment at the participating clinics, (3) fulfill the DSM-IV [18] criteria for major depressive disorder as a primary diagnosis, (4) have access to the Internet, and (5) have adequate proficiency in Dutch. Comorbidity other than bipolar or psychotic disorders was allowed. We excluded patients presenting with suicidal ideation from the trial. We also excluded patients who started antidepressant medication, switched type, or changed dosage 12 weeks before or during the first phase of the trial. Patients who were ineligible remained on the waiting list for face-to-face treatment.

We temporarily excluded new participants from any outpatient clinic where the waiting time fell below 8 weeks, until that clinic's waiting time for new patients again exceeded 8 weeks. We made this decision so as not to measure the effects of active treatment by the clinic.

Intervention

We based the Internet intervention on problem solving therapy using self-examination therapy as a general framework [19]. The intervention's intent is to teach skills that help patients to regain control over their problems. Patients learn to determine what really matters to them (session 1) and learn structured strategies to solve those problems that are related to what matters (sessions 2, 3, and 4). Furthermore, attention is paid to thinking less negatively about the unimportant problems (session 3) and to learn to accept those situations that cannot be changed (session 4). As the intervention had already proven to be effective in community samples in different studies [13,14,20,21], we presented the intervention to the patients as a way to make a head start in their treatment during the waiting time.

The intervention has been described in more detail in several other studies [13,14,17]. In brief, it is a short, structured, and highly manualized generic intervention consisting of 5 weekly sessions. Each session contains structured homework assignments on which the participants receive weekly online feedback by a coach. The total amount of time coaches had for responding to each patient's assignment was about 15 to 20 minutes. The feedback was of a nontherapeutic nature and was aimed at helping participants to become familiar with the presented techniques. In the first session, participants were required to determine what is important in their lives. Next to this, they had to make a list of current problems and worries and divide them into 3 categories: (1) not important (ie, not related to the list of important things), (2) important and unsolvable (eg, permanent loss of health or a loved one), or (3) important and solvable. In the second, third, and fourth sessions, participants were offered various coping skills related to each of the categories of problems. The main focus was on adopting a structured 6-step approach when encountering important, solvable problems. This structured approach consisted of identifying the problem; finding solutions; selecting one solution; creating a plan to solve the problem with this solution; executing the plan; and evaluating the plan. The last week of the intervention was reserved for both the reflection on long-term goals and the development of a structure to achieve these goals.

Participants could only move on to the next session once they had submitted the exercise in the previous session and when the research team had released feedback on this session. When they did not finish a session, participants received an email from their coach to encourage them to carry on and to offer assistance in case there were specific problems preventing further use of the intervention.

During the trial, we migrated the website to an updated version to safeguard participants' data according to Dutch law and to fix defects in website functionality. The content of the platform remained unchanged.

Control Condition

To increase participation rates in the control group, this group received a self-help book format without any form of guidance. The book was sent as is, without further instructions. Previous research showed that self-guided interventions resulted in only small effect sizes on levels of depression [7-9].

Participants in both conditions already had an appointment for face-to-face treatment at the clinic scheduled after the waitlist period. Waiting times were not affected by participation in this study.

Assessments

All outcome measures were administered by phone by trained research assistants at baseline and posttest (8 weeks from randomization). This short interval was to ensure that patients had not started with conventional psychotherapy at the clinics.

Primary Outcome Measure

The primary outcome, symptoms of depression, was measured by the Center for Epidemiological Studies Depression scale (CES-D) [22], consisting of 20 items with total scores ranging between 0 and 60. Higher scores indicate higher levels of depression and a score of ≥16 indicates a clinical level of depression. This questionnaire has been tested in various populations and has been found both valid and reliable [23].

Secondary Outcome Measures

Secondary outcome measures were symptoms of anxiety, symptoms of insomnia, quality of life, and mastery. We used the Anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A) to measure symptoms of anxiety. The Anxiety subscale consists of 7 items, with scores ranging from 0 to 21; higher scores indicate higher levels of anxiety. The HADS has been shown to be reliable in Dutch populations [24].

We administered the Insomnia Severity Index questionnaire (ISI) [25] to measure both the concerns associated with the perceived level of insomnia, and symptoms and consequences of insomnia. Each item is rated on a scale of 0 to 4; a higher score indicates more severe insomnia. ISI has been found to be internally consistent and reliable [26].

We used the EuroQol visual analog scale (EQ-5D VAS) [27] to measure the patients' self-rated health. Endpoints (0, 100) are labelled "Best imaginable health state" and "Worst imaginable health state."

We measured the amount of perceived control in a person's life by the Pearlin Mastery Scale [28]. The scale consists of 7 distinct items that are rated on a 4-point scale. Higher scores indicate more perceived control; scores range from 7 to 35. The scale has good reliability.

Process Outcome Measures

Process outcome measures were adherence, general satisfaction with the treatment, and the *Alles Onder Controle* (Everything Under Control) satisfaction questionnaire.

We defined treatment adherence (0=low adherence, 1=adherence) as completing at least 4 of the 5 lessons within the given time frame of 5 weeks. Participants who completed at least 80% of the Web-based material would have been exposed to the majority of the interventions described in the manual. We defined lesson completion as (1) reading the exercises, (2) doing the exercises, (3) receiving feedback on exercises, and (4) reading the feedback. Participants could move to the next session only when they had completed the exercises and opened the feedback from the coach, which we marked as read. We monitored these data through the intervention platform.

Satisfaction with the Internet intervention was measured by the Client Satisfaction Questionnaire-8 (CSQ-8), which consists of 8 questions; each question is scored on a Likert-type scale from 1 to 4 [29]. The questionnaire addresses several elements that contribute to overall service satisfaction and is reported in a single dimension of overall satisfaction. A high internal consistency has been reported [29].

The *Alles Onder Controle* satisfaction questionnaire was designed specifically to investigate to what degree participants were satisfied with this Internet-based intervention. It includes questions on the number of sessions completed and, if applicable, the reasons for not finishing the course. The questionnaire further researches satisfaction with the separate elements of the intervention, such as the quality of the feedback, the clarity of the website, and the appropriateness of the examples.

Statistical Analysis

We examined differences between groups on baseline characteristics by performing chi-square tests for categorical variables and 1-way analysis of variance for continuous variables. Baseline data were available for all participants. We analyzed missing values on the outcome measures in agreement with the intention-to-treat (ITT) principle, as per the CONSORT statement [30]. We used a logistic regression analysis with backward stepwise method to explore whether participants' characteristics could predict missing data at posttest.

Missing endpoints at posttest (31.6%, 85/269) were imputed using the multiple imputation function in IBM SPSS Statistics 20 (IBM Corporation), yielding 30 imputations with 30 iterations using the multiple imputation option with predictive mean matching. Predictors for the imputing procedure were pretest and nonmissing posttest scores, age, education level, sex, and randomization status.

We calculated the intraclass correlation to examine nonindependence of observations at the outpatient clinic level. We did not deem a multilevel approach for analyzing data to be necessary. Therefore, we preformed linear regression analyses to examine posttreatment differences between the intervention and the control group. The baseline score of the dependent variable was added as a covariate to adjust the outcome for baseline differences. Differences between the intervention and the control condition were denoted by a regression coefficient (B) and 95% CIs.

We also expressed the magnitude of the effects as Cohen *d* effect sizes by dividing the difference in mean scores of the 2 groups by their pooled standard deviation (Xexp-Xctrl/SDpooled). Effect sizes <0.2 are considered to be small, of 0.5 are moderate, and of 0.8 are large [31]. We calculated the effect sizes for all participants (ITT). We performed all analyses on both completer-only data and the imputed file. Furthermore, we performed a per-protocol analysis based on treatment completers (completed ≥4 sessions of the intervention).

Results

Sample Characteristics

Figure 1 shows the flow of participants through the trial. A total of 828 patients who signed up at the outpatient clinics agreed to be contacted by the research team. Of these, 300 did not meet the inclusion criteria, 254 declined to participate or did not provide informed consent, and 5 had other reasons for not participating in the study. We randomly allocated the remaining 269 participants to either the intervention group (n=136) or the control group (n=133).

Table 1 presents baseline data. The mean age of participants was 38.0 (SD 11.4), and 145 (53.9%) were women. Most of the participants were born in the Netherlands (223/269, 82.9%) and had an education level from middle (105/269, 39.0%; upper secondary general education, secondary vocational education, postsecondary education) to high (111/269, 41.3%; specialized vocational education, university or college education). Their income was mostly below the Dutch average (171/269, 63.6%) based on the average income for the years 2012/2013, which was €33.000. There were no significant differences between intervention and control group on demographic variables or any of the outcome measures at baseline.

Table 1. Baseline characteristics of outpatients receiving Internet-based therapy (intervention) or placed on a waitlist (control) for treatment of depression.

Participant characteristics	Intervention (n=136)	Control (n=133)	Total (N=269)	*P* value[a]
Sex, n (%)				.25
Male	58 (42.6)	66 (49.6)	124 (46.1)	
Female	78 (57.4)	67 (50.4)	145 (53.9)	
Age (years)				
Mean (SD)	38.6 (10.5)	37.4 (12.3)	38.0 (11.4)	.41
Range	18–64	18–79	18–79	
Born in the Netherlands, n (%)	111 (81.6)	112 (84.2)	223 (82.9)	.46
Income less than average[b], n (%)	86 (63.2)	85 (63.9)	171 (63.6)	.94
Educational level [c], n (%)				.69
Low	29 (21.8)	24 (17.6)	53 (19.7)	
Middle	51 (38.3)	54 (39.7)	105 (39.0)	
High	53 (39.8)	58 (42.6)	111 (41.3)	
Antidepressant medication, n (%)	29 (21.3)	38 (28.6)	67 (24.9)	.17
Treatment history, n (%)				
Psychological treatment	80 (58.8)	77 (57.9)	157 (58.4)	.88
Internet treatment	3 (2.2)	7 (5.3)	10 (3.7)	.19
Self-help book	31 (22.8)	29 (21.8)	60 (22.3)	.85
None	22 (16.2)	20 (15.0)	42 (15.6)	.87
Symptom measures, mean (SD)				
Depression (CES-D[d])	37.0 (11.6)	35.2 (12.2)	36.1 (11.9)	.22
Anxiety (HADS-A[e])	12.4 (3.9)	12.6 (4.7)	12.5 (4.3)	.67
Insomnia (ISI[f])	13.9 (6.5)	13.7 (6.1)	13.8 (6.3)	.39
Quality of life (EQ-5D VAS[g])	53.1 (17.4)	50.3 (17.1)	51.7 (17.3)	.20
Mastery (Pearlin Mastery Scale)	20.1 (4.0)	19.5 (3.5)	19.8 (3.8)	.20

[a] Tested with *t* test for continuous variables or chi-square test for categorical variables.

[b] Average income for 2012/2013 = €33.000 (Central Bureau for Statistics).

[c] Low: no education, preprimary, primary, lower secondary education, compulsory education, initial vocational education. Middle: upper secondary general education, secondary vocational education, postsecondary education. High: specialized vocational education, university or college education.

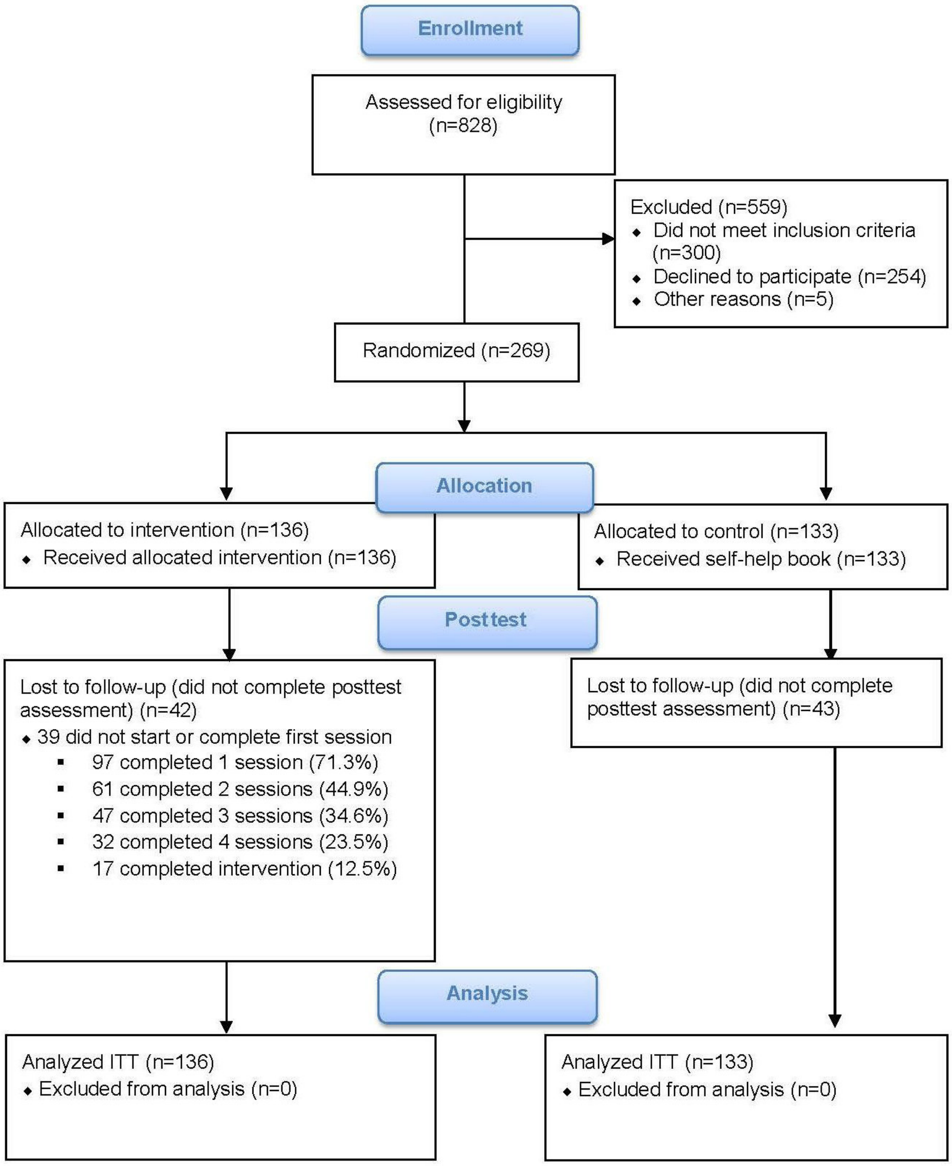
[d] CES-D: Center for Epidemiological Studies Depression scale.

[e] HADS-A: Hospital Anxiety and Depression Scale, Anxiety subscale.

[f] ISI: Insomnia Severity Index questionnaire.

[g] EQ-5D VAS: EuroQol visual analog scale.

Figure 1. Participant flowchart.



Study Attrition

Of the 269 patients who started pretest assessment, 184 (68.4%) completed the posttest assessment. We tested whether there were significant differences in baseline characteristics, as described in Table 1, between study completers and noncompleters. Noncompleters were more likely to be female, younger, and less educated and had a lower income. There were no differences in any of the clinical characteristics such as depression severity. Table 2 shows the statistically significant differences between noncompleters and completers; not reported baseline characteristics were not significant.

Treatment Adherence

Adherence to the intervention was low. About a third (49/136, 36%) received an adequate dosage of the intervention. They completed either 4 (n=32; 23.5%) or 5 (n=17; 12.5%) lessons. Treatment expectancy and credibility measures at baseline predicted higher adherence (B=1.086, *P*=.019). Not all participants reported reasons for nonadherence (85/119); however, the reported reasons for dropout where mostly lack of energy (35/85), that the course was not a priority (20/85), technical problems (16/85), no benefits from the course (12/85), or feeling better (2/85).

Effects

Both groups showed significant improvements between baseline and posttest on all outcomes measured (see Table 3).

Table 2. Baseline differences between outpatients with depressive disorder who completed and did not complete posttest assessments.

Characteristics	Completers (n=184)	Noncompleters (n=85)	*P* value[a]
Female, n (%)	90 (48.9)	55 (64.7)	.02
Age in years, mean (SD)	39.2 (11.5)	35.4 (11.0)	.01
Higher education[b], n (%)	86 (46.7)	25 (29.4)	.02
Low income[c], n (%)	106 (57.6)	65 (76.5)	.049

[a] Tested with chi-square or *t* test.

[b] Specialized vocational education, university or college education, doctorate, postdoctorate, and equivalent degrees.

[c] Less than average income in the Netherlands (average €33.000 for 2012/2013).

Table 3. Results of outcome measures for outpatients receiving Internet-based therapy (intervention) or placed on a waitlist (control) for treatment of depression: completers and intention-to-treat (ITT) sample.

Measure	Completers sample		ITT sample		Statistic ITT sample		Effect size[c]	
	Pretest mean (SD)	Posttest mean (SD)[a]	Pretest Mean (SD)	Posttest mean (SD)[a]	B[b]	95% CI	Within group	Between group
CES-D [d]					1.13	–2.495 to 4.763		0.07
Control	35.2 (12.2)	27.5 (12.3)	35.2 (12.1)	25.9 (14.9)			0.69	
Intervention	37.0 (11.6)	25.9 (12.6)	37.0(11.6)	27.0 (15.1)			0.75	
HADS-A [e]					0.47	–.793 to 1.722		0.09
Control	12.6 (4.7)	10.5 (4.2)	12.6 (4.6)	10.0 (5.5)			0.52	
Intervention	12.4 (3.9)	10.0 (4.3)	12.4 (3.9)	10.5 (5.4)			0.41	
ISI [f]					0.27	–1.424 to 1.955		0.04
Control	13.7 (6.1)	11.5 (5.4)	13.7 (6.1)	11.3 (7.6)			0.35	
Intervention	13.9 (6.5)	11.2 (5.6)	13.9 (6.4)	11.6 (7.2)			0.34	
EQ-5D VAS [g]					–1.76	–7.162 to 3.648		0.07
Control	50.3 (17.1)	57.3 (19.0)	50.3 (17.1)	59.3 (23.1)			0.44	
Intervention	53.1(17.3)	59.4 (19.3)	53.1 (17.3)	57.6 (23.3)			0.22	
Pearlin Mastery Scale					–.027	–.968 to .419		0.10
Control	19.5 (3.5)	27.1 (2.6)	19.5(3.5)	27.5 (3.1)			2.42	
Intervention	20.1 (4.0)	27.4 (2.6)	20.1 (4.0)	27.2 (2.9)			2.03	
CSQ-8 [h]					0.49	–.907 to 1.886		0.05
Control	NA[i]	20.5 (4.6)	NA	20.1 (5.3)			NA	
Intervention	NA	20.1 (4.8)	NA	20.4 (6.1)			NA	

[a] Controlled for baseline scores.

[b] Regression coefficient.

[c] Cohen *d*.

[d] CES-D: Center for Epidemiological Studies Depression scale.

[e] HADS-A: Hospital Anxiety and Depression Scale, Anxiety subscale.

[f] ISI: Insomnia Severity Index questionnaire.

[g] EQ-5D VAS: EuroQol visual analog scale.

[h] CSQ-8: Client Satisfaction Questionnaire-8.

[i] NA: not administered at that time point.

Primary Outcome Measure

The analysis showed that both groups improved significantly in depression scores from pre- to posttest (control group: B=0.56, 95% CI 0.34–0.78, *P*<.001; intervention group: B=0.61, 95% CI 0.38–0.84, *P*<.001). The within-group effect size Cohen *d* was moderate to large for both the intervention (*d*=0.75) and the control (*d*=0.69) groups. However, the between-group effect size was very small (*d*=0.07). Regression analysis on posttreatment CES-D scores controlling for pretreatment scores found no significant differences in posttreatment scores between the intervention group and the control group (*B*=1.134, 95% CI –2.495 to 4.763).

The per-protocol analysis (≥4 sessions completed) also did not yield significant results on the posttest differences in depressive symptoms between the 2 groups (B=1.154, 95% CI –1.978 to 7.637).

Secondary Outcome Measures

The within-group effect sizes were large for mastery, moderate for anxiety, and small to moderate for insomnia and quality of life. Between-group differences were small for all secondary outcomes, and differences between the groups were not significant.

Treatment Satisfaction

Treatment group participants who completed the posttreatment satisfaction questionnaire (n=92) were moderately positive about the intervention (average grade 7 out of 10, SD 1.08). A total of 69 reported that the intervention was useful to them and 29/92 reported that the program was either very useful or mostly helpful. A minority (7/92) rated the program as not helpful to their problems and needs.

Participants were mostly satisfied with the quality of the feedback, and only 4/92 were not satisfied with the feedback from their coach. Most participants in the intervention group (53/92) reported that they would have preferred to start their treatment with a face-to-face session with a therapist. Another 24 stated that they would have preferred to start with the Internet intervention and the remaining 15 participants reported that they didn't prefer one treatment modality over the other. The estimated mean score of the CSQ-8 was 20.4 (SD 6.1) among the 32 participants indicating a moderate degree of satisfaction.

Adverse Events

During the trial, 1 control group participant committed suicide. The participant had started face-to-face treatment at the outpatient clinic.

Discussion

Principal Findings

Although the efficacy of guided Internet-based treatment for depression has been firmly established [32], there is insufficient evidence of its effectiveness when delivered in routine outpatient mental health services. This study examined the effectiveness of a guided Internet-based self-help intervention, based on problem solving therapy, for patients with a depressive disorder who were awaiting face-to-face treatment at outpatient mental health clinics. We expected the guided Internet-based intervention to lead to better outcomes for patients compared with our control condition. The results did not support our hypothesis. Both groups demonstrated significant improvements in depression from pre- to posttest, with moderate to large within-group effect sizes. However, the between-group effect sizes were small and nonsignificant. The guided Internet-based intervention was not more effective than being on the waitlist with an unguided self-help book.

Compared with previous studies that examined the same Internet-based intervention against a pure waitlist control condition in community samples, the between-group effect size of our study is much smaller (*d*=0.47 [13], *d*=0.50 [14], current trial: *d*=0.07), but the change in depressive symptoms in our intervention group is similar to the change in symptoms in previous trials (ΔCES-D=11.3 [13], ΔCES-D=9.0 [14], current trial: ΔCES-D=10.0). The main difference is that our control group, against our expectations, showed significant improvements from pre- to posttest. This improvement in symptoms might have been caused by the self-help book, although previous trials found only small effects on depressive symptoms [7-9]. Other explanations might be that the reductions in symptoms in the control group were caused by test procedures (eg, telephone administered questionnaires), by the use of antidepressant medication (intervention group: 21.3%, control group: 28.6%; see Table 1) or by spontaneous improvement, which is not uncommon in depression. In any case, the reduction in symptoms in the control group may have led to a more conservative estimate of the between-group effect sizes.

Comparison With Prior Work

Most previous trials examined the effects of Internet treatment in community samples [13,14], general practitioners' offices [15], or specialized Internet clinics [12]. The results of these trials are much better in terms of adherence and effectiveness than the results of our trial involving regular outpatient mental health clinics. One explanation for the difference in outcome might be that this Internet intervention, based on problem solving therapy, wasn't effective for depressed patients who signed up for face-to-face treatment at regular outpatient clinics. This argument can be supported with the finding of low adherence to the intervention.

Another explanation might be the differences in study design. Previous trials [13,14] tested the exact same intervention against a waitlist control group that received no self-help book or any other treatment but were assigned to a pure waitlist condition. The previous trials also tested the intervention in community samples where participants actively signed up for Internet treatment without face-to-face sessions, as opposed to our participants, who signed up for regular treatment at specialized mental health clinics.

Furthermore, the initial levels of depression were higher in our sample than in the previous trials (baseline CES-D=29.9 [14], 31.9 [13], current trial: 37.0). The low-intensity Internet-based intervention may not have been suitable for severely depressed patients in this stage of their treatment. Perhaps these patients would have benefited more from an intervention of higher intensity. The low adherence might indicate that this short self-help intervention does not meet the needs of severely depressed patients, despite the findings from a recent meta-analysis of individual patient data [33] that showed that patients with more severe depression at baseline derived at least as much clinical benefit from low-intensity interventions as less severely depressed patients.

The results of our study also compare poorly with those of other studies of Internet-based cognitive behavioral therapy (iCBT) in routine care [12,15,34]. The difference in effectiveness might be explained by how the intervention was offered and the intensity of the treatment. In the Swedish iCBT clinic, for example, a face-to-face diagnostic assessment was offered before the start of Web-based treatment, a licensed psychologist carried out the treatment, and the iCBT consisted of more treatment sessions than we had in our intervention. Furthermore, those participants signed up for iCBT as their first choice of treatment, whereas in our study patients signed up for face-to-face treatment and were afterward referred to Internet treatment that was carried out by coaches of the university (masters-level students). The coaches' feedback in our study was not of a therapeutic nature, but was highly templated and focused on guiding the participant through the intervention. Even though the participants were mostly satisfied with the quality of the feedback, it did not lead to high adherence. Perhaps more intensive and therapeutic feedback from a clinician of the outpatient clinic would increase the completion rates. Also, the pace of 1 lesson per week may have been too rapid, and giving extra time could have led to higher completion rates. Furthermore, the patients in our study were already scheduled for a face-to-face appointment at the clinics, regardless of whether they finished the intervention. This might have lowered the motivation to persist with Internet treatment.

A final remark is that we accepted patients who had previously received treatment, including psychological treatments, for participation in our study. About 60% reported that they received psychological treatment before participating in this trial, 4% had received Internet treatment, and 22% had already used a self-help book; 16% reported no treatment history (see Table 1). Although those who had not received any prior psychological treatment completed more Internet sessions, this was not significant. The inclusion of participants who had previously received psychological treatment might have affected treatment outcome. Compared with studies that did not allow inclusion of participants who received prior psychological treatment, the participants in our sample might have been more treatment resistant than first-time treatment seekers. However, this remains speculative.

Overall, the results compare poorly with the results from previous studies in community samples and routine care. The low adherence to this intervention is a cause for concern because it is far lower than generally found in Internet-based interventions for depression [12,34-36].

Limitations

Some limitations of this randomized controlled trial are important to acknowledge. The first important limitation, as mentioned above, was the poor adherence to the intervention. Although we see adherence as an indicator of acceptability of the treatment, it may also be related to treatment outcome. The low adherence rates limited the extent to which our participants were exposed to the content of the intervention, thereby lowering the possible effects of the intervention.

Second, offering a self-help book without guidance may have influenced the between-group results, as the waitlist group may have improved using the self-help book. When we designed this trial, the literature showed small effect sizes for unguided self-help (ranging from d=0.06 to d=0.28 [7-9]) and larger effect sizes for guided Internet interventions (ranging from d=0.61 to d=0.78 [7,8]) compared with waitlist controls. However, more recent studies that have directly compared guided with newer self-guided Internet-based interventions found no difference in clinical outcomes for depression and anxiety [37,38]. Moreover, 28 (21%) of the participants in the control group stated that they had read the entire self-help book and 17 (12.8%) read half or more of the self-help book. These numbers indicate that the control group had read as much of the material as the intervention group did.

Third, not all participants completed posttest measurements. We corrected for missing values by using multiple imputation. However, imputing 31% of the data may have led to unreliable estimates. Regardless of the method for handling missing values, data on treatment satisfaction were available for only 92 of the intervention groups participants, of whom only 32 completed 4 or more lessons. The majority of the intervention group was thus not exposed to a large part of the intervention, and these results should be interpreted with caution.

In spite of these limitations, our study extends the current literature in an important way. To date, no randomized controlled trials have been conducted within existing regular outpatient mental health clinics that examined the effectiveness of Internet-based problem solving therapy for depression. In this trial we examined actual patients at actual outpatient clinics and were quite successful with the recruitment as compared with trial recruitment in primary care, which can be more difficult [39]. One study of the effects of iCBT for depression recruited only 7 participants from 11 general practices in 8 months [40]. In our trial, however, we were able to randomly allocate just over 50% of the 528 eligible patient. In all, 254 declined to participate in the study (before being screened), and 300 (36.2%) did not meet inclusion criteria. In total we were able to include 32.5% (269/828) of all referrals.

Conclusion

This study showed that Internet-based problem solving therapy is not more effective in reducing symptoms of depression than unguided self-help during the wait time at outpatient clinics. The between-group effect sizes were much smaller than those found in earlier trials in the general population and in primary care. Together with the low rates of adherence, the results indicate that the acceptability of the intervention at this stage of treatment in outpatient clinics is low for patients with depression. However, taking into account that there is much evidence for the efficacy of Internet-based treatments in the research setting, in particular for iCBT, it is too early to draw firm conclusions about the effectiveness of these treatments in outpatient clinics as a whole. While several countries are increasingly offering Internet treatments in clinical practice, more research is needed that examines who benefits from Internet-based treatments in outpatient settings. Only then can we draw firm conclusions about the feasibility, acceptability, and effectiveness of Internet-based interventions for a wider group of patients in regular mental health care.

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Authors' Contributions

RK authored the manuscript. AvS, PC, and AB provided feedback and suggestions for this manuscript. PC and AvS drafted the study protocol. All authors read and approved the final manuscript.

Conflicts of Interest

PC authored the intervention and self-help book but derives no personal or economic benefits from it.

Multimedia Appendix 1

Alles onder Controle Intervention.

[JPG File, 79KB - jmir_v18i3e80_app1.JPG]

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Abbreviations

CES-D: Center for Epidemiological Studies Depression scale
CSQ-8: Client Satisfaction Questionnaire-8
DSM-IV: Diagnostic and Statistical Manual of Disorders, fourth edition
EQ-5D VAS: EuroQol visual analog scale
HADS-A: Hospital Anxiety and Depression Scale Anxiety subscale
iCBT: Internet-based cognitive behavioral therapy
ISI: Insomnia Severity Index questionnaire
ITT: intention to treat

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Original Paper

Mobile Phone-Based Unobtrusive Ecological Momentary Assessment of Day-to-Day Mood: An Explorative Study

Joost Asselbergs[1,2], MSc; Jeroen Ruwaard[1,2], PhD; Michal Ejdys[3], MSc; Niels Schrader[3], MFA; Marit Sijbrandij[1,2], PhD; Heleen Riper[1,2,4,5], PhD

[1]Faculty of Behavioural and Movement Sciences, Section Clinical Psychology, Vrije Universiteit Amsterdam, Amsterdam, Netherlands
[2]EMGO Institute for Health Care and Research, VU University Medical Centre, Amsterdam, Netherlands
[3]Mind Design, Amsterdam, Netherlands
[4]GGZ inGeest, Amsterdam, Netherlands
[5]Health and Life Sciences Faculty, Telepsychiatry Unit, Southern Denmark University, Odense, Denmark

Corresponding Author:
Joost Asselbergs, MSc
Faculty of Behavioural and Movement Sciences
Section Clinical Psychology
Vrije Universiteit Amsterdam
Van der Boechorststraat 1
Amsterdam, 1081 BT
Netherlands
Phone: 31 20 59 88774
Fax: 31 20 5988758
Email: j.a.g.j.asselbergs@vu.nl

Abstract

Background: Ecological momentary assessment (EMA) is a useful method to tap the dynamics of psychological and behavioral phenomena in real-world contexts. However, the response burden of (self-report) EMA limits its clinical utility.

Objective: The aim was to explore mobile phone-based unobtrusive EMA, in which mobile phone usage logs are considered as proxy measures of clinically relevant user states and contexts.

Methods: This was an uncontrolled explorative pilot study. Our study consisted of 6 weeks of EMA/unobtrusive EMA data collection in a Dutch student population (N=33), followed by a regression modeling analysis. Participants self-monitored their mood on their mobile phone (EMA) with a one-dimensional mood measure (1 to 10) and a two-dimensional circumplex measure (arousal/valence, –2 to 2). Meanwhile, with participants’ consent, a mobile phone app unobtrusively collected (meta) data from six smartphone sensor logs (unobtrusive EMA: calls/short message service (SMS) text messages, screen time, application usage, accelerometer, and phone camera events). Through forward stepwise regression (FSR), we built personalized regression models from the unobtrusive EMA variables to predict day-to-day variation in EMA mood ratings. The predictive performance of these models (ie, cross-validated mean squared error and percentage of correct predictions) was compared to naive benchmark regression models (the mean model and a lag-2 history model).

Results: A total of 27 participants (81%) provided a mean 35.5 days (SD 3.8) of valid EMA/unobtrusive EMA data. The FSR models accurately predicted 55% to 76% of EMA mood scores. However, the predictive performance of these models was significantly inferior to that of naive benchmark models.

Conclusions: Mobile phone-based unobtrusive EMA is a technically feasible and potentially powerful EMA variant. The method is young and positive findings may not replicate. At present, we do not recommend the application of FSR-based mood prediction in real-world clinical settings. Further psychometric studies and more advanced data mining techniques are needed to unlock unobtrusive EMA’s true potential.

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KEYWORDS

affect; data mining; ecological momentary assessment; experience sampling; mobile phone sensing

Introduction

In mental health studies, researchers commonly rely on self-report questionnaires to follow the course of patients' clinical symptoms [1]. However, these instruments are limited. They are retrospective and, therefore, susceptible to recall bias [2]. In addition, they are typically administered in clinical settings, which limit the degree to which measurements can be generalized to everyday life [3]. To address these limitations, there has been growing interest in so-called ecological momentary assessment (EMA), in which psychological phenomena are repeatedly assessed within patients' natural environments [4,5].

Ecological momentary assessment includes various data collection methods and strategies, such as diaries and paper-and-pencil questionnaires. More recently, EMA consists of questions appearing on one's mobile phone that need to be completed/answered at prompted time points, often multiple times a day (eg, ”on a scale from 1 to 10, how would you rate your level of irritation in the past 30 minutes?”) or immediately after a specific event of interest has occurred (eg, making a record in one's diary or pressing a button on one's mobile phone when experiencing a negative thought) [1]. As such, EMA reduces recall bias and increases the ecological validity of measurements, allowing researchers to better capture the dynamics of behavioral and emotional processes in everyday life (eg, [6,7]).

Despite EMA's obvious advantages over retrospective questionnaires, self-report EMA—the dominant form in EMA research—still depends on explicit respondent input. This does not remove systematic biases such as social desirability. Furthermore, this dependence on explicit respondent input limits the amount of information that can be captured because study participants are usually willing to answer only a limited number of questions per day. When EMA is applied for too long, the cumulative response burden may negatively affect the validity of the measurements (eg, through reactivity) and response rates; for example, EMA compliance rates have been shown to erode significantly after 2 weeks of data collection [8]. These aspects limit the applicability of EMA in clinical practice and research.

Explicit respondent input may not be a necessary requirement of EMA because traces of behavior and experiences are already reflected in the log files of the technological devices that we use in everyday life. In what might be called “unobtrusive” EMA, hardware and software sensors embedded within mobile phones are used as unobtrusive monitors of user behavior (eg, physical activity, social activity) and contexts such as work or at home. Unobtrusive EMA silently samples data on a patient's mobile phone. Data are collected, continuously if useful, without the need to constantly prompt the patient, thus minimizing the response burden and biases related to explicit respondent input. As such, unobtrusive EMA holds promise as an EMA variant, enabling rich data to be collected over longer periods of time. Of course, unobtrusive EMA cannot directly tap mental states. However, it may be useful for monitoring proxies of mental health (ie, variables that are theoretically associated with mental health), such as physiological states, behavioral patterns (ie, activity, social interactions), and contextual triggers (ie, specific locations or social environments). For instance, mobile phone context sensing has been explored in relation to alcohol dependence [9], academic performance [10], and depression [11,12].

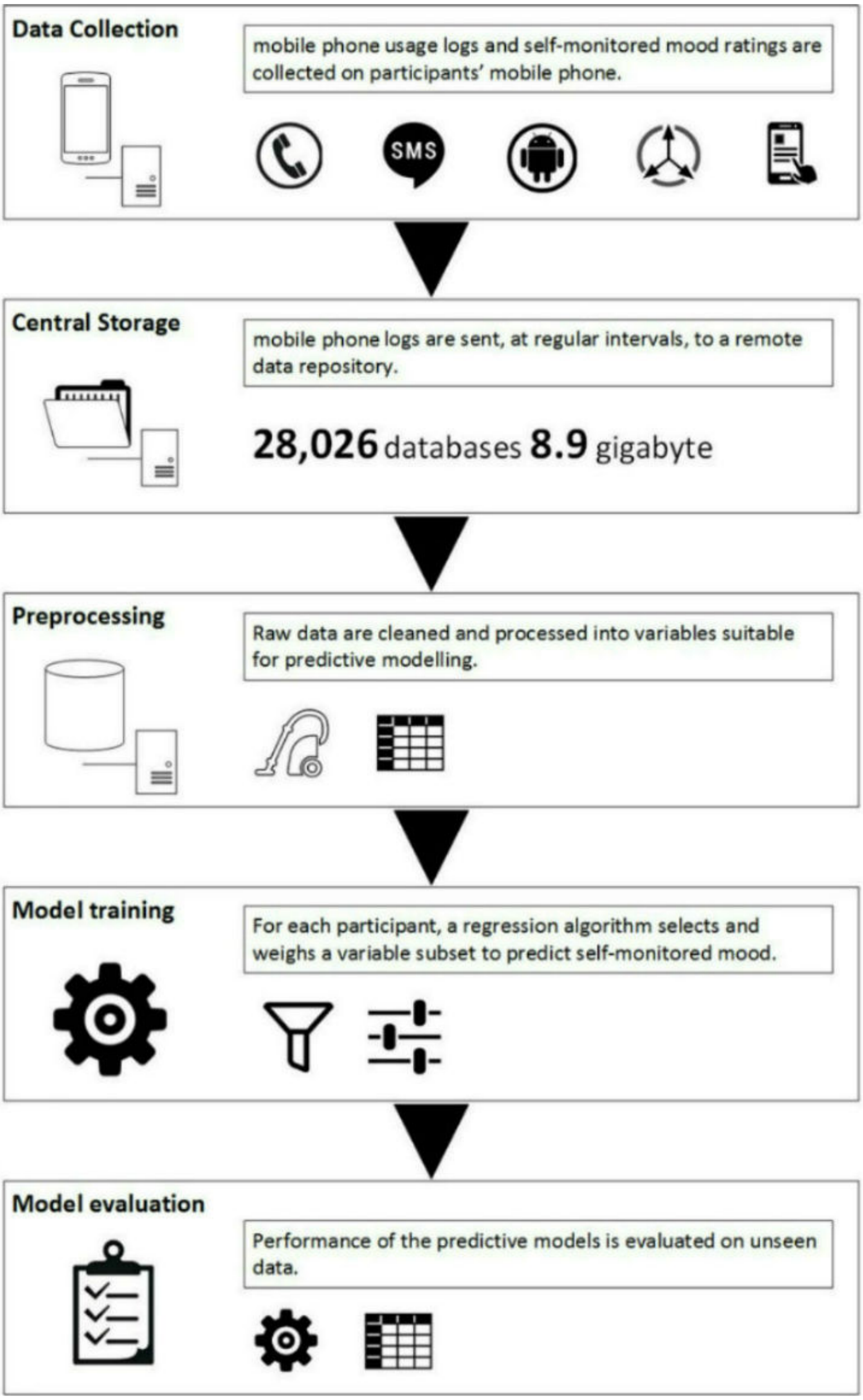
In a pioneering study, LiKamWa et al [13] explored personalized regression modeling to predict day-to-day fluctuations of self-monitored mood from unobtrusively collected proxy variables of social activity, physical activity, and general mobile phone use. With mobile phone-logged data collected from 32 participants over 2 months, they found the predictive accuracy of personalized models to be high. Up to 93% of self-reported mood scores were correctly predicted within a tolerated error margin. These results suggest that mood studies could potentially follow participants longer by reducing the assessment burden of study participants through a mix of self-report EMA and unobtrusive EMA. Intrigued by this, we conducted a pilot replication study to further explore the feasibility of unobtrusive EMA-based mood prediction and to gain a better understanding of the challenges associated with collecting and processing unobtrusive EMA data and personalized predictive regression modeling.

Methods

Design and Study Procedures

This was an explorative uncontrolled pilot study, replicating the methods of LiKamWa et al [13]. A small group of Dutch university students (N=27) self-monitored their mood on their mobile phones for 6 weeks. Meanwhile, a faceless mobile phone app unobtrusively collected proxy variables of social activity, physical activity, and general mobile phone use from mobile phone sensors and app logs. Data collection was followed by a predictive modeling study, in which we checked whether personalized regression models could accurately predict day-to-day fluctuations of self-monitored mood from the unobtrusively collected mobile phone variables (see Figure 1). Primary study data and the R-script used for analysis are available for download (see Multimedia Appendices 1 and documentation and the R-studio project ZIP file in Multimedia Appendix 3).

Figure 1. Overview of study setup.



Participants

Through information flyers, we invited students from the campus of the Vrije Universiteit Amsterdam, the Netherlands, to take part in this study. Inclusion criteria for participation were (1) age 18 years or older and (2) owning an Android smartphone (minimal OS 2.2) that would be in use as the primary mobile phone during the study period (6 weeks). Applicants were screened for depressive symptoms before the study because we did not want to include participants with severe levels of depression. For this, we used the Center for Epidemiologic Studies Depression Scale (CES-D), which is a validated and often used 20-item questionnaire to assess past-week depressive symptoms [14] (Dutch Version [15]). CES-D total scores range between 0 and 60, with scores greater than 16 signaling mild depressive symptoms and scores greater than 27 signaling clinical depressive symptoms [16,17]. Applicants reporting clinical depression symptoms (ie, CES-D>27) were excluded from the study and referred to their general practitioner. To encourage students to take part in our study, we offered them a monetary reward depending on EMA response rates (ie, EMA response rates ≥50%: €20; rates ≥75%: €35; rates ≥95%: €47.50). Approval for the study was obtained from both the Science Committee and the Research Ethics Committee of the Psychology Department of the Vrije Universiteit Amsterdam (reference number: VCW.1311.016). All participants signed an informed consent form.

Measures and Materials

Ecological Momentary Assessment of Mood

To collect self-monitored mood data (the target of the prediction task), we used eMate, an EMA mobile phone app developed at the Vrije Universiteit Amsterdam. This app prompted participants to rate their mood on their smartphone at five set time points per day (ie, approximately 09:00, 12:00, 15:00, 18:00, and 21:00). As in the study by LiKamWa et al [13], we assessed mood through the circumplex model of affect [18], which conceptualizes mood as a two-dimensional construct comprising different levels of valence (positive/negative affect) and arousal. Levels on both dimensions were tapped on a 5-point scale scored from -2 to 2 (low to high). Because recent studies suggest that single-item mood measures can provide predictive information on the development of depressive symptoms (eg, [19]), we also added a one-dimensional mood question, which asked participants to rate their current mood on a 10-point scale, with 1 as the negative and 10 as the positive pole.

Unobtrusive Ecological Momentary Assessment of Mood Predictors

For unobtrusive assessment, we developed iYouVU, a faceless mobile phone app based on the Funf open-sensing-framework [20,21] and prior research into communication habits based on mobile phone data collected without the user's full awareness [22]. This app runs in the background, unnoticeable to the user, to collect designated sensor data and app logs. The app logged call events (ie, time/date of the call, duration, and contact of both incoming and outgoing calls), short message service (SMS) text message events (ie, time/date and contact), screen on/off events (ie, time/date), app use (ie, what app was launched, when, and for how long), and mobile phone camera use (ie, the time/date a picture was taken). All collected sensitive personal data, such as contact details (names, phone numbers), were anonymized during data collection by the app through the built-in cryptographic hash functions of the Funf framework. At set intervals during each day, and only when participants' mobile phones were connected to Wi-Fi, the app sent collected data over the Internet to a remote central data server, in chunks of approximately 5 to 10 MB per data file.

We could not—or, in some cases, decided not to—monitor some of the features collected by LiKamWa et al [13]. Funf did not provide access to the metadata and content of email messages, so we could not include these variables in our study. Because Funf hashed browser history entries, we were not able to cluster the website domain. Furthermore, in a preliminary test, browser URL history did not function well enough to provide useful data; for that reason, we could not include this variable.

This was the first study with our experimental setup; therefore, we decided against collecting global positioning system (GPS) location data because we wanted to confirm adequate functioning of the technical setup before collecting highly sensitive personal data. Instead, as a proxy of activity, we collected accelerometer data.

Data Preprocessing and Feature Engineering

Raw EMA and unobtrusive EMA data were preprocessed into a data file that summarized each day of each participant in a row of 53 variables, as described subsequently.

Prediction Targets: Ecological Momentary Assessment Mood

As in the LiKamWa et al study [13], EMA data (ie, both the one-dimensional mood measure and the two measures of the circumplex model, valence and arousal) were aggregated to daily averages as targets for the mood prediction algorithms. Daily averages were standardized within each participant (ie, using means and standard deviations calculated for each participant separately).

Mood Prediction Feature Set

Raw unobtrusive EMA data were aggregated into daily summaries and from these daily summaries we derived the following features as presented in Table 1.

Table 1. Mood prediction feature set.

Raw data and feature	Variables, n	Range
Calls		
Caller top 5 contact frequency, 3-day window, normalized	5	0-1
Caller top 5 contact duration, 3-day window, normalized	5	0-1
SMS text message		
SMS text message top 5 contact frequency, 3-day window, normalized	5	0-1
Accelerometer		
Percentage of high activity	1	0-1
Screen		
Frequency of screen-on events (normalized within participant data)	1	–3 to 3[a]
Total screen duration events (normalized within participant data)	1	–3 to 3[a]
Apps		
Top 5 apps usage frequency, normalized	5	0-1
Top 5 apps usage duration, normalized	5	0-1
Categorized apps, usage frequency, normalized	11	0-1
Categorized apps, usage duration, normalized	11	0-1
Images		
Number of images taken (normalized within participant data)	1	0-1
Mood history		
Mood of yesterday, standardized	1	–3 to 3[a]
Mood of day before yesterday, standardized	1	–3 to 3[a]

[a] Standard normal distribution (ie, 99.7% of values ranging between –3 and 3).

For phone calls and SMS text messages, we counted the number of interactions participants had with their five most frequent contacts. Following LiKamWa et al [13], we created a histogram of this interaction frequency over a 3-day history window and used the normalized frequency count as samples in the feature table. Similarly, we created a normalized 3-day histogram of call durations with the top five contacts. Most participants interacted only incidentally with persons outside their top five through calls or SMS text messages. Therefore, we limited the histograms to the five most frequently interacted contacts, in contrast to LiKamWa [13], who monitored the top 10 contacts. Altogether, raw call/SMS text message data were summarized into three predictive features (top five call frequency and duration and top five contact SMS text message frequency), comprising 15 variables.

Raw mobile phone screen on/off events were transformed into two features: (1) the total number of times the screen was turned on per day and (2) the total amount of screen time per day (calculated as the differences between the times of the screen on/off events). Both features were transformed to standard normal variables within each participant.

Accelerometer data represents the acceleration of the smartphone on the x, y, and z planes. Acceleration was sampled for 5 seconds each minute (at sample frequencies estimated to vary from 20-200 Hz, as determined by the hardware and software characteristics of participants' mobile phones). Raw data were summarized (on the phone through Funf's ActivityProbe) into a high activity variable by calculating the percentage of time at which the summed variance of the device's acceleration (on the x, y, z planes) was above a set "high activity" threshold (ie, in which the summed variance exceeded 10 m/s^2). These percentages were aggregated to the day level to provide an approximate measure of daily activity.

As daily measures of mobile phone app use, we created two 3-day normalized histograms for the daily frequency and duration of the five most frequently used mobile phone apps. In addition, we created normalized histograms of frequency and duration of the use of app categories. In accordance with the LiKamWa et al study [13], we categorized apps as either built-in, communication, entertainment, finance, games, office, social, travel, utilities, other, or unknown (11 categories). Categories of logged apps were determined through a scripted query of the Google Play Store. Apps that were unknown to the Google Play Store were manually categorized on the basis of an Internet search. In sum, the final dataset consisted of four features based on app usage logs: top five app frequency, top five app duration, app category frequency (11 categories), and app category duration (11 categories). These features resulted in 32 variables (5+5+11+11).

Phone camera logs were summarized to the number of photos taken per day. Next, this summary was transformed to the 0-1 scale for each participant separately by dividing all values by the maximum number of photos taken.

Finally, similarly to LiKamWa et al [13], we extended the predictive feature set with a simple representation of mood history, by adding lag 1 and lag 2 transformations of each mood variable (standardized within each participant).

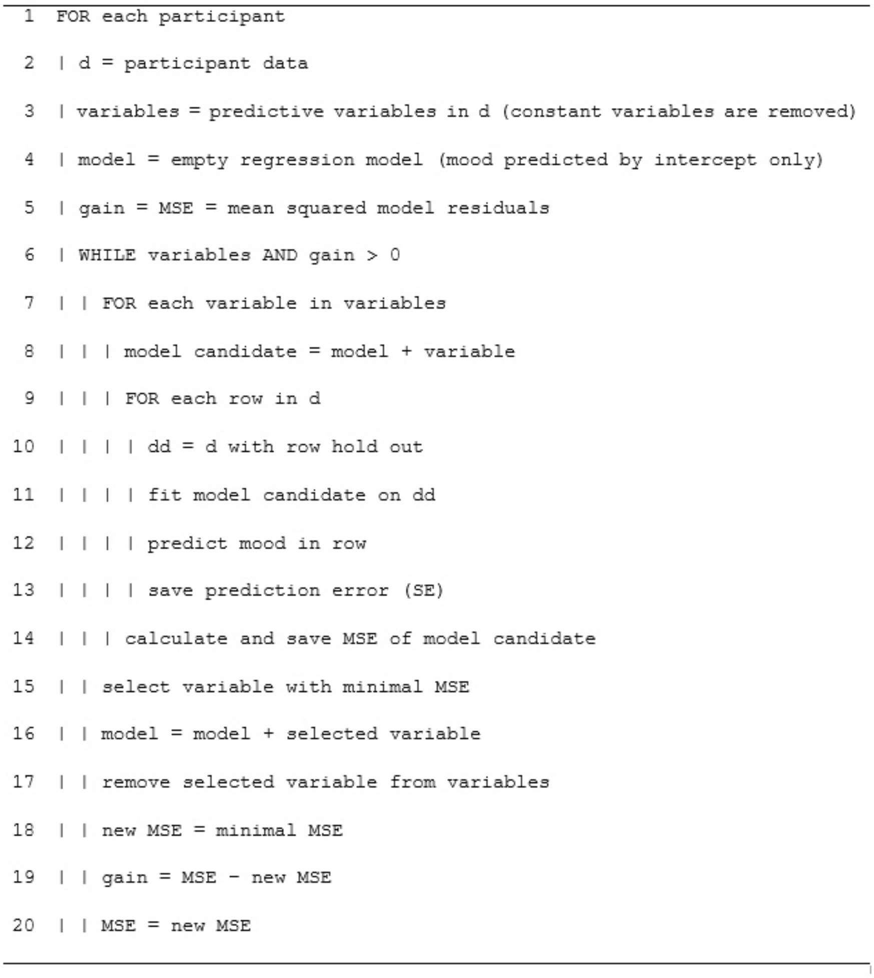
In total, we derived a 53-dimensional variable set from 13 distinctive predictive features (Table 1). Because regression models are sensitive to large differences in the scales of independent variables, we transformed the scales of the variables to the standard normal distribution (ie, 99.7% of values ranging between –3 and 3). Interrelated variables (eg, top 5 call and top 5 app use) were normalized to the 0-1 range, following the methods of LiKamWa et al [13].

Statistical Analysis

Personalized Predictive Model Training Algorithms

Replicating LiKamWa et al [13], personalized mood prediction models were trained using forward stepwise regression (FSR), a multiple linear regression technique in which variables relevant to the prediction task are sequentially selected. We examined two FSR-variants: (1) the stepAIC procedure, as defined in the standard MASS toolbox of R [23], in which variables are selected on the basis of the Akaike information criterion (AIC) [24], and (2) the stepCV procedure, in which variables are selected based on their ability to minimize the cross-validated mean squared error. The algorithm of the second variant is outlined in Figure 2. For each participant, starting with the empty model (intercept only), the procedure sequentially adds, one by one, those predictive variables to the model that reduce the cross-validated mean squared error (MSE) the most until the MSE starts to increase. For the cross-validation in this algorithm, we used leave-one-out cross-validation (LOOCV), which was implemented by using the predicted residual sum of squares (PRESS) statistic on a single model run [25]. To prevent severe overfitting of regression models, we maximized the number of predictive variables in the models to the number of data points divided by 5 (ie, amounting to a maximum of eight variables with 42 data points).

Figure 2. Predictive model building algorithm: forward stepwise regression with leave-one-out cross-validation.



```
FOR each participant
    d = participant data
    variables = predictive variables in d (constant variables are removed)
    model = empty regression model (mood predicted by intercept only)
    gain = MSE = mean squared model residuals
    WHILE variables AND gain > 0
        FOR each variable in variables
            model candidate = model + variable
            FOR each row in d
                dd = d with row hold out
                fit model candidate on dd
                predict mood in row
                save prediction error (SE)
            calculate and save MSE of model candidate
        select variable with minimal MSE
        model = model + selected variable
        remove selected variable from variables
        new MSE = minimal MSE
        gain = MSE - new MSE
        MSE = new MSE
```

Predictive Performance Assessment

We assessed the predictive performance of the two FSR procedures through LOOCV. For each participant observation, we noted the differences between the observed mood rating and the mood rating predicted by the personalized FSR model trained on all other observations of that participant. Because we used both lagged mood prediction variables (ie, lag 1 and lag 2), we started to train our models from day 3 (ie, use a model trained on day 3:41 to predict day 42, etc). Thus, we assessed the degree to which the selected models could be generalized to unseen data.

We adopted two prediction performance measures. As a continuous measure, we used the cross-validated MSE (ie, the average squared difference between cross-validated predicted and observed scores). To compare results to those reported by LiKamWa et al [13], we also used a dichotomous "correct/incorrect" performance measure by recording whether cross-validated predicted scores fell within a preset tolerated error margin of 0.5 around observed scores.

Benchmark Model Comparisons

To evaluate the personalized predictive regression models, we compared their performance to that of two naive benchmark prediction models that were agnostic of mobile phone usage data. The first benchmark model, the mean model, predicted the current mood state to be equal to the average observed mood state (ie, an intercept-only model). The second model, the history model, used a more dynamic time-series approach by assuming that the current mood state would be more similar to recent mood states. This was implemented as a linear regression model that included an intercept and two variables that represented the mood entries of the last 2 days (ie, the lag 1 and lag 2 of the dependent variable). Differences between the models in MSE and percentages of correct responses were tested for significance with the nonparametric Wilcoxon signed rank tests at a significance level of $\alpha=.05$ because core assumptions of the parametric alternative (the paired *t* test) were not met.

Incremental Predictive Performance Assessment

Using the full dataset (ie, 42 days) to predict mood at day 10 does not provide a valid test of how the algorithm would perform in an applied setting, in which increasing amounts of data become available over time. Therefore, we also assessed how trained models performed with increasing number of training days. For this, we applied the full training procedures iteratively on data from increasing numbers of training days (ie, day 4, 5, 41). For each number of training days, we tested how the trained models performed in predicting mood on the next day (ie, days 1 to 7 were used to predict mood on day 8, days 1 to 8 to predict mood on day 9, and so on). As we considered any attempt to predict scores on less than 7 days of data to be unfeasible, only mood scores between days 8 to 42 were included in this test. We hypothesized that the predictive performance of the models would increase with training sample size. We tested this by fitting a multiple regression model on the differences between the aggregated performance measures between the personalized models and the mean model (eg, with stepAIC MSE–mean model MSE as the dependent variable and the intercept and study day as independent variables). The intercept estimate of this model informed us on the comparative performance of the model at the start of the study period, whereas the study day regression parameter estimate informed us on the effect of increasing data points on the predictive performance of personalized models, in comparison to the most simple nonpersonalized benchmark model.

Results

Recruitment Process and Participants

In response to the recruitment information flyers, 42 students signed up for the study. Four participants scored above the CES-D cut-off (and were excluded) and five participants withdrew before collecting mobile phone data; therefore, 33 participants started the study. Mobile phone data of two participants did not reach the central study data server and data from four additional participants were not included in the analyses because these participants provided less than 20 days of complete data (ie, EMA and/or unobtrusive EMA data were missing on too many days to allow valid inferences). Thus, the final pruned dataset consisted of data from 27 participants. Table 2 shows the participants' characteristics. Participants were young adults aged between 18 and 25 years. Mean CES-D screening score was 9.4 (SD 5.8, range 1-25). Three participants reported scores greater than 16, indicating mild depressive symptoms.

Description of Ecological Momentary Assessment Measures

Ecological Momentary Assessment

In total, 4368 EMA mood ratings were collected. Of 27 participants, 18 (66%) provided mood ratings up to the study day 42 (range 28-42 days; mean 40.3, SD 3.3 days). Because some participants provided data intermittently, the mean number of days with valid data was 35.5 (SD 3.8). On sampled days, EMA schedule adherence, defined as the number of days on which participants contributed at least one mood rating to the dataset, was 88.80% (959/1080 days). On 91.9% (881/959) of sampled days, participants provided four or more ratings. EMA mood scores, on average, were neutral to positive (one-dimensional mood: mean 7.0, SD 0.95; valence: mean 0.7, SD 0.63; arousal: mean –0.1, SD 1.00) (Table 2).

Unobtrusive Ecological Momentary Assessment

Through the unobtrusive EMA mobile phone app, participants contributed 28,026 mobile phone log databases with a total disk size of 8.9 GB. Raw data logs detailed metadata of 5242 phone calls, 1800 text messages, 11,158 images, 22,973 hourly accelerometer-based activity summaries, 96,601 screen-on events, and 233,533 instances of app usage.

Table 2. Participant demographics, study adherence, and EMA summary statistics (N=27).

Measurements	Descriptive statistics
Demographic characteristics	
Sex (female), n (%)	22 (78)
Age (years), mean (SD)	21.1 (2.2)
CES-D[a] baseline score, mean (SD)	9.4 (5.8)
EMA study adherence	
Number of days in study, mean (SD)	35.5 (3.8)
Last day rated, mean (SD)	40.3 (3.3)
Up to 42 days in study, n (%)	18 (67)
Responses per day (n), n (%)	
1	9 (1)
2	25 (3)
3	44 (5)
4	228 (24)
5	653 (68)
EMA mood measures, [b] **mean (SD)**	
One-dimensional mood	7.0 (0.95)
Circumplex: valence	0.7 (0.63)
Circumplex: arousal	–0.1 (1.00)

[a] CES-D: Center for Epidemiologic Studies Depression Scale (clinical cut-off: 16).

[b] One-dimensional mood: 1-10 scale; circumplex-based mood: –2 to 2 scale.

Predictive Performance of Personalized Models

Leave-One-Out Cross-Validation Results

Figure 3 shows observed versus predicted responses of a representative participant, for days 3 to 42, without cross-validation (in-sample; top) and with cross-validation (out-of-sample; bottom). As expected, prediction errors were larger with cross-validation.

Figure 4 shows the development of the cross-validated MSE and the percentage of correct responses during the stepCV training process, in which variables were sequentially added to the personalized model for each participant. With 42 days of training data, up to eight variables were selected (ie, the preset maximum of variables was reached). Governed by the algorithm, the MSE gradually decreased with each added variable. With regard to the correct predictions, the percentages tended to increase with increasing model complexity as well, but not continuously and not for each participant. This was expected because the percentage of correct predictions was not a parameter in the model optimization process.

Table 3 summarizes the predictive performance of the personalized models and the benchmark models, when trained on 42 days of data. Averaged over all participants, the percentage of correct cross-validated predictions of the personalized models ranged from 55% to 76%. Consistently, however, personalized model predictions were significantly inferior to those of naive benchmark models (all Wilcoxon signed rank test comparisons of differences in both performance measures were $P<.02$ in favor of the benchmark models). Compared with personalized models, the naive models improved the percentage of correct predictions by 5% to 9%. With regard to MSE, these improvements ranged from 0.07 to 0.27.

Table 3. Predictive performance of personalized models and naive benchmark models.[a]

Model[b]	One-dimensional mood, mean (95% CI)[c]		Multidimensional mood (circumplex), mean (95% CI)[c]			
	Correct	MSE	Valence		Arousal	
			Correct	MSE	Correct	MSE
Step CV	57% (50%-64%)	0.67 (0.35-0.98)	76% (71%-81%)	0.22 (0.17-0.27)	54% (47%-61%)	0.58 (0.40-0.76)
Step AIC	55% (49%-61%)	0.58 (0.41-0.75)	76% (71%-81%)	0.23 0.17-0.29)	55% (49%-61%)	0.58 (0.42-0.74)
Mean	62% (56%-68%)	0.41 (0.30-0.52)	85% (81%-89%)	0.15 0.12-0.18)	63% (57%-69%)	0.34 (0.27-0.41)
History	64% (58%-70%)	0.40 (0.29-0.51)	83% (79%-87%)	0.15 (0.12-0.18)	63% (58%-68%)	0.33 (0.27-0.39)

[a] Results shown are those obtained with 42 days of training data for N=27 participants.

[b] In personalized prediction models, Step CV and Step AIC, multiple regression models were constructed through stepwise forward variable selection based on cross-validated MSE (see Figure 2) and the Akaike information criterion (AIC), respectively. The mean model included the intercept only and the history model included the intercept and mood at T1 and T2.

[c] The MSE column shows the mean of the (cross-validated) squared prediction residuals, and the correct column shows the percentage of predictions that fell within the tolerated error margin around the observed score (ie, cross-validated residual ≤0.5). All differences between the performance criteria of the personalized model approaches and the benchmark models were significant (Wilcoxon signed rank tests: *P*<.02).

Figure 3. Observed versus predicted daily (one-dimensional) mood mean (range 1-10) for one participant with a personalized model trained on data including the predicted day (top) or excluding the predicted day (bottom) from the training procedure (ie, in-sample vs out-of-sample performance, respectively).

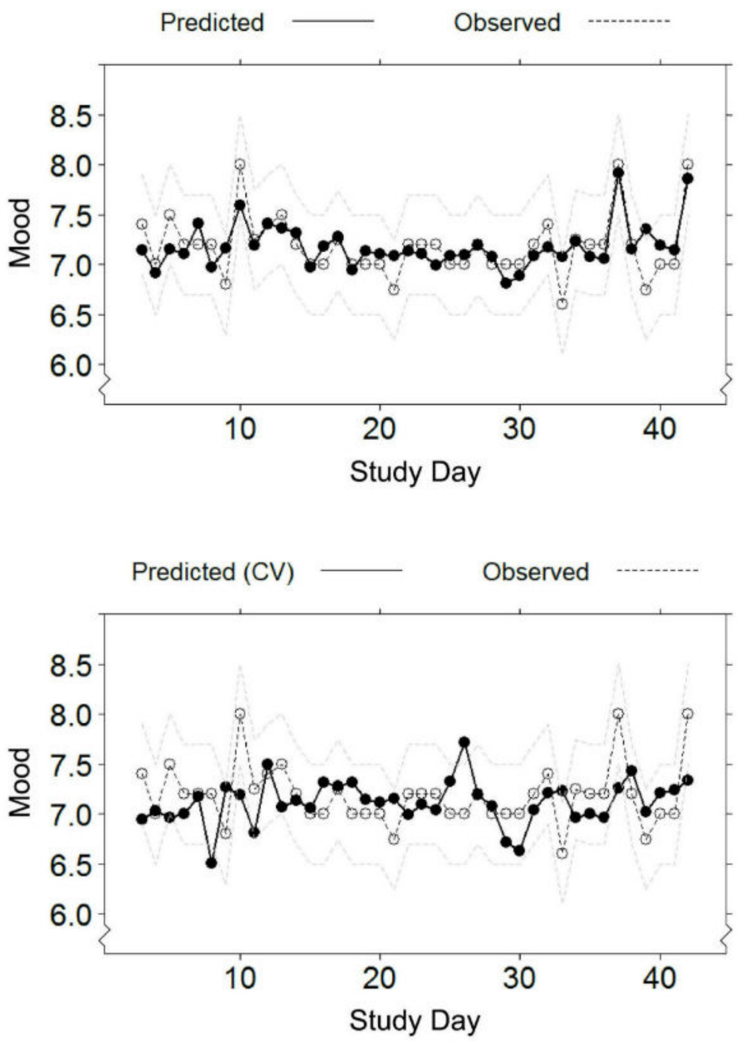
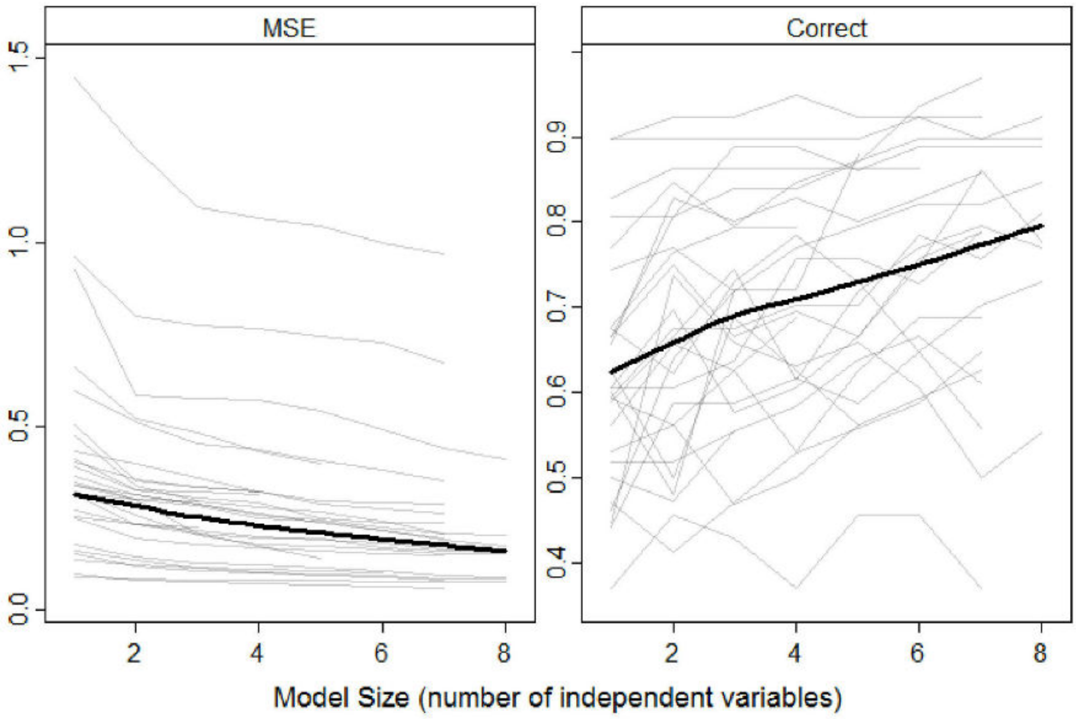


Figure 4. Predictive performance (mean squared error and % correct predictions) of the personalized models as observed for the prediction of the one-dimensional EMA mood measure for each participant (N=27) during cross-validated forward selection regression (stepCV).



Incremental Performance

In the incremental test, predictive models were built using increasing days of training data. After 1 week, data up to day d–1 were used to predict mood from unseen data collected at day d (ie, days 1 to 7 to predict mood at day 8, days 1 to 8 at day 9). As shown in Table 4 (for all outcomes), and illustrated by Figure 5 (for one-dimensional mood), MSE was predominantly higher in the personalized models in comparison to the MSE of the mean model across the study period, whereas the percentage of correct responses was lower. The predictive performance in both procedures improved slightly with increasing amounts of training data (ie, see the "study day" regression parameter estimates in Table 4). However, these improvements were significant for only 3 of 12 tests of the effect of study day on predictive performance (see Table 4).

Table 4. Relative predictive performance of the personalized models compared to the intercept-only benchmark regression model.[a]

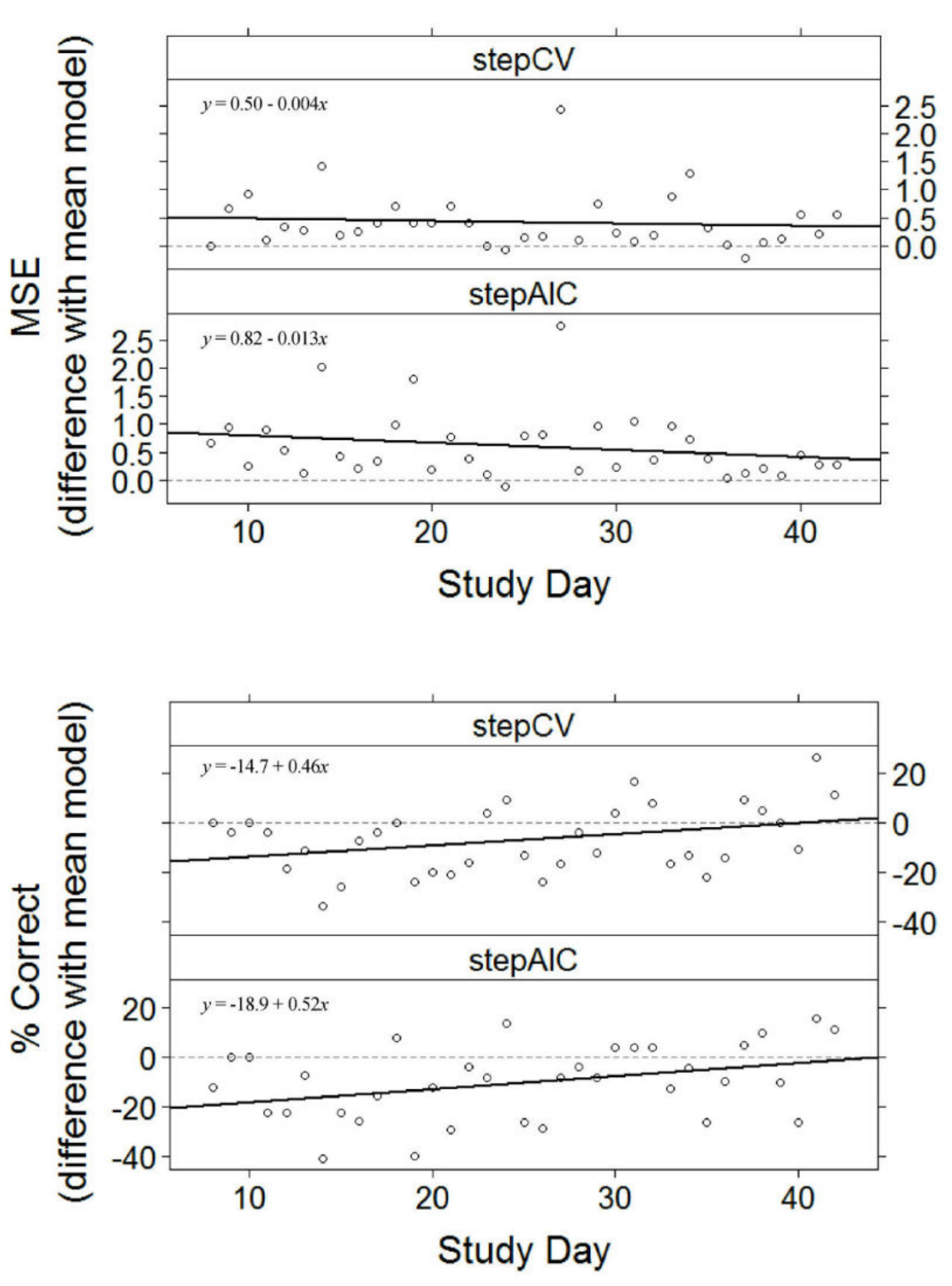
Measure	MSE, b (SE)		% Correct, b (SE)	
	Intercept[b]	Study day	Intercept[b]	Study day
Mood				
stepAIC	0.82 (0.20)	–0.0126 (0.0100)	–18.9 (4.7)	0.52 (0.24)[c]
stepCV	0.50 (0.17)	–0.0045 (0.0086)	–14.7 (4.2)	0.46 (0.21)[c]
Circumplex: valence				
stepAIC	0.94 (0.40)	–0.0261 (0.0201)	–21.2 (3.1)	0.34 (0.16)[c]
stepCV	0.25 (0.08)	–0.0041 (0.0042)	–12.1 (3.0)	0.03 (0.15)
Circumplex: arousal				
stepAIC	0.49 (0.12)	–0.0003 (0.0061)	–14.8 (3.0)	0.29 (0.15)
stepCV	0.47 (0.13)	0.0002 (0.0064)	–10.2 (3.6)	0.02 (0.18)

[a] Results show the estimated parameters of the linear regression model (ie, mood ~1 + "study day"); MSE: mean squared error; b: regression estimate (unstandardized); SE: standard error of regression estimate.

[b] All intercept estimates were significant at α=.05.

[c] These study day estimates were significant.

Figure 5. Relative predictive performance of stepAIC and stepCV (in comparison to the intercept-only model) as a function of increasing training data size (one-dimensional mood).



Discussion

In this pilot study following up on previous research [13], we examined whether personalized regression models could accurately predict day-to-day fluctuations of self-monitored mood from mobile phone usage logs. We found that personalized regression models, trained through FSR, correctly predicted 55% to 76% of self-reported EMA mood ratings. However, the predictive performance of the FSR models was clearly inferior to that of naive nonpersonalized predictive benchmark models. The performance of the personalized models tended to improve over time. Nonetheless, within our 42-day study period, these improvements were not large enough to compensate for the poor relative predictive performance of the FSR approach.

Comparison to Previous Findings

Our study provides a sobering adjunct to the study of LiKamWa et al [13], in which personalized FSR models predicted self-reported mood ratings with 93% accuracy (and also considerably higher than benchmark models). Their results implied that mood inference models could be successfully trained through FSR on personal unobtrusive EMA data. In our replication, by contrast, we found no clear benefits of the personalized feature selection approach over naive benchmark prediction models. Based on our results and Ockham’s law of parsimony (that the simplest of competing models should be preferred), we would recommend against FSR modeling on unobtrusive EMA data to predict short-term mood variation. To predict short-term mood variation, at least in the first 42 days and with study groups similar to ours, our results suggest that it would suffice to simply predict the mean of past responses.

Forward stepwise regression may not be the most suitable basis for automated predictive modeling of day-to-day mood fluctuations. Among other problems, the procedure is known to be vulnerable to overfitting (ie, the selection of overly complex models that perform poorly on unseen data) [26,27]. When the number of potential predictive variables exceeds the number of training samples, as was the case in our study, FSR appears to be too sensitive to random fluctuations in the training data and instability of the regression parameters, resulting in poor generalization to new data. We tried to avoid this by building LOOCV into a variant of the FSR model selection procedure (through the PRESS statistic); unfortunately, this did not improve outcomes.

It should be noted that the 93% predictive accuracy rate in the LiKamWa et al study [13] was observed with 60 days of data, whereas we only collected data for 42 days. If more training data had been collected, the performance of the FSR models might have been better. As stated, we found some evidence that the performance of the models improved slightly over time. But how many individuals would be willing to self-report mood ratings for 60 days? Our participants were paid and their adherence to the 42-day EMA self-report schedule was satisfactory probably for that reason. In real-life settings, however, we expect the assessment burden of continued self-report EMA to result in large dropout rates, even before day 42. LiKamWa et al [13] recognized this problem. They proposed a “hybrid personalized/all user” modeling approach as a solution, in which data of other users are used to construct a base predictive model, which is then tuned to individual data. This approach might reduce the required amount of training days. Unfortunately, due to time restrictions, we could not follow up on this interesting suggestion.

The different outcomes of our study and that of LiKamWa et al [13] may also be explained by differences in study populations (ie, Dutch students versus a predominantly Chinese student population). The performance of predictive algorithms may be sensitive to the cultural background of study respondents. Previous studies have found qualitative differences in the presentation of psychopathological symptoms in Chinese and Western participants [28]. In addition, we note that we excluded individuals with severe depressive symptoms from our study sample, whereas LiKamWa et al [13] did not. This possibly reduced the variance in the mood data somewhat, making it more difficult for the feature selection algorithms to select effective predictors. Some support for this explanation can be found in the similar results that were obtained with both benchmark models (ie, the history model, which added recent mood entries to the mean model, did not substantially improve the predictive performance). However, because only four eligible participants were excluded on the basis of this exclusion criteria, we feel that this difference cannot fully explain the divergent results. A new replication study in a clinical population would be informative to explore whether the predictive approach works better when mood variations are more salient.

Our study also differed from that of LiKamWa et al [13] in terms of the type of unobtrusive variables that were assessed. By using the Funf framework, we were not able to access detailed email data (which was identified as one of the more discriminative features in the LiKamWa study). Likewise, we could not adequately capture anonymized browser history data. Finally, we also refrained from collecting GPS location data. It is possible that the availability of these omitted features would have resulted in stronger predictive models. However, we doubt whether the primary finding of our study, namely the inferior predictive performance of the unobtrusive EMA regression models, would have been different if email, browser history, and GPS location data had been available. Even if these features had been included in our feature set, we fear that FSR’s proneness to overfitting would still result in the selection of models that would explain too much of the variation in the training data and too little of the variation in unseen data.

Finally, we should consider the reliability of the self-report EMA mood measures. The circumplex model is a common EMA mood measure and recent studies have suggested that single-item mood measures can provide predictive information on the development of depressive symptoms (eg, [19]). However, there certainly remains much to be learned with regard to the psychometric properties of single-item EMA measures in different populations and contexts. Therefore, readers are reminded that we cannot rule out the possibility that our results were negatively affected by noisy measurement of the day-to-day mood variations.

Next Steps

We wish to stress that the sobering results of our study—in our opinion—do not dismiss the unobtrusive EMA method. On the contrary, based on our experiences, we would argue that mobile phone-based unobtrusive EMA is a technically feasible and potentially powerful assessment method to collect a continuous stream of objective patient data with little to no respondent burden. Mobile phone-based unobtrusive EMA requires innovative technology to capture mobile phone sensor data and send the data to a remote central storage server. Its technical requirements are complex. Despite this complexity, however, data collection was quite successful in this study. Thus, although we do not recommend real-world application of FSR-based mood predictions in the field, we do recommend further exploration and refinement of unobtrusive EMA methods.

Although conducting this study was instructive, we feel that substantial progress can and should be made with regard to unobtrusive EMA feature engineering. In our opinion, one of the reasons for the poor performance of the predictive models should be sought in the rather tentative and distant relationship between the included unobtrusive predictors and mood. Transforming raw data into meaningful features can significantly improve predictive power [29]. This was recently shown by Saeb et al [12], who transformed raw GPS data into several variables relevant to depression. Unprocessed, GPS data are not predictive of depressive symptoms. However, transformed into features that represent, for example, home stay, number of locations visited (clusters), or circadian movement patterns, Saeb et al [12] revealed significant correlations with a validated depression measure. If we relate this to our dataset, we might be able to transform raw accelerometer data into a circadian rhythm index to construct a more relevant feature. Personalized modeling and data mining are exciting fields. In the short term, however, most progress will probably come from taking one step back to construct meaningful, theoretically relevant features that can be derived from (combinations of) raw unobtrusive EMA data.

The aim of this study was to replicate the study of LiKamWa et al [13] as much as possible; therefore, we did not deviate from using FSR. For future feature selection/personalized modeling studies with unobtrusive EMA data, however, more advanced statistical techniques might have to be considered, such as time-series analysis (eg, [30]), regression trees, support vector machines, or LASSO/ridge regression [31]. The success of these statistical techniques will probably also depend on the availability of adequate training samples. From this perspective, we recommend against the aggregation of unobtrusive EMA data in future studies. By aggregating the unobtrusive EMA data into daily summaries, as we did in this study to replicate LiKamWa et al [13], one of the more interesting aspects of unobtrusive EMA measures, their semicontinuous sample frequency, was lost. With it, information was lost on processes occurring during the day and statistical power was greatly reduced. In short, we expect better results with unaggregated unobtrusive EMA data.

Conclusion

Mobile phone-based unobtrusive EMA is a technically feasible and potentially powerful EMA variant that may be key to future advances in the study and treatment of psychiatric symptoms. However, the unobtrusive EMA method is young and positive experiences with early apps may not replicate. Forward stepwise regression appears to be too vulnerable to overfitting to accurately predict day-to-day mood fluctuations from aggregated unobtrusive EMA data. Based on our results, and in contrast to previous reports, we do not recommend the application of this modeling strategy in real-world clinical settings. To come up with more robust solutions, future studies should address feature engineering and explore alternative advanced data mining techniques.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Study data description.

[PDF File (Adobe PDF File), 41KB - jmir_v18i3e72_app1.pdf]

Multimedia Appendix 2

R source code.

[PDF File (Adobe PDF File), 57KB - jmir_v18i3e72_app2.pdf]

Multimedia Appendix 3

Zipfile R project containing the data and analyses used in this manuscript.

[RAR File, 639KB - jmir_v18i3e72_app3.rar]

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Abbreviations

AIC: Akaike information criterion
CES-D: Center for Epidemiologic Studies Depression Scale
EMA: ecological momentary assessment
FSR: forward stepwise regression
GPS: global positioning system
LOOCV: leave-one-out cross-validation
MSE: mean squared error
PRESS: predicted residual sum of squares
SMS: short message service

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Original Paper

100 Million Views of Electronic Cigarette YouTube Videos and Counting: Quantification, Content Evaluation, and Engagement Levels of Videos

Jidong Huang[1*], PhD; Rachel Kornfield[2*], MA; Sherry L Emery[1*], PhD

[1]Health Media Collaboratory, Institute for Health Research and Policy, University of Illinois at Chicago, Chicago, IL, United States

[2]School of Journalism and Mass Communication, University of Wisconsin-Madison, Madison, WI, United States

[*]all authors contributed equally

Corresponding Author:
Jidong Huang, PhD
Health Media Collaboratory
Institute for Health Research and Policy
University of Illinois at Chicago
1747 West Roosevelt Road
Chicago, IL, 60608
United States
Phone: 1 312 355 0195
Fax: 1 312 996 2703
Email: jhuang12@uic.edu

Abstract

Background: The video-sharing website, YouTube, has become an important avenue for product marketing, including tobacco products. It may also serve as an important medium for promoting electronic cigarettes, which have rapidly increased in popularity and are heavily marketed online. While a few studies have examined a limited subset of tobacco-related videos on YouTube, none has explored e-cigarette videos' overall presence on the platform.

Objective: To quantify e-cigarette-related videos on YouTube, assess their content, and characterize levels of engagement with those videos. Understanding promotion and discussion of e-cigarettes on YouTube may help clarify the platform's impact on consumer attitudes and behaviors and inform regulations.

Methods: Using an automated crawling procedure and keyword rules, e-cigarette-related videos posted on YouTube and their associated metadata were collected between July 1, 2012, and June 30, 2013. Metadata were analyzed to describe posting and viewing time trends, number of views, comments, and ratings. Metadata were content coded for mentions of health, safety, smoking cessation, promotional offers, Web addresses, product types, top-selling brands, or names of celebrity endorsers.

Results: As of June 30, 2013, approximately 28,000 videos related to e-cigarettes were captured. Videos were posted by approximately 10,000 unique YouTube accounts, viewed more than 100 million times, rated over 380,000 times, and commented on more than 280,000 times. More than 2200 new videos were being uploaded every month by June 2013. The top 1% of most-viewed videos accounted for 44% of total views. Text fields for the majority of videos mentioned websites (70.11%); many referenced health (13.63%), safety (10.12%), smoking cessation (9.22%), or top e-cigarette brands (33.39%). The number of e-cigarette-related YouTube videos was projected to exceed 65,000 by the end of 2014, with approximately 190 million views.

Conclusions: YouTube is a major information-sharing platform for electronic cigarettes. YouTube appears to be used unevenly for promotional purposes by e-cigarette brands, and our analyses indicated a high level of user engagement with a small subset of content. There is evidence that YouTube videos promote e-cigarettes as cigarette smoking cessation tools. Presence and reach of e-cigarette videos on YouTube warrants attention from public health professionals and policymakers.

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KEYWORDS

electronic cigarettes; electronic nicotine delivery systems; ENDS; tobacco products; YouTube; social media

Introduction

YouTube is the third most visited site on the Internet [1] with a large and growing youth presence [2]. It provides a platform for individuals to upload, view, share, and respond to videos. While YouTube was intended for original, user-generated content, it also has become an important avenue for individuals and companies to reach wide audiences and market products, including tobacco products [3,4]. Prior studies have analyzed strategies of tobacco promotion on YouTube [5-7] as well as public attitudes toward tobacco products, finding that pro tobacco messages are prevalent and easy accessible relative to antismoking messages [8-10]. Videos related to electronic cigarettes and other alternative tobacco products (eg, little cigars, cigarillos, waterpipes, and smokeless tobacco) may portray these products in a particularly positive light [11-14]. Informational and promotional content available to consumers via social networks such as YouTube has the potential to shape how tobacco products are perceived and used, and thus has major public health implications [9,15,16].

YouTube may also be an important medium for spreading information and promotional messages about electronic nicotine delivery systems (ENDS) or *e-cigarettes*, which have increased rapidly in popularity and are heavily marketed and promoted online [17-19]. These products have raised controversy among the public health community; some evidence indicates their harm-reduction potential while others argue they may sustain nicotine dependence without reliably supporting tobacco cessation [20]. A 2010 US district court decision blocked e-cigarette manufacturers from marketing e-cigarettes as quit-smoking devices [21]. However, advertisers use indirect tactics such as affiliate marketing to circumvent that decision [10,22]; claims about the products' health and safety profile and their role in smoking cessation may be commonplace on social networks despite the ruling [18,23]. E-cigarette companies and retailers may use YouTube to engage with customers and to disseminate largely unmonitored promotional messages. E-cigarette users (or *vapers*) may use YouTube to share experiences and advice regarding e-cigarettes, to organize around e-cigarette advocacy, and to engage in affiliate marketing [24]. YouTube is particularly suited for e-cigarette promotion and marketing because it allows subscribers to easily post content, including text, audio, and visual content, across several channels. Users can also easily interact with one another by subscribing to each other's YouTube channels [25].

Little is known about the extent and type of e-cigarette content on YouTube and the level of engagement with such content. One 2009 study of smoking imagery on YouTube found that, of the most popular videos retrieved for cigarette-related keywords, e-cigarette videos represented approximately 8%, and these tended to include branding or claims about health benefits of e-cigarettes in comparison to cigarettes [9]. However, the number of e-cigarette videos included in this study was small (n=9) and e-cigarette popularity has since increased rapidly [17]. Another study compared typical usage patterns (eg, puff duration) between electronic and traditional cigarettes represented in YouTube videos, finding that e-cigarette users take longer puffs than conventional cigarette users, perhaps to compensate for low or unreliable levels of nicotine [26]. A recent study found that, among all UK Top 40 YouTube music videos over a 12-week period in 2013/2014, electronic cigarette branding appeared in 1% (95% CI 0-3) of videos [4]. Another recent study examined the top 20 YouTube search results using a number of e-cigarette-related keywords—196 videos in total—and found these videos to be overwhelmingly *pro* e-cigarettes (94%). In addition, this study found that the top three most prevalent genres among these videos were advertising, user sharing, and product reviews. A total of 84.3% of *pro* videos contained Web links for e-cigarette purchase. A total of 71.4% of *pro* videos claimed that e-cigarettes were healthier than conventional cigarettes. However, this study did not characterize the overall extent or type of e-cigarette content on YouTube [13]. Studies of tobacco-related videos on YouTube have typically relied on samples of top search results rather than quantifying the total number of relevant videos [4,5,7,9,11-14,27,28].

To date, tobacco control policies explicitly regulating e-cigarettes have been enacted only at the state [29] and municipal [30] levels. In April 2014, the US Food and Drug Administration (FDA) proposed a deeming rule that would extend its regulatory authority over tobacco products to include electronic cigarettes. The proposed rule also bans the sale of e-cigarettes to minors and requires those purchasing the products to show proof of age [31]. The FDA has not yet addressed regulations on e-cigarette marketing on television, radio, and/or social media. However, should the deeming rule become finalized, the agency may propose additional rules restricting e-cigarette marketing and promotion. Understanding how YouTube—one of the top social media platforms—is used to promote and discuss e-cigarettes can clarify the potential impact of such discussion on consumers' vaping-related attitudes and behaviors, a priority research topic identified by the recent National Institutes of Health (NIH) Electronic Cigarette Workshop [32], and also may suggest appropriate ways to regulate social media marketing for e-cigarettes and other tobacco products.

This paper characterized the overall extent and type of e-cigarette relevant content and level of engagement with that content on YouTube as of June 30, 2013, and predicted the number of e-cigarette videos that existed as of December 31, 2014. The research employed an automated YouTube crawling program, ContextMiner [33], to approximate the total number of videos related to e-cigarettes by continually compiling daily search results for a list of e-cigarette-related keywords. We used metadata for relevant videos to describe trends in video posting and engagement, and to assess the fraction of videos for which uploader-provided text fields—titles, descriptions, and tags—include discussion of smoking cessation, health, or safety; link to websites; or mention specific brands or component parts.

Methods

Retrieving E-Cigarette-Related YouTube Videos

This study employed a YouTube crawling program, ContextMiner [33], to retrieve the videos related to e-cigarettes available on YouTube as of June 30, 2013. To identify e-cigarette-related videos, we first compiled a list of 70 e-cigarette keyword rules (see Multimedia Appendix 1). Our keyword rules were developed through expert consensus and were expanded via an iterative process wherein an initial set of limited keywords, such as *e cig* and *electronic cigarettes*, were used to retrieve content and identify co-occurring words, which were then tested for relevance and added to form new keyword rules [34]. For each keyword rule, daily YouTube crawls were performed for 1 year between July 1, 2012, and June 30, 2013; metadata—title, description, tags, channels, posting date—for matching videos were retrieved and downloaded to a database. Videos were retrieved on the basis of YouTube's *relevance* algorithm, which ranks videos in descending order of presumed relevance for a given keyword query. Since YouTube limited the number of videos retrieved by each crawl, we also conducted separate crawls where matching videos were retrieved on the basis of posting dates. Through the combination of two YouTube search techniques—relevance and posting date—and repeated daily crawls to overcome YouTube limits, we built a set of videos that YouTube’s algorithm deemed related to our e-cigarette keywords.

Deduplicating and Refining

While the YouTube Web interface provides an approximation of the number of videos retrieved for a keyword search (eg, typing *electronic cigarettes* into the YouTube search bar yielded 89,800 results on April 8, 2015), this number is an approximation and may include numerous irrelevant videos. We reviewed our YouTube e-cigarette video database and excluded duplicate videos using the YouTube video ID, a unique identifier assigned by YouTube. Deduplication yielded 42,484 unique videos retrieved by one or more of our keyword rules over the study period. Unique videos were then reviewed to assess relevance of each video to electronic cigarettes. During this process, we noted that our database included many videos—mainly music videos—that did not contain e-cigarette-related keywords in any collected metadata fields and that did not include e-cigarette content in the videos themselves. This finding likely reflects that YouTube’s search algorithms incorporate additional metadata not collected in our crawls, and possibly indicates that some videos were uploaded in order to boost the relevance of related videos (ie, posted in response to e-cigarette videos) [35]. To exclude videos not relevant to e-cigarettes, we used a two-step method. First, two coders viewed the top 50 most viewed videos in our database to assess whether they were relevant to e-cigarettes. The reason for manual review of the top 50 most viewed videos was to ensure that our view calculation was not artificially inflated by nonrelevant videos, which tended to be associated with higher view counts. Five videos were deemed irrelevant by both coders during this process. In the second step, we searched metadata fields—description, tags, and title—using a list of e-cigarette-specific terms (see Multimedia Appendix 2) and classified relevant videos as those that contained such terms in their metadata fields. Our keyword algorithm was highly accurate in discerning between relevant and irrelevant content in a random sample of 500 retrieved videos, with 95% of allocations agreeing with a human coder. Approximately one-third (34%) of videos were classified as irrelevant in this step and were excluded from our database. The final database contained 28,089 e-cigarette-relevant videos.

Types of Metadata

For all e-cigarette-related videos in our database, two main types of metadata were collected: static video characteristics and, where available, dynamic engagement data. Static video characteristics included video title and description, any tags the uploader provided, YouTube channel with which the video was associated (eg, *Tech*, *HowTo*, and *Entertainment*), posting date, name of uploader account, and video URL. Dynamic daily engagement data included view count, number of comments, number of ratings, and average rating.

Overall Presence and Content Coding

Measuring Engagement With Videos

Metadata associated with each video were used to describe time trends in video posting and viewing on YouTube and to tabulate the total number of views, comments, and ratings as of June 30, 2013. Simple linear extrapolations were used to project time trends in video posting and viewing predicted to occur from July 2013 to December 2014.

Content Coding

Video titles, descriptions, and tag fields were searched to assess the frequency with which they mentioned several themes of interest to informing policy and public health: health-related themes, safety themes, smoking cessation themes, promotional offers, Web addresses, product types (eg, e-hookah and e-liquid), or specific top-selling brands [36]. We also searched metadata fields for names of celebrities known to have promoted or demonstrated electronic cigarette use [37,38], such as actress Katherine Heigl who smoked one on The Late Show with David Letterman.

We conducted searches via the YouTube search interface among our collected videos to identify accounts that appeared affiliated with the top 10 e-cigarette brands. These were identified by retail store sales via the Nielsen store scanner data [36] on the basis of brand-related account names and links to official brand websites on account pages. For these accounts, we tabulated the number of videos posted, number of subscribers, and the total view count.

Age Restrictions

We examined the existence of age restrictions for e-cigarette YouTube videos on a simple random sample of 280 videos (1%) from our database. Those videos were viewed from a Web browser cleared of previous browsing history and other identifiers, such as cookies and plug-ins, to determine any age restrictions applied by YouTube (ie, whether log-in was required to access content).

Results

The first electronic cigarette videos in our sample were posted to YouTube in early 2007. The rate of posting increased over the study period from several new videos per month in 2007 to over 100 per month by late 2009, over 1000 per month by late 2012, and close to 2000 per month by June 2013 (see Figure

1). By the end of June 2013, there were 28,089 unique e-cigarette videos available on YouTube. We projected that the number of e-cigarette videos on YouTube would exceed 65,000 by December 2014, with more than 2500 new e-cigarette videos posted on the platform every month. No seasonal trends in posting rate were observed, although we observed a spike in posting in April 2012 when more than 2500 e-cigarette-related videos were posted—more than three times the monthly average for 2012. Over 80% of these videos mentioned the website EcigsFreeTrialOffer.com in video description fields. However, as of publication of this paper, the website is no longer active.

For approximately 85% of e-cigarette videos where dynamic engagement data were available, we plotted the trend in total views (see Figure 2). Combined view counts for e-cigarette videos in our database nearly doubled over the study period, increasing at a rate of approximately 4 million views per month, from 54 million in July 2012 to over 101 million by June 2013. By December 2014, total view counts of e-cigarette videos on YouTube were projected to exceed 188 million.

The 28,089 electronic cigarette videos identified in this study were posted by 9756 unique YouTube accounts (see Table 1). Posting was concentrated among a number of highly active accounts, with the top 1% of users posting 22% of videos in the sample. View count was even more highly concentrated, with 1% of videos accounting for 44% of total views. The most viewed video, with over 2.3 million views, was the music video *Life is a Roller Coaster* by Ronan Keating; there was no mention of e-cigarettes in the video itself, but the description field advertised an electronic cigarette retailer and the video tags mentioned several top e-cigarette brands. The second most viewed video, with 1.7 million views, was a UK television advertisement for E-lites, an e-cigarette brand. In total, the included videos had almost 101 million views and garnered over 380,000 ratings and over 280,000 comments.

Nearly all of the videos were classified under five YouTube categories (see Table 2): *People* (7610/28,089, 27.09%), *Tech* (6279/28,089, 22.35%), *HowTo* (5470/28,089, 19.47%), *Entertainment* (2891/28,089, 10.29%), and *Education* (2879/28,089, 10.25%).

Table 3 summarizes our content coding. A total of 13.63% (3828/28,089) of video tags, titles, or descriptions referenced health; 10.12% (2842/28,089) referenced safety; and 9.22% (2591/28,089) referenced smoking cessation. A total of 11.06% (3108/28,089) mentioned discounts. The majority of videos included Web addresses (19,694/28,089, 70.11%). The most common website we identified was EcigsFreeTrialOffer.com (2257/28,089, 8.04%) (no longer active), followed by youtube.com (718/28,089, 2.56%), v2cigs.com (388/28,089, 1.38%), facebook.com (334/28,089, 1.19%), and E-Cig-Reviews.com (307/28,089, 1.09%). Metadata for 42.57% (11,957/28,089) of videos mentioned reviews, although these videos had a lower-than-average view count. Mentions of e-cigarette component parts were also common: 27.19% (7637/28,089) mentioned e-liquid, 14.05% (3946/28,089) referenced *mods* (ie, modifications), 12.93% (3631/28,089) referenced atomizers, and 11.88% (3338/28,089) referenced batteries. Blu was the most mentioned brand, occurring in metadata for 3507/28,089 videos (12.49%). NJOY mentions were present for 1235 out of 28,089 videos (4.40%), and the remaining top 10 best-selling brands were associated with fewer than 300 videos each. We tabulated frequency of mentions for additional brands that had high occurrence in the dataset and for two brands recently introduced by tobacco companies—Vuse by RJ Reynolds and MarkTen by Altria. We found frequent mentions of eGo (3103/28,089, 11.05%), V2 (2783/28,089, 9.91%), and Joyetech (2395/28,089, 8.53%). Vuse and MarkTen were associated with very low frequency.

Table 4 summarizes official YouTube accounts associated with top-selling [36]—based on retail store scanner data—e-cigarette brands in the United States. While the number of videos posted by official e-cigarette company accounts is small, the view counts are quite high. For example, although Blu's YouTube account had posted only 32 videos as of June 2013, those videos have garnered close to half a million views.

In a sample of 280 random videos, none was age restricted by YouTube, although 2 (0.7%) did include age-related disclaimers at the beginning of video content. All but 2 videos (278/280, 99.3%) included mentions or images of e-cigarettes in video content; the remaining 2 videos (0.7%) mentioned e-cigarettes in text fields only.

Table 1. Characteristics of e-cigarette-related YouTube videos as of June 30, 2013.

Video characteristics	Value
Total videos, n	28,089
Posting accounts, n	9756
Average videos/account, mean (SD)	2.88 (8.81)
Average video duration (minutes), mean (SD)	4.97 (8.34)
Total view count, n	106,963,322
Average view count, mean (SD)	3967 (29,350)
Total number of ratings, n	380,075
Average ratings/video, mean (SD)	14.1 (99.7) (range 0-7024)
Average rating (1-5)	4.5
Total comments, n	282,020
Average number of comments, mean (SD)	10.5 (58.1) (range 0-3969)

Table 2. Categories of e-cigarette-related YouTube videos with metadata as of June 30, 2013.

Category[a]	Videos (n=18,103), n (%)
People	7610 (27.09)
Tech	6279 (22.35)
HowTo	5470 (19.47)
Entertainment	2891 (10.29)
Education	2879 (10.25)
Film	825 (2.94)
News	804 (2.86)
Comedy	587 (2.09)
Nonprofit	200 (0.71)
Music	190 (0.68)
Autos	81 (0.29)
Sports	77 (0.27)
Travel	73 (0.26)
Animals	66 (0.23)
Games	51 (0.18)
Shows	6 (0.02)

[a] Categories are mutually exclusive.

Table 3. Content of metadata for e-cigarette-related videos on YouTube as of June 30, 2013.

Content category	Search query	Videos (N=28,089), n (%)	View count (N=106,963,322), n (%)
Claims and promotions			
Health	"*health*"	3828 (13.63)	15,298,094 (14.30)
Safety	"*safe*"	2842 (10.12)	7,915,121 (7.40)
Cessation	"*quit sm*", "*stop sm*", "*cold turkey*", "*give up sm*", "*quitting sm*", "*quitsmok*", "*cessation*"	2591 (9.22)	9,956,254 (9.31)
Any health, safety, or cessation		7036 (25.05)	25,547,563 (23.88)
Ban	"* ban *", "*banned*", "ban *", "* ban,*", "ban,*"	484 (1.72)	3,925,388 (3.67)
Discount	"*discount*", "*coupon*"	3108 (11.06)	8,297,899 (7.76)
Free trial	"*free trial*", "*freetrial*"	2641 (9.40)	1,236,881 (1.16)
Web address	"*http*", "*.com*"	19,694 (70.11)	74,142,105 (69.32)
Type of video			
Review	"*review*"	11,957 (42.57)	36,075,723 (33.73)
Demo	"*demo*", "*how to*", "*howto*"	2673 (9.52)	15,255,278 (14.26)
Celebrity	Like "*katherine heigl*", Or Like"*stephen dorff*", Or Like "*bruno mars*", Or Like "*courtney love*"	153 (0.54)	2,303,049 (2.15)
DIY[a] mention	"* DIY *", "DIY *", "* DIY,*", "DIY,*"	1288 (4.59)	1,183,187 (1.11)
Product types			
Starter kit	"*starter kit*", "*starterkit*"	3023 (10.76)	9,805,395 (9.17)
Disposable	"*disposable*"	1263 (4.50)	4,710,782 (4.40)
E-hookah	"*hooka*", "*shisha*", "*eshish*"	667 (2.37)	4,618,779 (4.32)
E-cigar	"*cigar *"	746 (2.66)	1,203,781 (1.13)
Mods (modifications)	"* mod *", "* mods *", "mod *", "* mod,*", "mod,*", "mods *", "* mods,*", "mods,*"	3946 (14.05)	9,999,591 (9.35)
Cartomizer	"*cartomizer*"	2157 (7.68)	7,681,730 (7.18)
Atomizer	"*atomizer*"	3631 (12.93)	10,161,207 (9.50)
Cartridge	"*cartridge*"	2774 (9.88)	11,790,246 (11.02)
Battery	"*battery*"	3338 (11.88)	15,013,078 (14.04)
E-liquid	"*juice*", "*liquid*"	7637 (27.19)	25,626,650 (23.96)
Refill	"*refill*"	2650 (9.43)	8,355,835 (7.81)
Flavor	"*flavor*"	2979 (10.61)	7,754,066 (7.25)
Nicotine free	"*zero nicotine*", "*nicotine free*", "*no nicotine*", "*without nicotine*", "*nicotinefree*"	192 (0.68)	1,273,715 (1.19)
Dual use			
Marijuana	"*weed*", "*marijuana*"	909 (3.24)	2,993,990 (2.80)
Brands (sales rank)			
Blu (1)	"* blu *", "*blucig*", "blu *", "* blu,*", "blu,*"	3507 (12.49)	11,764,026 (11.00)
NJOY (2)	"* njoy*", "njoy*"	1235 (4.40)	7,460,512 (6.97)
Mistic (3)	"*mistic*"	55 (0.20)	159,961 (0.15)
21st Century Smoke (4)	"*21st cent*", "*21stcentury*", "*21 cent*", "*21century*"	223 (0.79)	124,381 (0.12)

Content category	Search query	Videos (N=28,089), n (%)	View count (N=106,963,322), n (%)
Logic (5)	"* logic *", "logic *", "* logic,*", "logic,*"	263 (0.94)	326,800 (0.31)
Finiti (6)	"* finiti *", "finiti *", "* finiti,*", "finiti,*"	142 (0.51)	47,246 (0.04)
Nicotek (7)	"*nicotek*"	40 (0.14)	14,551 (0.01)
Cigirex (8)	"*cigirex*"	1 (0)	453 (0)
Cig20 (9)	"*cig20*"	2 (0.01)	15 (0)
Green Smart Living (10)	"*green smart*", "*greensmart*"	16 (0.06)	17,833 (0.02)
Top 10 best-selling brands		4280 (15.24)	15,678,220 (14.66)
eGo	"* ego *", "ego *", "* ego,*", "ego,*"	3103 (11.05)	10,191,677 (9.53)
V2	"* v2 *", "v2 *", "* v2,*", "v2,*"	2783 (9.91)	5,386,900 (5.04)
Vuse	"*vuse*"	6 (0.02)	12,002 (0.01)
MarkTen	"*markten*"	2 (0.01)	58 (0)
Green Smoke	"*green smoke*"	1281 (4.56)	4,813,150 (4.50)
Joyetech	"* joye *", "*joyetech*", "joye *", "* joye,*", "*joye,*"	2395 (8.53)	12,742,376 (11.91)
Volcano	"*volcano*"	1891 (6.73)	4,887,673 (4.57)
LavaTube	"*lavaTube*", "*lava tube*"	1205 (4.29)	3,276,914 (3.06)
Any brands		9379 (33.39)	38,240,598 (35.75)

[a] DIY: do it yourself.

Table 4. YouTube account activity for top-selling e-cigarette brands as of June 30, 2013.

Brand	Account name	Videos posted, n	View count, n	Subscribers, n	Collected videos, n
Blu	BluCigs	32	463,157	1510	32
NJOY	NJOYeCigs	3	279,736	279	8
Mistic	MisticEcigs	8	868	6	2
21st Century Smoke	21stCenturySmokeECig	1	1196	0	1
Logic	LogicDisposableEcigs	8	2262	28	8
Finiti	MyFiniti	13	22,871	24	6
Nicotek	Nicotekecigs	30	7284	15	31
Cigirex	CigirexUK	1	580	0	0
Green Smart Living	DeanGreenSmart	2	598	3	1

Figure 1. Monthly uploads of electronic cigarette-related videos from January 2007 to December 2014.

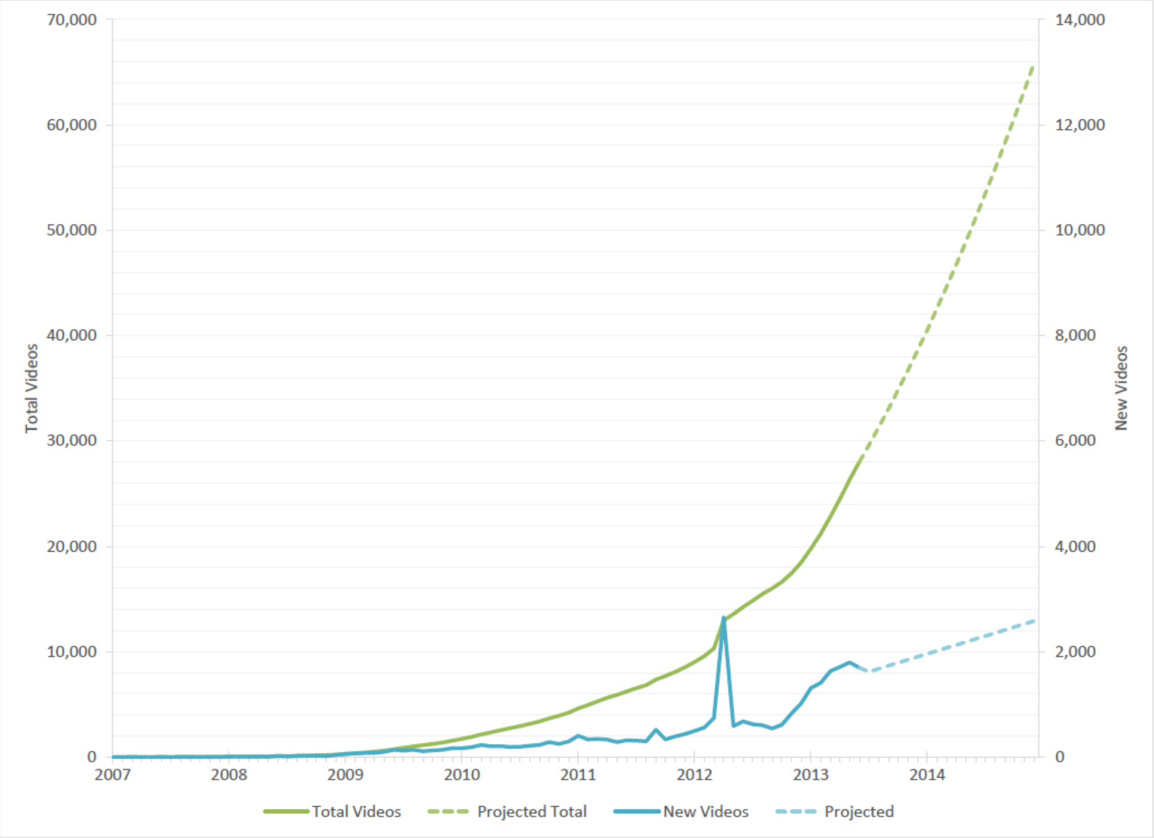
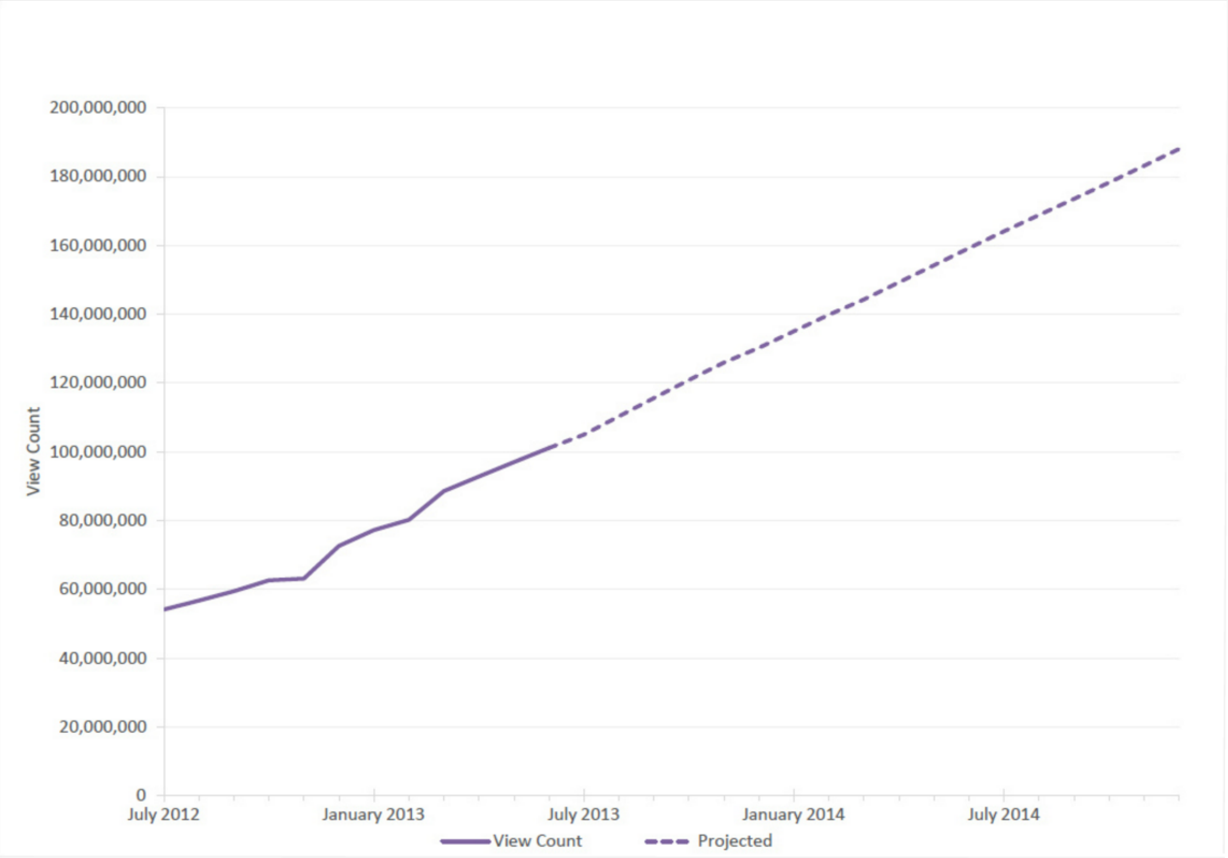


Figure 2. Total view counts for electronic cigarette-related videos from July 2012 to December 2014. View counts DO NOT include approximately 16% of videos with incomplete engagement data.



Discussion

Principal Findings

The regulatory status of e-cigarettes has major implications for their marketing and promotion. In 2008, a federal district court ruled that the FDA could not regulate e-cigarettes as drugs or devices unless they were marketed for therapeutic purposes (ie, smoking cessation). This ruling was later upheld by the US Court of Appeals. However, the appeals court clarified that e-cigarettes may be subject to regulation as “tobacco products” since they contain nicotine, which is derived from tobacco [21]. Such regulation could make e-cigarettes subject to the marketing guidelines that govern traditional tobacco products, including ingredient listing; good manufacturing practice; mandated health warnings; and prohibitions against television and radio advertising, event sponsorship, and youth-targeted advertising [39]. In April 2014, the FDA issued a proposed rule to deem electronic cigarettes, among other products, as tobacco products. If finalized, the FDA’s proposed Deeming Rule would extend FDA regulatory authority to e-cigarettes and other tobacco products, allowing the FDA to propose rules that restrict the manufacture, distribution, and marketing of e-cigarettes, including advertising and promotion restrictions. Until then, e-cigarette manufacturers and distributors can continue to make relatively unrestricted advertising appeals. Despite prohibitions, promotional claims about the role of e-cigarettes in smoking cessation may be common and may have contributed to increased e-cigarette use [23]. On YouTube, over 2500 e-cigarette videos mention smoking cessation in text fields and thus may be retrieved by consumer searches related to quitting.

Our analyses suggest that YouTube is heavily utilized for promotional and networking purposes, with 70% of videos including Web addresses; however, the platform appears to be very unevenly utilized for brand-specific promotion. For example, we noted that only 15% of videos included mentions of the top 10 best-selling brands, with only Blu and NJOY representing greater than 1% of total videos or views. Further, the vast majority of brand mentions were not made through company accounts. For example, videos from the account BluCigs accounted for only 32 videos and approximately 500,000 views, representing 0.8% of total videos mentioning Blu and 4% of total views. Videos uploaded by NJOYecigs accounted for 0.3% of videos mentioning NJOY and for 4% of total views. Efforts by some vendors, nonetheless, had potential to change the landscape of available content; one website, EcigsFreeTrialOffer.com (no longer active), accounted for 80% of new videos posted in April 2012. This spike coincided with the launch of the first *Tips from Former Smokers* campaign, a major antismoking media effort sponsored by the US Centers for Disease Control and Prevention. Keyword searches for additional brands revealed variable presence on YouTube: following Blu, eGo and V2 comprised the second and third highest fraction of content. Most e-cigarette liquids contain 6, 12, 18, or 24 mg/mL nicotine levels, but concentrations of 36 mg/mL and 100 mg/mL solutions for making e-liquid also are available [40]. Given this wide variability in nicotine delivery and manufacturing standards for e-cigarettes, heavy promotion of certain brands may lead to use of devices not optimized for nicotine delivery and thus ineffective for smoking cessation. It is unknown how marketing appeals of smaller brands may differ from those of larger companies.

Our results show a high level of user engagement with e-cigarette content, with over 100 million total views for e-cigarette-related videos as of June 2013. To put this finding into context, the e-cigarette TV ads reached 29 million youth and young adults in 2013 [41]. Furthermore, 43% of videos included the keyword *review* and 10% included keywords indicating product demonstrations, both of which suggest videos originating from consumers or affiliated marketers. Mentions of mods, atomizers, e-liquids, and marijuana suggest that customization plays a large role in e-cigarette discourse on YouTube. Consumers’ ability to choose and manipulate aspects of their e-cigarette experience, including flavor, nicotine content, and battery, may have contributed to their rising popularity, but also raises questions about uneven efficacy in tobacco replacement and the potential gateway to other substance abuse. The availability of flavored juices has been criticized by some, since they may appeal to nonsmokers, including younger consumers [42].

In a sample of 280 e-cigarette videos, we found none to be age restricted by YouTube, indicating that youth can easily view and access e-cigarette videos on YouTube. Since the vast majority of these videos provide links to vendors or branded websites, these videos may enhance opportunities for underage e-cigarette purchase.

While e-cigarette marketing efforts largely leverage new media channels, traditional media plays an increasing and interconnected role. Cigarette advertising has been prohibited from US television and radio since 1971, but in recent years, e-cigarette brands have introduced television-advertising campaigns [43]. Television advertisements may use many strategies employed by cigarette advertisers in the past, including jingles, celebrity endorsers, and mascots [44]. Television advertising may also drive activity on social media channels, including YouTube. For example, we noted that a UK advertisement for E-lites garnered an additional 2 million views when posted on YouTube. Several studies have noted additional television content, including footage of actress Katherine Heigl smoking an e-cigarette on The Late Show with David Letterman and a clip from the program The Doctors [37]. Our search for a list of several celebrities featured in viral and traditional marketing campaigns (ie, Katherine Heigl, Stephen Dorff, Bruno Mars, and Courtney Love) retrieved only 153 unique videos, yet these videos were associated with view counts almost four times higher than average, comprising over 2 million total views.

Limitations

Our study has several limitations and raises questions for further research. First, the study relies on keywords to capture and categorize content relevant to e-cigarettes, and any set of keywords is necessarily incomplete since new brands and terminology are continually emerging. In particular, we may have overlooked some non-English e-cigarette keywords as well as variations of the slang term *vape*. As a result, our estimates of e-cigarette videos and their view counts underestimate their true overall presence and impact on

YouTube. However, given that the vast majority of videos in our dataset include multiple e-cigarette keywords, we believe we likely captured the majority of relevant content. We cannot exclude the possibility that there are YouTube videos that discuss e-cigarettes but do not reference them in any metadata field, but such videos would be unlikely to represent influential content, since attracting viewers relies on effective retrieval of videos by e-cigarette-related search queries.

We also used keyword rules to characterize themes within e-cigarette videos; again, this method is likely to underestimate the true presence of these themes. Further, we did not analyze variations of messages within each theme, for example, to characterize differences between various health claims or to investigate mentions of smoking-related disease. The keyword query rules applied were simple and thus not sensitive to context, in either the video content or the metadata. We did not undertake content analysis of the videos themselves, a task that fell outside the scope of this study but may have yielded rich results. Certain content elements are of considerable interest, but were not discernible by our methodology; for example, we could not reliably distinguish between promotional efforts and noncommercial consumer perspectives. Even with review of video content, such categorization would be challenging given that those affiliated with e-cigarette brands or companies may represent themselves as consumers as a marketing strategy [5,19].

More work is required to discern whether health, safety, and commercial claims derive from commercial or individual accounts. Characterizing commercial claims may clarify social media marketing guidelines. Identifying consumer experiences may help clarify whether and how e-cigarettes are used for smoking cessation, and thus contribute to public health efforts to optimize these products' harm reduction potential. Characteristics of influential users may be explored by examining posts and comments data for individual accounts [45]. Finally, we did not examine targeted advertising that accompanies searching for and viewing content on YouTube, which may be another important way in which consumers are exposed to e-cigarette-related content [9].

Conclusions

In summary, our study provides an approximation of the total amount of content and consumer engagement on YouTube related to e-cigarette use. Our analyses suggest uneven use of YouTube for promotional purposes by e-cigarette brands, and a high level of engagement with a small subset of content. Further research is needed to establish the information contained in e-cigarette-relevant YouTube videos and how these videos impact consumers' attitudes, beliefs, and risk perceptions about e-cigarettes and subsequent decisions regarding use of e-cigarettes, conventional cigarettes, and evidence-based smoking cessation aids. A better understanding about the extent, content, and impact of e-cigarette YouTube videos can aid the public health community and policymakers to ensure appropriate e-cigarette marketing regulations on social media platforms.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

E-cigarette keyword rules.

[PDF File (Adobe PDF File), 18KB - jmir_v18i3e67_app1.pdf]

Multimedia Appendix 2

Metadata search terms.

[PDF File (Adobe PDF File), 15KB - jmir_v18i3e67_app2.pdf]

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Abbreviations

CTP: Center for Tobacco Products
DIY: do it yourself
ENDS: electronic nicotine delivery systems
FDA: Food and Drug Administration
NCI: National Cancer Institute
NIH: National Institutes of Health

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Original Paper

Motivation and Treatment Credibility Predicts Dropout, Treatment Adherence, and Clinical Outcomes in an Internet-Based Cognitive Behavioral Relaxation Program: A Randomized Controlled Trial

Sven Alfonsson[1], PhD; Erik Olsson[1], PhD; Timo Hursti[2], PhD

[1]Clinical Psychology in Healthcare, Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden

[2]Clinical Psychology, Department of Psychology, Uppsala University, Uppsala, Sweden

Corresponding Author:
Sven Alfonsson, PhD
Clinical Psychology in Healthcare
Department of Public Health and Caring Sciences
Uppsala University
Husargatan/Dag Hammarskjölds väg
BMC ingång A11
Uppsala, 751 22
Sweden
Phone: 46 18 471 00 00
Fax: 46 18 471 66 75
Email: sven.alfonsson@pubcare.uu.se

Abstract

Background: In previous research, variables such as age, education, treatment credibility, and therapeutic alliance have shown to affect patients' treatment adherence and outcome in Internet-based psychotherapy. A more detailed understanding of how such variables are associated with different measures of adherence and clinical outcomes may help in designing more effective online therapy.

Objective: The aims of this study were to investigate demographical, psychological, and treatment-specific variables that could predict dropout, treatment adherence, and treatment outcomes in a study of online relaxation for mild to moderate stress symptoms.

Methods: Participant dropout and attrition as well as data from self-report instruments completed before, during, and after the online relaxation program were analyzed. Multiple linear and logistical regression analyses were conducted to predict early dropout, overall attrition, online treatment progress, number of registered relaxation exercises, posttreatment symptom levels, and reliable improvement.

Results: Dropout was significantly predicted by treatment credibility, whereas overall attrition was associated with reporting a focus on immediate consequences and experiencing a low level of intrinsic motivation for the treatment. Treatment progress was predicted by education level and treatment credibility, whereas number of registered relaxation exercises was associated with experiencing intrinsic motivation for the treatment. Posttreatment stress symptoms were positively predicted by feeling external pressure to participate in the treatment and negatively predicted by treatment credibility. Reporting reliable symptom improvement after treatment was predicted by treatment credibility and therapeutic bond.

Conclusions: This study confirmed that treatment credibility and a good working alliance are factors associated with successful Internet-based psychotherapy. Further, the study showed that measuring adherence in different ways provides somewhat different results, which underscore the importance of carefully defining treatment adherence in psychotherapy research. Lastly, the results suggest that finding the treatment interesting and engaging may help patients carry through with the intervention and complete prescribed assignments, a result that may help guide the design of future interventions.

Trial Registration: Clinicaltrials.gov NCT02535598; http://clinicaltrials.gov/ct2/show/NCT02535598 (Archived by WebCite at http://www.webcitation.org/6fl38ms7y).

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KEYWORDS

Internet; adherence; psychotherapy; motivation; patient compliance

Introduction

It is well established that therapist-guided Internet-based cognitive behavior therapy (ICBT) and other behavioral interventions can be effective in improving psychological symptoms and well-being [1]. However, not all patients are helped and one reason for this could be that treatment adherence may be somewhat lower in Internet-based psychotherapy compared to traditional face-to-face therapy [2]. This difference may be important because adherence is associated with treatment outcome in both face-to-face and Internet-based therapy [3]. Little is known about factors that affect treatment adherence to Internet-based interventions, but it is clear that therapist online support improves adherence substantially [4]. With the growth of Internet-based interventions, there has been an increased interest in trying to find variables that affect treatment adherence and outcomes [5-7]. However, the association between treatment adherence and outcome is complex and in previous studies it has been shown that increased adherence does not automatically lead to better treatment outcomes [8,9]. It is also unknown to what degree treatment adherence can be affected by therapist behaviors because background variables such as education and personality traits affect patients' ability to carry through and benefit from ICBT [10]. In order to develop and evaluate effective Internet-based interventions, it is important to further investigate factors that are associated with adherence and outcome [11,12].

Adherence to Internet-based treatments can be operationalized in different ways, including working with the intervention by reading texts and watching video clips on a webpage or adhering to the behavioral prescriptions in everyday life (eg, by completing homework assignments) [6,13]. In other words, one may separate the administration of the intervention (ie, providing the treatment content) and the proposed behavioral mechanisms (ie, everyday behavior change) that more directly lead to symptom change [14-16]. In Internet interventions, therapist support is hypothesized to help participants both to work with the online material and to complete behavioral assignments. The effect of human support can be explained by operant principles and by models such as self-determination theory (SDT), which is a framework that describes motivation and behavior change in congruence with operant conditioning principles [17]. According to SDT, behavior is governed by external motivation (behavior governed by external factors or consequences) and four forms of internal motivation: introjected motivation (behavior governed by reduced negative affect), identified and integrated motivation (behavior governed by goals or values), and intrinsic motivation (behavior that is in itself rewarding).

Self-determination theory has been applied to health behaviors and it seems that different forms of motivation may have different effects on treatment adherence [18]. For example, behaviors that are governed by intrinsic, identified, or integrated motivation are more likely to occur and to be enduring over time compared to behaviors that are governed by external motivation. Because some behavioral prescriptions in psychotherapy, such as exposure exercises, are not intrinsically rewarding, patients are helped by therapists to instead employ identified or integrated motivation to facilitate behavior change [19]. That therapists' follow-up on assignments may also be an example where introjected or external motivation may be beneficiary for treatment adherence.

Previous studies have shown that adherence to an intervention, as well as treatment outcome, may be influenced by demographical variables, such as gender, age, and education [20-22]. Another background factor that may be important in this context is the ability to focus on either future or present consequences [23-25]. According to Zimbardo's model of behavior and postponed reward, there are three types of time perspectives: future, hedonistic, and fatalistic. A future-oriented time perspective is goal-driven and has been associated with health behaviors, whereas the opposite is true for people with the hedonistic time perspective who are highly influenced by immediate consequences and stimulation [26]. Lastly, a person with a fatalistic time perspective may show a pattern of health-destructive behaviors [27]. Thus, time perspective is closely associated with executive functioning and the ability to postpone reinforcement and to act based on future goals rather than present needs [28-30]. Therefore, it may be an important construct that can help explain some of the variance in participants' adherence to psychological interventions.

Finally, patients' belief in a treatment may have a very strong effect on the outcome as seen in studies on placebo effects [31]. However, the credibility of a treatment may also explain why a patient engages in treatment and completes assignments that are not intrinsically rewarding. Thus, belief may be associated with internal motivation and can have an indirect but real effect on outcome in the case of psychotherapy [22,32].

This study aimed at investigating variables that may predict three different types of outcome variables in ICBT: (1) dropout and attrition from treatment, (2) treatment adherence, and (3) clinical outcomes. More specifically, the aim was to assess the predictive value of different background variables as well as the variables time perspective, treatment credibility, motivation, and therapeutic bond on early dropout, attrition, treatment progress, adherence to behavioral prescriptions, posttreatment symptoms, and reliable improvement in a previously conducted study of a brief online stress management treatment. A secondary aim was to investigate whether treatment adherence could predict clinical outcomes.

Methods

Design, Procedure, and Participants

Data for this study were retrieved from a previously conducted study on Internet-based relaxation training for people with mild to moderate stress and anxiety symptoms [9]. Participants were recruited from the general population primarily by online advertisement. Inclusion criterion was self-reported stress symptoms, whereas the exclusion criteria were elevated symptom levels of anxiety or depression or other severe psychological or somatic problems that warranted immediate care, younger than 18 years of age, insufficient mastery of the Swedish language, or lacking daily access to computer, Internet, and cell phone. In the study, a total of 162 included participants were presented with an online intervention and were randomized to either normal or enhanced treatment presentation and either normal or enhanced therapist support in a full factorial design [9]. In the normal treatment condition, the treatment was presented as black-and-white text files, whereas in the enhanced presentation condition, the treatment was presented in full color and also in video format. In the normal support condition, participants received support from trained therapists at least once a week, whereas in the enhanced support condition, participants received daily support from therapists based on motivational interviewing. The intervention consisted of a brief 4-week program of applied relaxation similar to what has been used and empirically tested in previous studies [33]. Each week of the program included webpage material, assigned relaxation exercises, and contact with a therapist via the webpage. All participants were asked to answer a battery of self-report instruments before, during, and after the intervention; of the 162 participants, 157 had complete data from the pre- and midtreatment assessments, whereas 96 participants had complete data also from the posttreatment assessment.

Outcome Variables

Early dropout (yes/no) was assessed by counting the number of participants who discontinued the study before completing the first week of the treatment program; attrition (yes/no) was assessed by counting the total number of participants who discontinued the study before the posttreatment assessment. Treatment adherence was divided into the two variables treatment progress and registered exercises, both on continuous scales. Treatment progress was assessed by measuring how much of the Web-based treatment material (eg, texts, examples, assignments) each participant accessed before dropping out or completing the treatment. Because the treatment consisted of 25 such items, this variable ranged from zero (not accessed the treatment) to 25 (accessed the whole treatment). Registered exercises were measured by the mean number of prescribed exercises of applied relaxation that the participant had registered on the webpage each week. The weekly number of registered exercises ranged from zero (not completed any exercises) to 14 (completed all prescribed exercises). As a measure of stress symptoms and treatment outcome, the Perceived Stress Scale (PSS) [34] was chosen. The short version of the PSS used in this study contains 14 items scored on a scale between zero and 4, which provides a total score between zero and 56 with a higher score indicating more symptoms of stress. In the current study, the PSS had an internal reliability of α=.72. In previous studies, the PSS has showed adequate psychometric properties [35]. To assess reliable improvement (yes/no), the Reliable Change Index for PSS was calculated (described subsequently).

Predictor Variables

The predictor variables consisted of the background variables age, gender, level of education (primary/secondary/university), occupation (student/unemployed/employed/sick leave/retired), and computer expertise (low/intermediate/high). In order to facilitate interpretation, education and occupation were transformed into dichotomous variables (nonuniversity vs university; employed/student/retired vs unemployed/sick leave). Four psychological predictor variables were collected by self-report instruments at baseline: time perspective, treatment credibility, and internal and external motivation. Intrinsic motivation and therapeutic bond were measured at midtreatment and stress symptoms were measured both at baseline as a predictor variable and at postmeasurement as an outcome variable. Because a previous analysis [9] had shown that enhanced support was associated with higher adherence to the online treatment program, treatment condition (normal vs enhanced therapeutic support) was also included as a predictor variable in the analyses. No other independent variable was significantly associated with any outcome variables.

Time perspective was measured with the Zimbardo Time Perspective Inventory Short Form (ZTPI) [36,37]. The version of the ZTPI used in this study has three subscales—future, hedonistic, and fatalistic—and comprise 22 items scored on a scale from 1 to 5 [38]. The ZTPI has been evaluated for research in health psychology and has shown adequate psychometric properties [39]. The ZTPI subscales had internal reliabilities of α=.69-.73 in this study.

Treatment credibility was measured with the Treatment Credibility Scale (TCS), which is often used in studies of Internet interventions and is an adaptation from Borkovec and Nau [40]. The TCS consists of five items scored on a scale from 1 to 10 with a higher score indicating more trust in the current treatment. The TCS had an internal reliability of α=.83 in this study.

Internal (ie, identified and integrated motivation) and external motivation were measured with the Treatment Self-Regulation Questionnaire (TSRQ) [41]. The TSRQ consists of two subscales—internal motivation (IM) and external motivation (EM)—each measured with six items that were adapted to suit the Internet intervention used in this study. Each subscale provides a score between 6 and 42 with a higher score corresponding to a higher degree of motivation. The TSRQ has been used in studies on motivation and health behaviors and has shown adequate psychometric properties [42]. In the present study, the TSRQ-IM and TSRQ-EM had internal reliabilities of α=.70 and α=.68, respectively.

Intrinsic motivation was measured with the Intrinsic Motivation Inventory (IMI) [43]. The IMI aims at measuring how pleasant, interesting, and meaningful a task is perceived and has nine items scored on a scale between 1 and 7 which provides a total score of 9 to 63 with a higher score indicating a more positive experience of the task. Due to mixed findings concerning the factor structure of the IMI, only the total score was used [44]. The IMI had α=.71 in this study.

Therapist bond was measured with the Working Alliance Questionnaire Short Form (WAI) [45]. The WAI has been widely used in psychotherapy research and has shown adequate psychometric properties [46]. The short form WAI consists of three subscales—Goal, Task, and Bond—each with a score between 4 and 28 where a higher score equals a higher degree of therapeutic alliance. The WAI total scale had an internal reliability of α=.73 in this study.

Analysis

Before analysis, data were screened for outliers and normality, linearity, and homoscedasticity were evaluated by scrutinizing the residual scatterplots between predicted variables and errors of prediction and found adequate. Because subscales were entered into the analyses, multicollinearity was assessed by analyzing the variance inflation factor for each predictor variable and found to be nonproblematic.

Reliable improvement was computed by dividing the difference between the pretreatment and posttreatment scores by the standard error of the difference between the two scores. If the Reliable Change Index was greater than 1.96, a change of that magnitude would not be expected due to the unreliability of the measure [47]. Using this procedure, the reliable improvement criterion for PSS was a change score of 10 or more in this study.

Modeled after deGraaf et al [48], bivariate regression analysis was first used to identify candidate ($P<.10$) predictor variables for each outcome variable. All identified predictor variables were included in subsequent multiple regression analyses using a backward deletion process for each outcome variable. Logistic regression was used for the dichotomous outcome variables dropout and attrition and linear regression was used for continuous outcome variables. Cox-Snell R^2 and Nagelkerke R^2 were used as a measure of overall model fit in the logistic regression analyses and R^2 was used in the linear regression analyses. Because some of the variables had distributions that deviated somewhat from normality, the final regression models were confirmed using robust regression analyses with bootstrap and bias correction. The sample size of 157 was deemed adequate for regression analysis of a maximum of eight predictor variables for each outcome variable except stress symptoms and reliable improvement for which the sample size of 96 was deemed adequate for six predictor variables. Single missing values (n<1%) were imputed using expectation-maximization estimates. A *P* value of .05 was considered the threshold for statistical significance if not stated otherwise; exact *P* values were reported for the final analyses.

Results

Of the 157 participants in this study, 115 (73.2%) were women and the mean age was 34.5 (SD 13.1) years. The background variables education, occupation, and computer expertise are shown in Table 1. A total of 39 of 157 (24.8%) participants dropped out before completing the first week of treatment; the total attrition was 61 (38.9%) participants at the postmeasurement. The mean treatment progress among all participants was 14.9 (SD 9.7) items out of 25 (60%) and the mean number of weekly exercises was 8.5 (SD 4.0) out of the prescribed 14 (61%).

Table 1. Background predictor variables (N=157).

Factor	n (%)
Education	
Primary	8 (5.1)
Secondary	57 (36.3)
University	92 (58.6)
Occupation	
Studying	43 (27.4)
Unemployed	9 (5.7)
Employed	81 (51.6)
Sick leave	16 (10.2)
Retired	8 (5.1)
Computer expertise	
Low	54 (34.4)
Intermediate	51 (32.5)
High	52 (33.1)

There were no significant differences for any of the predictor variables between the treatment groups of the original study. Of the background variables, only education and occupation were significant predictors for any outcome variable in the initial bivariate regression analyses. Of the self-reported psychological variables, the TSRQ-IM showed markedly higher standard deviation compared to other variables and it was the only variable that failed to significantly predict any outcome variable, so it was removed from further analyses. The results of these bivariate analyses for each outcome variable can be found in Multimedia Appendices 1 and 2.

Dropout and Attrition

The multivariate logistic regression analyses showed that early dropout could be significantly negatively predicted by the TCS (B=–0.14, $\chi^2_1=10.5$, $P=.001$), whereas total attrition to postmeasurement was predicted by baseline stress symptoms (B=0.08, χ^2_1=3.2, *P*=.05), the ZTPI Hedonistic subscale (B=0.32, χ^2_1=10.3, *P*=.001), and the IMI (B=–0.06, χ^2_1=5.7, *P*=.02) (see Table 2). Early dropout was associated with a low belief in the treatment model, whereas dropout during the course of treatment was associated with having elevated stress symptoms, being more focused on the immediate consequences of behaviors, and finding the treatment uninteresting or unengaging.

Table 2. Significant predictor variables for early dropout and attrition after backward deletion (N=157).

Treatment dropout[a]	Cox-Snell R^2	Nagelkerke R^2	B (SE)	χ^2_1	*P*	OR (95% CI)
Early dropout	.18	.39				
TCS			–0.14 (0.04)	10.5	.001	0.87 (0.80-0.95)
Attrition	.19	.28				
Baseline stress symptoms			0.08 (0.05)	3.2	.05	1.08 (1.00-1.18)
ZTPI Hedonistic			0.32 (0.10)	10.3	.001	1.37 (1.13-1.66)
IMI			–0.06 (0.03)	5.7	.02	0.94 (0.90-0.99)

[a] IMI: Intrinsic Motivation Inventory; TCS: Treatment Credibility Scale; ZTPI: Zimbardo Time Perspective Inventory.

Treatment Adherence

After controlling for level of support, treatment progress was positively predicted by level of education (beta=.24, t_{153}=2.33, *P*=.02) and by the TCS (beta=.35, t_{153}=3.36, *P*=.001), whereas registered exercises was significantly predicted only by the IMI (beta=.29, t_{155}=2.43, *P*=.02) (see Table 3). All other predictor variables were nonsignificant in the multiple regression analyses for treatment adherence. Accessing the online treatment material was associated with a priori belief in the treatment model, whereas complying with the prescribed homework assignments was associated with experiencing interest and engagement in the treatment.

Table 3. Significant predictor variables for treatment adherence after backward deletion (N=157).

Treatment adherence[a]	R^2	B (SE)	β	*t* (*df*)	*P*
Treatment progress	.36				
Enhanced support		2.84 (0.88)	.33	3.23 (153)	.002
University education		1.95 (0.84)	.24	2.33 (153)	.02
TCS		0.15 (0.04)	.35	3.36 (153)	.001
Registered exercises	.13				
IMI		0.10 (0.04)	.29	2.43 (155)	.02

[a] IMI: Intrinsic Motivation Inventory; TCS: Treatment Credibility Scale.

Treatment Outcome

Posttreatment stress symptoms were significantly and positively predicted by the baseline stress symptoms (beta=.47, t_{91}=4.43, *P*<.001) and by the TSRQ-EM (beta=.25, t_{91}=2.40, *P*=.02) while negatively predicted by the TCS (beta=–.28, t_{91}=3.53, *P*=.001) (see Table 4). Reliable improvement was positively predicted by baseline stress symptoms (B=0.11, χ^2_1=4.5, *P*=.03), by the TCS (B=0.09, χ^2_1=3.3, *P*=.05) and by the WAI (B=0.14, χ^2_1=3.9, *P*=.049) (see Table 5). Reporting external pressure to complete the treatment was associated with worse treatment outcome, whereas a good therapeutic bond was associated with a substantial positive treatment effect. Treatment credibility predicted both overall symptom levels and substantial improvement.

Table 4. Significant predictor variables for post treatment stress symptoms after stepwise deletion (n=96).

Predictor variable[a]	R^2	B (SE)	β	t_{91}	*P*
Postmeasurement stress symptoms	.42				
Baseline stress symptoms		0.53 (0.12)	.47	4.43	<.001
TSRQ-EM		0.48 (0.20)	.25	2.40	.02
TCS		–0.28 (0.08)	–.35	3.53	.001

[a] TCS: Treatment Credibility Scale; TSRQ-EM: Treatment Self-Regulation Questionnaire Extrinsic Motivation.

Table 5. Significant predictor variables for reliable improvement after stepwise deletion (n=96).

Predictor variable[a]	Cox-Snell R^2	Nagelkerke R^2	B (SE)	χ^2_1	P	OR (95% CI)
Reliably improved	.32	.47				
Baseline stress symptoms			0.11 (0.05)	4.5	.03	1.12 (1.01-1.25)
TCS			0.09 (0.05)	3.3	.05	1.10 (1.00-1.20)
WAI total			0.14 (0.07)	3.9	.049	1.15 (1.01-1.32)

[a] TCS: Treatment Credibility Scale; WAI: Working Alliance Inventory.

Associations Between Treatment Adherence and Outcomes

In bivariate regression analyses and after controlling for baseline PSS score, posttreatment stress symptoms was significantly negatively predicted by both treatment progress (beta=–.31, t_{92}=3.29, P=.001) and registered exercises (beta=–.21, t_{92}=1.98, P=.05). The same pattern was seen for reliable improvement, which was significantly predicted by both treatment progress (B=0.26, χ^2_1=8.0, P=.005; OR 1.29, 95% CI 1.08-1.55) and registered exercises (B=0.20, χ^2_1=7.5, P=.006; OR 1.23, 95% CI 1.06-1.42). Whether treatment effect was mediated through treatment adherence could not be further investigated in this study because the power calculations had not accounted for this type of analyses.

Discussion

Predicting Dropout, Attrition, and Adherence

The analyses showed that different ways of operationalizing (ie, measuring) dropout, treatment adherence, and treatment outcomes was related to somewhat different predictor variables, something that may be important to consider in psychotherapy process research. First, there was a difference in that early treatment dropout could be predicted by treatment credibility, whereas further attrition was predicted by a personality pattern of focusing of immediate consequences and by finding the treatment unengaging, two variables that are probably connected. People whose behavior is generally governed by immediate consequences and reward may find an online behavioral treatment largely consisting of abstract instructions and texts unsatisfying and boring. This pattern suggests that some people with low expectations of the treatment start the program, but very soon realize it does not suit them and quit. Whether these participants should receive more motivational support from therapists to stay in the online treatment or efforts should be made to guide them to other forms of treatment needs further investigation. Participants who dropped out later in the treatment reported a lower tendency to focus on future goals and also experienced the treatment as unrewarding. These results are in line with previous results showing that being able to focus on the future and to postpone rewards is associated with higher levels of education and health behaviors [23]. Although the treatment may be designed to be more interesting and engaging (eg, by employing media content or using features of gamification [49]), it may be difficult to counter the fact that most health behaviors rely on an ability to postpone rewards and a focus on future consequences. However, strategies such as repeated reminding of treatment goals and using everyday prompts may be alternatives for further investigation [50].

Treatment adherence showed a somewhat similar pattern to dropout with online treatment progress predicted by education and treatment credibility. Thus, working with the online material was associated with a probable familiarity of working with texts and thinking in abstract terms. Treatment credibility may correspond to a familiarity and interest in using the Internet for learning about health behaviors and perhaps previous positive experiences of online courses. Treatment credibility may also represent participants' belief in the treatment model and specifically in using relaxation to target stress symptoms. Finally, the association between treatment credibility and treatment progress may represent the different reasons why people undergo Internet-based psychotherapy; for some it is a preferred choice, whereas for others it may be the only available option. Completion of homework assignments, similar to staying in the treatment program, was predicted by finding the treatment engaging. That the IMI was significantly associated with adherence in this study may be partly explained by the nature of relaxation exercises that may actually be pleasant in contrast to exposure exercises, for example. It is worth noting that the instrument used to measure intrinsic motivation, the IMI, is designed to measure different forms of intrinsic reward and comprise items concerning experiences of interest, enjoyment, and meaningfulness [41]. It may capture participants' experience that the treatment suits them and their needs rather than the treatment being "fun." Whether results from this study of relaxation exercises can be generalized to other types of assignments used in CBT needs further study. In short, the results from this study suggest that a high level of education and belief in the treatment model may be beneficiary for overcoming the effort needed to work with the online program, but participants who find the treatment suits them work with the prescribed assignments to a higher degree. However, few of the variables in this study could significantly predict adherence to the assignments, so there are probably other unknown variables that could help explain this behavior.

Predicting Treatment Outcomes

Among participants who did not dropout and remained in the study, treatment outcome, as measured by the posttreatment stress symptoms, was significantly positively predicted by baseline stress symptoms, but also by the TSRQ-EM measuring external motivation. External motivation corresponds to feeling pressured by others, mostly in a negative way, to complete tasks. In previous studies, external motivation has been associated with difficulties in sustaining behavior and a reliance on accountability [19]. That external motivation was associated with worse outcome in this study implies that people who complete the intervention because of feeling obliged to do so benefit less from the treatment. In a recent study of negative effects in online psychotherapy, some participants reported feeling pressured by their online therapist or the demands of the treatment schedule [51], but in this study, external motivation was measured at baseline and corresponded to the reasons why participants took part in the study. Why some participants reported external pressure is unknown and difficult to speculate about because this study was based on self-referral recruitment. It is important to note the different nature of psychotherapy compared to the workplace environment, where most of the research on motivation has been conducted. In studies of psychotherapy, results may rely more on participants being engaged and involved than in most workplace research. For example, unlike work tasks, psychotherapy aims at making participants generalize behaviors from the therapy situation to their everyday life, something that may be more probable if the patient experiences the treatment as meaningful. Also, the Internet format may deemphasize external motivation because of the perceived anonymity of both patients and participants [52,53]. Previous studies have shown that therapists' prompts and reminders can have a relatively minor impact on treatment adherence among participants who may lack internal motivation [54]. Posttreatment stress symptoms were further negatively predicted by treatment credibility, an effect also seen in previous studies [21,22]. Belief in the treatment format and model seems to be a consistent predictor for positive outcome and may be used as a measure for identifying people for whom the online format and minimal therapist contact may be beneficiary. It is important to note that suggesting or persuading people to try Internet-based psychotherapy or a treatment model they do not believe in may be counterproductive, both given the effect seen for external motivation and the effect of treatment credibility on treatment outcome. However, given the positive results of many online behavioral interventions, it may be beneficiary to better inform skeptical participants about the treatment format (eg, by pretreatment vignettes or examples). After controlling for baseline stress symptoms, reliable improvement after the treatment program was predicted by treatment credibility, but also by therapeutic bond, an effect that has been seen in other studies as well [55]. Interestingly, this effect in this study was seen only among participants who improved substantially, further providing support for the notion that working alliance is as an important variable in online psychotherapy as in face-to-face therapy [56].

Identified Difficulties and Study Limitations

In this study, many of the proposed predictor variables could not significantly predict the outcome variables in the multivariate analyses. This suggests that several of the predictor variables covaried to a large degree; therefore, finding the best predictor variables is difficult. The multivariate analyses with backward deletion resulted in models with acceptable levels of model fit except for registered exercises (R^2=.13); so far, there is limited understanding of the processes that may be involved in following prescribed homework in ICBT. That personality traits associated with conscientiousness and delay discounting could predict carrying through with the treatment seemed reasonable, but it was somewhat surprising that working alliance could not. A strong working alliance is often associated with treatment adherence, but in this study this association was overshadowed by the impact of education and treatment credibility. The weak association between working alliance and treatment adherence was unexpected given that therapeutic alliance has shown to be strongly associated with adherence and outcome in several other studies of ICBT [57]. Finding the intervention engaging, interesting, and meaningful were crucial factors for participants in successful ICBT as seen in previous studies [58]. Although intrinsic motivation was a predictor for treatment adherence, it was not associated with treatment outcome; this was surprising given the association between treatment adherence and outcome. This study was not designed to investigate mediation effect; therefore; it was unfortunately underpowered to further analyze these processes.

This study has a number of limitations. First, several of the predictor and outcome variables were difficult to measure accurately. For example, the measurement of registered exercises was constructed to assess the treatment's effective mechanism, but may have failed to fully capture changes in participants' everyday behavior. The intervention encouraged participants to conduct relaxation exercises and highly engaged participants may have done so without registering on the webpage. Further, several of the self-report instruments have not been used in psychotherapy research before and their psychometric properties in this context are unknown. For example, the internal reliability of some questionnaires seemed to be somewhat lower in this study compared to previously reported figures. Second, a more complex design with repeated measurements of adherence could have been conducted to show causal mediation, but this would also have demanded a much larger sample size. Third, the lack of a control group or a face-to-face treatment condition limits the generalizability of the results. Therefore, whether the conclusions from this study are valid for other treatment modalities are unknown. Finally, and most importantly, there was large dropout (39%) at postmeasurement and although investigating dropout from Internet-based interventions was one of the aims of this study, it also meant loss of follow-up data. This also means that the conclusions regarding predictors of clinical outcome are only valid for participants who stay in the study or treatment, which limits the generalizability of the results. A more thorough analysis of participants who dropped out may have resulted in a better understanding of this group.

Conclusions

In conclusion, this study confirms the importance of treatment credibility and working alliance in Internet-based psychotherapy and also suggests that experiencing intrinsic reward from participating in the treatment may be important. In contrast, external pressure to try online therapy may be counterproductive and lead to worse outcomes. Apart from identifying people who believe in the online treatment format and continue to explore the best methods for online therapist support, it may also be valuable to further investigate what makes participants engage in an intervention and what features makes the intervention interesting and meaningful [55]. However, given that quite rudimentary online treatment programs seem to be effective, it is possible that Internet-based interventions simply suit some participants better than others and that the focus should be on identifying these participants early [59]. Future studies may investigate both what makes treatments engaging while recognizing that different participants may have different requests and wishes for an intervention [60]. A good match between participant expectations and needs on the one hand and the intervention content and design on the other hand may be one of the reasons clinical assessment before treatment and tailoring treatment to better suit different patients may be beneficiary for treatment outcomes in Internet-based interventions [61]. Believing in the online treatment format and finding working with the online program rewarding may be two aspects of a process that could be investigated further to develop even more effective treatment programs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Identified candidate predictor variables from the bivariate analyses for nominal outcome variables.

[PDF File (Adobe PDF File), 20KB - jmir_v18i3e52_app1.pdf]

Multimedia Appendix 2

Identified candidate predictor variables from the bivariate analyses for continous outcome variables.

[PDF File (Adobe PDF File), 20KB - jmir_v18i3e52_app2.pdf]

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Abbreviations

ICBT: Internet-based cognitive behavior therapy
IM: internal motivation
IMI: Intrinsic Motivation Inventory
PSS: Perceived Stress Scale
SDT: self-determination theory
TCS: Treatment Credibility Scale
TSRQ: Treatment Self-Regulation Questionnaire

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Original Paper

Acceptability of Mental Health Apps for Aboriginal and Torres Strait Islander Australians: A Qualitative Study

Josie Povey[1,2], BOccThy, MPH; Patj Patj Janama Robert Mills[2]; Kylie Maree Dingwall[3], BA (Psych) Hon, PhD; Anne Lowell[4], BAppSci, GradDip, PhD; Judy Singer[5], PhD; Darlene Rotumah[5], BA, M Indigenous Studies; James Bennett-Levy[5], MPhil, PhD; Tricia Nagel[2], MBBS, FRANZCP, PhD

[1]Darwin Remote Mental Health Service, Top End Mental Health Service, Northern Territory Department of Health, Darwin, Australia
[2]Menzies School of Health Research, Institute of Advanced Studies, Charles Darwin University, Casuarina, Australia
[3]Menzies School of Health Research, Institute of Advanced Studies, Charles Darwin University, Alice Springs, Australia
[4]School of Health, Charles Darwin University, Darwin, Australia
[5]University Centre for Rural Health (North Coast), University of Sydney, Lismore, Australia

Corresponding Author:
Josie Povey, BOccThy, MPH
Menzies School of Health Research
Institute of Advanced Studies
Charles Darwin University
PO Box 41096
Casuarina, 0811
Australia
Phone: 61 407399919
Fax: 61 8 8927 5187
Email: josie_povey@hotmail.com

Abstract

Background: Aboriginal and Torres Strait Islander Australians experience high rates of mental illness and psychological distress compared to their non-Indigenous counterparts. E-mental health tools offer an opportunity for accessible, effective, and acceptable treatment. The AIMhi Stay Strong app and the ibobbly suicide prevention app are treatment tools designed to combat the disproportionately high levels of mental illness and stress experienced within the Aboriginal and Torres Strait Islander community.

Objective: This study aimed to explore Aboriginal and Torres Strait Islander community members' experiences of using two culturally responsive e-mental health apps and identify factors that influence the acceptability of these approaches.

Methods: Using qualitative methods aligned with a phenomenological approach, we explored the acceptability of two culturally responsive e-mental health apps through a series of three 3-hour focus groups with nine Aboriginal and Torres Strait Islander community members. Thematic analysis was conducted and coresearcher and member checking were used to verify findings.

Results: Findings suggest strong support for the concept of e-mental health apps and optimism for their potential. Factors that influenced acceptability related to three key themes: personal factors (eg, motivation, severity and awareness of illness, technological competence, and literacy and language differences), environmental factors (eg, community awareness, stigma, and availability of support), and app characteristics (eg, ease of use, content, graphics, access, and security and information sharing). Specific adaptations, such as local production, culturally relevant content and graphics, a purposeful journey, clear navigation, meaningful language, options to assist people with language differences, offline use, and password protection may aid uptake.

Conclusions: When designed to meet the needs of Aboriginal and Torres Strait Islander Australians, e-mental health tools add an important element to public health approaches for improving the well-being of Aboriginal and Torres Strait Islander people.

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KEYWORDS

mobile apps; mental health; indigenous populations; therapeutics; cognitive behavioral therapy; acceptance and commitment therapy; culturally competent care

Introduction

Aboriginal and Torres Strait Islander Mental Health and Service Access

Aboriginal and Torres Strait Islander Australians experience much higher rates of psychological distress compared to non-Indigenous Australians [1]. Tragically, consequences such as suicide also occur at higher rates—twice that of non-Indigenous Australians [2]. Younger Aboriginal and Torres Strait Islander Australians are at the greatest risk, with suicide rates 5.9 (female) and 4.4 (male) times higher than non-Indigenous Australians aged 15 to 19 years [3]. Despite this, 35% of Aboriginal and Torres Strait Islander people with high to very high levels of psychological distress report difficulties accessing health services [1]. Barriers include ineffective communication, differences in worldview from Western treatment models, stigma, and distance to appropriate services [4].

Treatment approaches that equalize power and facilitate genuine communication are favored [5]. Two-way learning, incorporating local knowledge and worldview into treatment, is most likely to be effective [6-8]. Access to such services in rural and remote areas is limited and technological innovation provides an important opportunity to bridge geographic and sociocultural divides.

The Potential of E-Mental Health

E-mental health approaches use electronic media for the delivery of therapy/treatment [9] and are emerging as a safe, therapeutically effective, and acceptable treatment option for common mental health concerns [10]. They have the potential to increase access by overcoming barriers such as distance and cost, and improve flexibility by being available at times suitable to the person, with relative anonymity if desired [11]. Recognizing these benefits, in 2012 the Australian Government released its National e-Mental Health Strategy including a comprehensive commitment to improving access for all Australians [9].

Some studies have shown Internet-delivered cognitive behavioral therapy (CBT) to be as effective as face-to-face therapy for depression, anxiety, and social phobia [10,12,13]. However, these findings cannot be generalized to all Australians. Many online CBT treatments recommend 4 to 6 hours of weekly participation and require medium to high literacy levels, regular access to the Internet, and a high level of computer and Internet competence. Given these criteria, it is not surprising that many studies report variable adherence and completion rates [14,15] raising questions about satisfaction with e-mental health approaches [16]. Understanding what drives acceptability is an important next step for successful e-mental health uptake.

Technology in the Aboriginal and Torres Strait Islander Health Context

Despite the potential appeal of e-mental health approaches, the vast majority of effectiveness, accessibility, and acceptability findings to date relate to non-Indigenous Australians. Aboriginal and Torres Strait Islander people generally have less access to technology than non-Indigenous Australians [17]. Significant investment by the Australian Government is being made to increase access through programs such as the National Broadband Network [9]. Increased access has led to increased use. Estimates suggest 60% to 80% of people 10 years and older living in some remote Northern Territory (NT) communities have access to and use a mobile phone regularly [18]. In these settings, mobile phones are mostly used for communication with family and Internet browsing; however, they have also been shown to support health care treatment and clinical trial retention [18,19].

Locally produced eHealth strategies that use culturally appropriate graphics and videos, limited text, and Aboriginal and Torres Strait Islander voices reportedly have the best chance of successful implementation [20,21].

Introducing Two Culturally Responsive E-Mental Health Tools: AIMhi and ibobbly

Two culturally responsive e-mental health tools have recently been developed with local input: the AIMhi Stay Strong iPad app and the ibobbly suicide prevention app [22,23].

The Australian Integrated Mental Health Initiative (AIMhi) began in the NT in 2003 and sought to incorporate local Aboriginal and Torres Strait Islander knowledge and worldviews into treatment. Extensive community consultation resulted in the generation of a culturally responsive brief therapy (AIMhi Stay Strong Plan). This brief therapy was tested in a randomized controlled trial (RCT) in 2009. Results showed significant improvements in well-being, substance use, and self-management following the therapy [24]. The AIMhi Stay Strong Plan is a therapist-supported strengths-based brief intervention integrating motivational interviewing and low-intensity CBT techniques [25]. It follows a 4-step process exploring family, strengths, and worries, before goal setting. The goal-setting phase integrates the strengths and worries discussion into specific lifestyle changes chosen by the client and adapted to their values and sociocultural context [24].

The AIMhi Stay Strong app (Figure 1) translated the paper-based care plan into an electronic format. The app uses colorful graphics, audio, and animation with limited text. Information is entered through selecting icons, typing text, and drop-down selection boxes, with an option of including a photograph of the client. Care plans can be saved, stored, copied, emailed, printed, and reaccessed to facilitate an ongoing therapeutic monitoring tool. Once downloaded, the app does not require continuous Internet connection for use.

The ibobbly suicide prevention app (Figure 2) was developed in northern Western Australia (WA) for Aboriginal people aged 18 to 35 years. The app is based on acceptance and commitment therapy and uses mindfulness and values-based action strategies. The app is a self-help tool and includes three self-assessment and three activity modules. Self-assessment modules ask the user if they are experiencing intrusive thoughts, including thoughts of suicide; if so, they are directed to call 000 Emergency, Lifeline, or Kidshelp line. Three activity modules use interactive activities, stories, and videos, aiming to help users manage upsetting thoughts and emotions, identify ideals, and set small, realistic goals. An audio icon on every page assists people with limited literacy. A summary page prompts reflection. Once downloaded, the app does not require continuous Internet connection.

The first version of ibobbly was evaluated through a pilot study in the Kimberley region, WA. In all, 61 participants completed the trial. Preliminary analysis suggests that the group using ibobbly had reductions in psychological distress, depression, and suicidal thinking (personal written communication, F Shand, May 27, 2015). Results will be published soon. A national RCT began in 2015.

The Australian Government's e-Mental Health Strategy seeks to increase availability of e-mental health services and provide training and support to primary, allied health and Aboriginal and Torres Strait Islander Health Workers through the e-Mental Health in Practice (eMHPrac) Project [9]. The present study is linked with the eMHPrac project. E-mental health services may provide an opportunity to deliver structured, cost-effective, and accessible mental health services to Aboriginal and Torres Strait Islander people; however, their acceptability is not well understood. This study aimed to explore Aboriginal and Torres Strait Islander community members' experiences of using two culturally responsive e-mental health apps and identify factors that influence the acceptability of these approaches.

Figure 1. Screenshots of AIMhi app. Reproduced with permission.

People Who Keep Me Strong

Write name here / Select Relationship / Select Role

Write name here / Select Relationship / Select Role

Wendy / Sister / Is there for me

belinda / Cousin / Role model

John / Uncle / Someone I can talk to

terry / Cousin / Cares about me

Things That Keep Me Strong

My Worries

My Summary

Things that help me stay strong are:

Spiritual and Cultural: Spirituality, Going to Country

Family, Social and Work: Work or Jobs, Teach Kids, Family and Friends, Dog

Mental and Emotional: Understanding Health, Exercise

Physical: Good Tucker, Exercise

Things that take my strength away are:

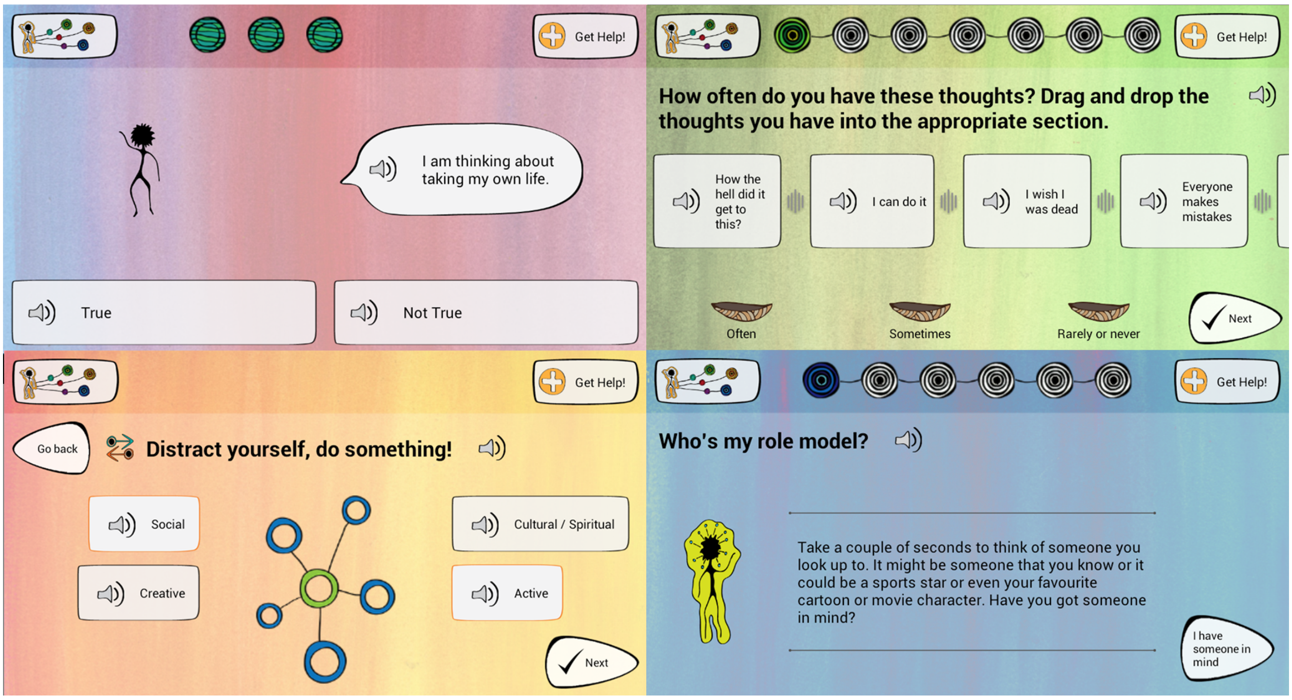
Spiritual and Cultural: Identity, Culture Worry, Missing Country, Missing Culture

Family, Social and Work: Work

Physical: Unhealthy Lifestyle

Mental and Emotional: Anxious or Sad

Figure 2. Screenshots of ibobbly app. Reproduced with permission.



I am thinking about taking my own life.

How often do you have these thoughts? Drag and drop the thoughts you have into the appropriate section.

Distract yourself, do something!

Who's my role model?

Take a couple of seconds to think of someone you look up to. It might be someone that you know or it could be a sports star or even your favourite cartoon or movie character. Have you got someone in mind?

Methods

We used a qualitative design, aligned with a phenomenological approach, to explore the experiences and perspectives of participants in relation to the apps. A series of three focus groups were held with participants who identified as members of the Aboriginal and Torres Strait Islander community in Darwin, NT. The design drew from a larger study conducted in northern New South Wales [26]. The design, sampling, and recruitment strategy were discussed with the Aboriginal researcher and an expert reference group that guides other e-mental health projects in the NT to ensure local relevance. Ethics approval was granted through the Human Research and Ethics Committee for the NT Department of Health and Menzies School of Health Research, Darwin, NT including Aboriginal and Torres Strait Islander subcommittee.

Recruitment

Purposive sampling was used, aiming to recruit 6 to 8 Aboriginal and Torres Strait Islander community members. Local service providers (education, health, and community) were asked to provide nominations based on inclusion/exclusion criteria. Eligible participants were aged at least 18 years, able to attend all three 3-hour groups, willing and capable of talking in a group setting in English, did not have a florid or severe level of mental illness, identified as Aboriginal or Torres Strait Islander, had basic familiarity with computers, and were not currently employed as a health worker. Prospective participants provided demographic information and addressed the preceding criteria through an expression of interest form. The research team selected participants for maximum variation, aiming for even numbers of male/females and a wide range of ages.

Data Collection

Three focus groups were held in a period of one week in December 2014. The groups were facilitated by a female non-Indigenous researcher and a male Aboriginal researcher. Both facilitators have experience working with Aboriginal and Torres Strait Islander people with mental illness, one as a remote public service clinician and one as a mentor and e-mental health cotrainer. Each focus group started with a statement requesting confidentiality from group members, risk management strategies, a short introductory video, and a brief demonstration of how to use each app. Participants were then asked to use the apps individually (ibobbly) or in pairs (AIMhi). The difference in process reflected the different developer recommendations; the AIMhi app is a therapist-guided intervention, whereas the ibobbly app is designed as a self-driven tool. The sessions then reviewed participants' experiences of using the apps and factors they thought may influence acceptability. Participants were reimbursed for their time, transport, and other expenses by an AUS $80 shopping voucher per 3-hour session. Written informed consent for participation and voice recording was obtained from all research participants. The sessions were voice recorded and back-up field notes were taken, including researcher reflections and observations.

Data Analysis

The first author (JP) led the analysis in consultation with the Aboriginal researcher (PPJRM). Audio recordings were transcribed by the first author and data from all sources (transcripts, field notes) were entered into NVivo qualitative data analysis software version 10 (QSR International Pty Ltd). Initial inductive analysis identified emerging themes which were further refined through collaborative analysis between the first author and the Aboriginal researcher. This strengthened the authenticity of findings because the analysis process was informed by an Aboriginal perspective. A thematic map was developed and discussed within the research team. A member-checking group was run 5 months following the initial focus groups, involving three members of the initial groups. These members were selected because they varied in age and gender, showed interest and enthusiasm, and were available. Reimbursement was equivalent to the initial focus groups. The aim of the member-checking session was to review the thematic map and main findings with participants, who confirmed that these reflected their experiences and perspectives related to acceptability of the apps. It is likely data saturation was achieved given that the methodology chosen resulted in a dataset that was both rich (detailed and nuanced commentary) and thick (several hours of interactive discussion). Triangulation of data sources, coresearcher checking, and member-checking strategies were used to enhance the trustworthiness of the findings.

Results

Participants

Ten expressions of interest were received through four service providers. A total of nine people (3 male, 6 female) were accepted into the focus groups. One female was excluded to ensure more equal gender distribution. Ages ranged from 18 to 60 years with a mean age of 33 (SD 17) years. All participants identified as Aboriginal or Torres Strait Islander, resided in the local area, and identified English as the main language they spoke at home. Eight of 9 (88%) participants provided an email address, 7 of 9 (77%) identified they had access to the Internet at home, and 2 of 9 (22%) owned a mobile phone with Internet capability. Eight of 9 (88%) identified they were interested in the topic.

Nine participants attended the first focus group (100%), 8 attended the second (88%), and 6 attended the third (66%). The Aboriginal researcher was only able to attend the first group and member-checking group. Reasons given for nonattendance included funeral attendance, family, and work commitments.

Overview and Thematic Map

All participants expressed enthusiasm and optimism for the concept of an app and the progressiveness of improving mental health and well-being using apps:

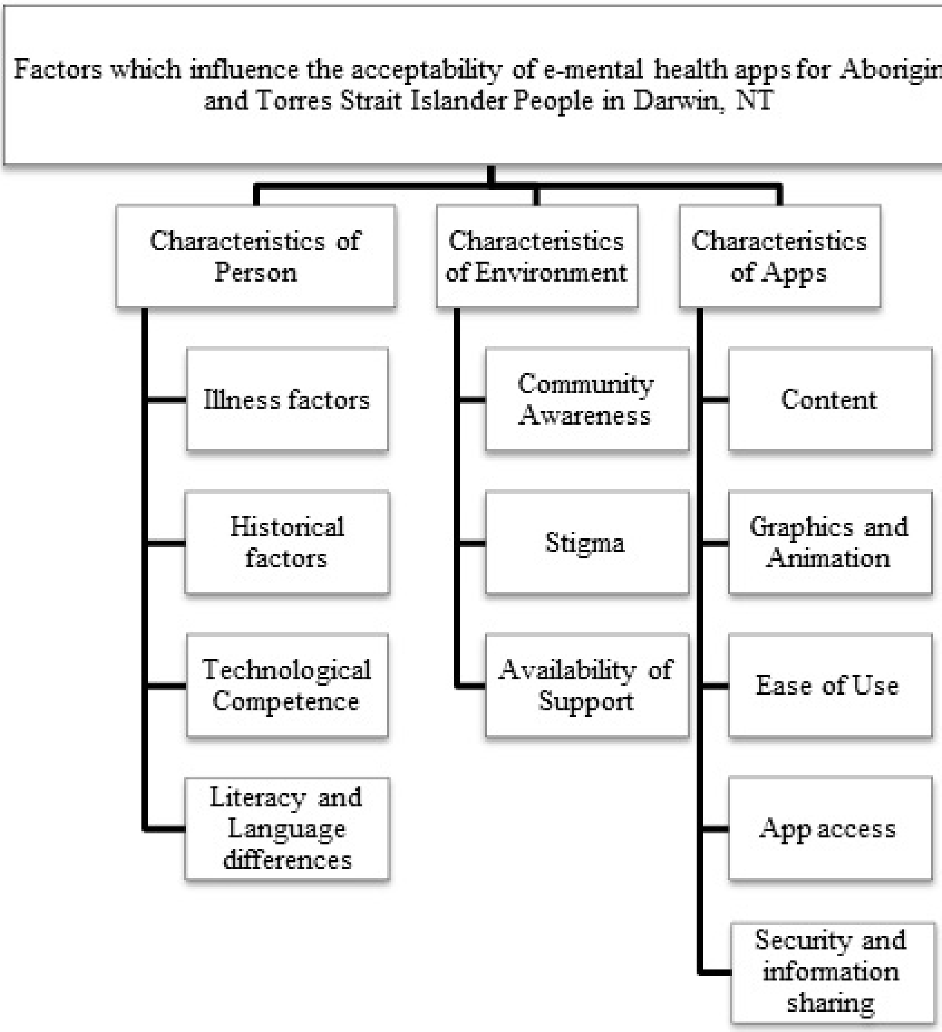
> *I like the app idea; I think it is fantastic, I think it is great to move with the times.* [56-year-old female]

Specific benefits identified were the opportunity to reach larger audiences, the ability to provide immediate access to help, ability for an individual to have greater independence, and the possibility of anonymity:

> *Just being able to intervene in a timely manner and help someone through their difficult struggle.* [60-year-old female]
>
> *I think for the individual it might be an increased level of independence and privacy. You know they can look at the app without having to speak to someone.* [50-year-old female]

Three main themes emerged related to the acceptability of e-mental health tools: factors related to the person, the environment, and the apps (see Figure 3).

Figure 3. Factors affecting acceptability of e-mental health apps for Aboriginal and Torres Strait Islander people in Darwin, NT.



Characteristics of Person

Illness factors, including a person’s awareness of their mental illness and motivation to change, were suggested as potential influences on help-seeking and app use:

> *...if they did have a mental illness, and they were not really aware of it, there would be no reason for them to use the app.* [60-year-old female]
>
> *It is just a matter of the motivation and like wanting to get better and everything.* [18-year-old female]

Both apps were considered to be most appropriate for people with less severe mental illnesses:

> *So it could be a good thing for people who have some minor mental health things to help them get along. If you have that there, like Stay Strong, that might help them or encourage them to overcome it. You know-that don’t have really serious mental health issues* [AIMhi, 50-year-old female]

Historical factors were seen to cause mental ill health and influence acceptability of the apps to participants. The negative impact of colonization on the well-being of Aboriginal and Torres Strait Islander people was highlighted in the discussion, along with uncertainty about the role of apps in addressing such concerns:

> *I am someone who can sit here and say, I have got a problem, with all that, and there are people who just do whatever to try and get out of it, because they can’t talk about it. I wanna go back to country, I want my song, I want my dance, I want my ceremony, I want my country, they can’t talk about it, and how does it happen. How does this help you deal with those type of things?* [AIMhi, 56-year-old female]

Two participants expressed a sense of helplessness in preventing suicide. This impacted on their perception of the utility of the apps:

> *Suicide though, suicide is a very different thing, to other things, it’s very different isn’t it, a state of mind, you know what questions could you ask someone who is in that state of mind.* [AIMhi, 56-year-old female]
>
> *You know it is a big claim calling it a suicide prevention app, maybe another name. Another term for that, I don’t think it is really going to prevent suicide; it is just a tool that someone can use, to go through their emotions and self-assess where they are at.* [ibobbly, 60-year-old female]

Technological competence was identified as influencing the acceptability of e-mental health apps. One older participant noted:

> *You know you got some young people who said, yeah it's pretty easy to use, and they are very more computer literate, and some older people that find it difficult to go back, it is across the board but you need to look at the app [AIMhi] to be user friendly I suppose.* [50-year-old female]

Literacy and language differences were identified by some participants as potential barriers to app use. Some participants stated that these tools may not be appropriate for their family in remote communities:

> *My people are from Alice Springs. So yeah, if it is like mob [Aboriginal people] that can't understand English language, they won't understand anything, you will have to teach them like pretty much everything I got taught at school.* [19-year-old male]

Characteristics of Environment

Community awareness of available e-mental health tools was reported to be very limited. Inclusion in the research increased participant's awareness:

> *I—on Wednesday—had no idea this existed. I did have a look on the website and seen a bit and thought, oh yeah that must be it.* [AIMhi, 50-year-old female]

Suggested strategies to overcome a lack of community awareness included promotion in schools, advertising in newspapers, local radio, television ads, and promotion in health centers by health professionals.

Community involvement in development was identified as important, with some participants questioning potential uptake in other communities:

> *I think it is great that it is the community who have pushed for the tool to be created; it will be interesting to see how it maps out in that community...I think there is a real need for it, especially that way [Northern WA] and here in the NT...And if it is successful in that community because the community made it, it would be interesting to see, you know sharing it with other areas.* [ibobbly, 30-year-old female]

Stigma was seen as a barrier for people accessing help:

> *Well we have to get that stigma out of the way. We have got to deal with that because that is one of the biggest problems and it is a very serious problem.* [60-year-old female]

One participant noted that apps have the potential to "get around shame job" (26-year-old male).

Availability of support was identified as an influence on uptake and effective use of e-mental health apps. Participants identified that the clinician-supported nature of the AIMhi app would mitigate some challenges related to motivation, literacy, and familiarity with technology. When asked if you need to know how to use an iPad to use the AIMhi app, one participant noted:

> *Not if you are working with a clinician. If you are doing it on your own you would have to have knowledge of how to use it.* [60-year-old female]

Suggestions for other ways of integrating apps into care pathways included their use as a screening tool, communication aid, immediate help option, self-help tool, or in conjunction with face-to-face help.

The need to link the apps to other supports, particularly emergency help, was also identified. The following are comments on the help box on the ibobbly app:

> *I think it is good that it is there.* [18-year-old female]
>
> *Yeah if someone has access to a phone, they can talk to someone. But yeah, it's not human, the question, it's not like someone is actually asking it. If someone was actually asking it, it would be more meaningful.* [19-year-old male]

Online videoconferencing, instant messenger, and websites were suggested as alternatives and participants felt these could provide a personal touch that may improve outcomes. Participants discussed potential constraints regarding availability of these services due to credit, Internet, or phone access, and suggested any recommended services needed to be free to access from mobile phones.

Characteristics of Apps

Ease of use was identified as a main factor in facilitating engagement with the apps. Participants who found the apps hard to navigate were less likely to use the app or recommend it to others:

> *Yeah I don't know, this is my opinion and everyone is entitled to their opinion, but I don't see it working—no. Not for any age group. But that is just my thing. I got totally lost, totally confused.* [ibobbly, 56-year-old female]

Recommendations included clear navigation buttons, a home page or "dashboard" which is easily understood, and the use of checklists or clearly marked progress bars to indicate progress through the apps.

Content gaps discussed (in one or other of the apps) included colonization, intergenerational trauma, identity, methamphetamines, cyberbullying, and the influence of peers. Participants recommended additions to the apps to prompt consideration of these topics.

Participants also identified the need for the apps to have a clear and purposeful journey, where individuals were virtually supported through a journey or story which was relevant to them and ended with resolution:

> *I thought it would take me on a journey, but I didn't see that at all. You know what is your problem, how can we help, what can you do, but I didn't feel that* [ibobbly, 56-year-old female]

Participants recommended approaches that allowed clients to define their own problems and solutions:

> *If you word it so people feel comfortable, so I am going to put that in, but only if they are invited, only if they want to say more about themselves, not preaching, not dictating...* [56-year-old female]

Clear, concise, and relevant language were acknowledged as important. Words that could be difficult to understand needed to be supported by explanations or short video clips, as discussed in the following example in reference to the word "resilience" within ibobbly:

> *I only really in the last couple of years, found out what resilience means...I sorta relate it to, when I am working and like stressed out; I say my resilience is low, whereas when I am going with the flow I am very resilient. Is that what it means?...Maybe if you have a breakdown of someone giving an example of a particular word.* [30-year-old female]

The inclusion of Aboriginal and Torres Strait Islander languages was considered to enhance engagement and understanding:

> *Some people might want to use their own language instead of saying "deadly." It would be ideally, pie-in-the-sky dreaming, that your language comes up, or you write it in, instead of "deadly" like "manymak" or "gumul."* [ibobbly, 56-year-old female]

Graphics and animation were perceived as supporting motivation. Culturally relevant graphics, voices, animation, and optional short video clips may assist in engagement with the content, improve understanding, and overcome literacy issues. Recognizing the diversity of Aboriginal and Torres Strait Islander communities, participants identified the need for regionally specific graphics or language to be described including meanings and interpretations to aid wider acceptability.

Some participants were concerned the metaphors could be interpreted differently by people with low literacy or had concern about the degree to which the metaphors aligned with user interests (eg, only related to males when a football analogy was used to introduce goal setting in the AIMhi app). Modifications suggested included personalization of the graphics and metaphors to enhance relatability.

App access was deemed to be improved by availability, not only on tablet devices, but also on all brands of mobile phones. Cost was perceived to negatively influence access and could be addressed through free download of e-mental health apps for individuals and the option of offline use once downloaded to preserve credit.

Security and information sharing was not discussed by participants until prompted by the facilitators. There was some concern expressed about storage of personal health information on the Internet. However, most participants noted that other personal information being seen would concern them more than information on either app:

> *Wouldn't bother me at all, photos and messages and emails and things would bother me more.* [60-year-old female]

Password protection and the ability to share app information with health professionals and personal electronic heath records were also considered important. One participant suggested that the collection of statistics for service planning would be a logical inclusion in any e-mental health tool:

> *Well I think that is. Not names, just information. I think it is necessary isn't it. Isn't that the whole idea?* [60-year-old female]

Discussion

Principal Results

This is one of the first studies to explore the factors that influence acceptability of e-mental health apps for Aboriginal and Torres Strait Islander community members. This study identifies characteristics of person, environment, and e-mental health apps that influence acceptability. Although no other technology acceptance models currently exist which focus on e-mental health or are tailored to an Indigenous population, our findings have similarities to the Health Information Technology Acceptance Model [27]. This model identifies similar attributes of person, community, and technology (e-tool) as influences on the acceptability and uptake of health information technology.

Personal characteristics reported by our participants to influence acceptability include illness factors (severity of illness, motivation to change, awareness of mental illness), historical factors, technological competence, and literacy and language differences. Our participants' perceptions that e-mental health approaches are more acceptable for people with less severe mental illnesses are consistent with a similar belief that is widely held by health professionals and community members alike [16,22]. However, others have found e-mental health treatment may also be acceptable for people with more severe longstanding illnesses than often assumed [28]. Therefore, further research is warranted to examine e-mental health tool acceptability for Aboriginal and Torres Strait Islander people with more severe illnesses.

The possession of the skills necessary to make full use of e-mental health tools affects their uptake and adherence [29]. In addition, limited instruction, technological issues, inexperience with mobile Internet browsing, and a lack of motivation have been reasons identified for discontinuation [14]. In line with these findings, participants in this study reported motivation, technological competence, and literacy and language differences as likely to influence acceptability. Participants perceived that apps have broad applicability to people of all ages and varied skill groups, provided they were suited to the target audience. For some Aboriginal and Torres Strait Islander people, English is not spoken at home and English literacy may not be attained through formal education [30]. Aboriginal and Torres Strait Islander people may also have less access to technology than non-Indigenous Australians [17]; therefore, specific app adaptations responding to the needs of the target group will aid uptake.

Within our study, environmental characteristics perceived to impact uptake included community awareness, stigma, and availability of support. The ability to successfully navigate the apps was a direct influence on our participants' perception of the content, perceived journey, and overall experience. Importantly, when support was given either by the facilitators or other group members, participants' experiences improved. This offers insight into the potential role friends and family could play in supporting e-mental health tool use in a community setting. Participants suggested that clinician support, which includes Aboriginal Health Workers and primary health care workers, may overcome barriers related to limited English literacy, limited ability with technology, and/or motivation. Other studies have found that introduction of e-mental health tools in a structured environment (eg, schools) or with therapist support, enhance adherence [29,31]. The intention of e-mental health tools is not to replace face-to-face services, rather to complement or offer alternative treatment options for people wanting to access mental health care [9]. Our findings support this goal with participants identifying a clear preference for e-mental health apps to integrate with established treatment pathways rather than as stand-alone interventions.

Our participants identified community involvement in development as a good strategy for improving acceptability, adherence, and uptake of e-mental health apps in a location specific community. This accords with the findings of others and strengthens the evidence for collaborative development of eHealth tools [20,21]. Recognizing the diversity of Aboriginal and Torres Strait Islander communities, our participants identified the need for regionally specific graphics or language to be described, including meanings and interpretations to improve acceptability in other parts of Australia. Such adaptations are particularly relevant given the potentially nationwide availability of e-mental health apps through Internet sharing.

The importance of app design and characteristics should not be underestimated. E-mental health programs need to be attractive to the user and present themselves as a good match to the person's needs [29]. Others have found that relevant and interesting content and flexible accessibility were reasons identified for initiating and continuing use of e-mental health programs [14]. In keeping with these findings, our participants highlighted the need for apps to be easy to use, contain relevant content and instructions on navigation, have culturally relevant language and graphics, incorporate a clear purposeful journey ending in resolution, include options to support people with language differences, and allow for offline use and password protection. Incorporation of Aboriginal Languages was considered to enhance engagement. Participants highlighted the potential barriers of developing apps in every Aboriginal language and, therefore, suggested alternative ways to incorporate language, such as options for voice recording/playback and text box entry.

Security is considered by many to be "paramount and drive all other considerations" when designing interventions [14,23,32]. In contrast, our participants expressed concern about security only when prompted and felt dissemination of other information stored on their phones (eg, emails, photos) would cause greater concern than information stored on either app. This could partly be attributable to the apps themselves because neither stores personal details (full name, date of birth, contact details). Participants felt that password protection was important, but needed to be balanced with usability because some found the regular inputting of passwords inhibited flow and interest. Others have received similar feedback supporting the need for careful consideration of the balance between security and usability [33].

Our participants considered that lack of compatibility across devices (mobile phone/tablet) and platforms (Apple or Android), high data charges, and limited mobile coverage could be barriers to use. Others have identified similar barriers; however, they suggested that with targeted investment in increasing mobile networks, decreasing usage costs, and increases in technology, these issues may become redundant [14]. Nevertheless, given that rural and remote regions where Aboriginal and Torres Strait Islander people often reside tend to lag behind in terms of such advances [34], such considerations are particularly important in the design of culturally responsive tools.

Limitations

The size of this study was small with only nine participants drawn from one location. Five of nine participants and the Aboriginal researcher knew one another before being included in the groups. This occurred by chance and did not appear to impact on participant's willingness to express their views. Nevertheless, the purposive selection process (targeting those with fluency in English and established computer literacy) may have introduced bias resulting in a group more likely to favor the acceptability of these tools.

Three members of the research team were involved in the development of the AIMhi app, including the Aboriginal researcher, thus introducing another potential source of bias toward acceptability. Finally, three of the nine participants were not within the target age range for the ibobbly app (18-35 years) suggesting that comments relating to acceptability of this app need to be interpreted with caution. Despite these limitations, the study allowed active participation by all participants who presented a range of perspectives that have not yet been heard in relation to current innovations in technology and mental health.

Conclusions

E-mental health apps could be an acceptable way of enhancing services to Aboriginal and Torres Strait Islander people through attention to design that incorporates local community perspectives and thoughtful adaptation according to the target group. Further research with Aboriginal and Torres Strait Islander people to explore effectiveness of e-mental health tools is needed, particularly with a broader target population that recognizes diversity of culture and considers variations in literacy, language, background, and type of well-being concern.

E-mental health tools represent an opportunity to promote mental health awareness, to enhance early intervention strategies, and to promote access to evidence-based treatment. When designed to meet the needs of Aboriginal and Torres Strait Islander people, e-mental health tools add an important element to public health approaches aimed to improve the mental health and well-being of Aboriginal and Torres Strait Islander Australians.

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Conflicts of Interest

None declared.

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Abbreviations

AIMhi: Australian Integrated Mental Health Initiative
CBT: cognitive behavioral therapy
eMHPrac: e-mental health in practice
NT: Northern Territory
RCT: randomized controlled trial
WA: Western Australia

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Original Paper

An Online Intervention for Co-Occurring Depression and Problematic Alcohol Use in Young People: Primary Outcomes From a Randomized Controlled Trial

Mark Deady[1], PhD; Katherine L Mills[1], PhD; Maree Teesson[1], PhD; Frances Kay-Lambkin[1,2], PhD

[1]National Health and Medical Research Council Centre for Research Excellence in Mental Health and Substance Use, National Drug and Alcohol Research Centre, Kensington, Australia

[2]The University of Newcastle, Priority Research Centre for Translational Neuroscience and Mental Health, Callaghan, Australia

Corresponding Author:
Mark Deady, PhD
National Health and Medical Research Council Centre for Research Excellence in Mental Health and Substance Use
National Drug and Alcohol Research Centre
University of New South Wales
Kensington, 2052
Australia
Phone: 61 293850320
Fax: 61 293850222
Email: m.deady@unsw.edu.au

Abstract

Background: Depression and problematic alcohol use represent two of the major causes of disease burden in young adults. These conditions frequently co-occur and this is associated with increased harm and poorer outcomes than either disorder in isolation. Integrated treatments have been shown to be effective; however, there remains a significant gap between those in need of treatment and those receiving it. The increased availability of eHealth programs presents a unique opportunity to treat these conditions.

Objective: This study aimed to evaluate the feasibility and preliminary efficacy of an automated Web-based self-help intervention (DEAL Project) in treating co-occurring depressive symptoms and problematic alcohol use in young people.

Methods: Young people (aged 18 to 25 years) with moderate depression symptoms and drinking at hazardous levels (recruited largely via social media) were randomly allocated to the DEAL Project (n=60) or a Web-based attention-control condition (HealthWatch; n=44). The trial consisted of a 4-week intervention phase with follow-up assessment at posttreatment and at 3 and 6 months postbaseline. The primary outcomes were change in depression severity according to the Patient Health Questionnaire-9 as well as quantity and frequency of alcohol use (TOT-AL).

Results: The DEAL Project was associated with statistically significant improvement in depression symptom severity (d=0.71) and reductions in alcohol use quantity (d=0.99) and frequency (d=0.76) in the short term compared to the control group. At 6-month follow-up, the improvements in the intervention group were maintained; however, the differences between the intervention and control groups were no longer statistically significant, such that between-group effects were in the small to moderate range at 6 months (depression symptoms: d=0.39; alcohol quantity: d=–0.09; alcohol frequency: d=0.24).

Conclusions: Overall, the DEAL Project was associated with more rapid improvement in both depression symptoms and alcohol use outcomes in young people with these co-occurring conditions relative to an attention-control condition. However, long-term outcomes are less clear.

Trial Registration: Australian New Zealand Clinical Trials Registry (ANZCTR): ACTRN12613000033741; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=363461 (Archived by WebCite at http://www.webcitation.org/6fpsLEGOy)

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KEYWORDS

depression; alcohol use, alcohol abuse, problem drinking; young people at risk populations; Internet; intervention online therapy, eHealth; comorbidity

Introduction

Major depressive disorder and alcohol use disorders are two of the top five leading causes of years of life lost to disability in the developed world [1] with young people bearing a disproportionately large share of the burden [2]. Early intervention is imperative to averting the development of more severe, ingrained morbidity [3], yet less than 25% of affected young Australians access traditional health services in a 12-month period [4]. Comorbidity across the disorder classes is common [5] and is associated with considerable adverse outcomes [6,7]. Furthermore, young people with mental health issues rate "'coping" as a key motive for substance use [8] with comorbid disorders often maintaining and exacerbating one another [9]. Thus, there is increasing support for integrated approaches to comorbidity treatment [10,11]. Baker and colleagues [12] have demonstrated that concurrent treatment of depression and problem drinking is more effective than treating either condition alone and more effective than general counseling.

The advantages of Web-based interventions, including flexibility, anonymity, and accessibility, appear particularly useful for individuals who are less likely to access traditional services, such as young people [13]. Web-based depression and alcohol interventions have been shown to produce effect sizes equivalent to those of traditional face-to-face therapy (0.28-0.78, 0.22-0.48) [13-21], although it has been argued that this is dependent on therapist guidance; generally, interventions with little or no therapist guidance have significantly smaller treatment effect sizes [22]. Nevertheless, guided interventions are not as cost-effective to disseminate, perhaps limiting their ability to overcome traditional barriers to treatment access, particularly among young people [23]. So far, there are no youth-focused Web-based interventions reported in the research literature for individuals experiencing both depressive and alcohol problems. Furthermore, in the general population only one computerized intervention targeting both of these disorders has been evaluated: Self-Help for Alcohol/other drug use and Depression (SHADE) [24,25]. Evaluations of SHADE indicate electronic forms of treatment for co-occurring disorders are viable and effective, especially when combined with brief therapist guidance. Two randomized controlled trials (RCTs) have found SHADE plus therapist guidance to be associated with equivalent outcomes to those achieved by therapist-delivered treatment, with superior results as far as reducing alcohol consumption over 3 and 12 months [24,25]. The only other study of this kind examined the use of a single session of online personalized feedback and psychoeducation provided to college students; as such, it was not specifically a youth-focused intervention [26]. The study compared alcohol feedback only, depressed mood feedback only, integrated feedback, and an assessment-only condition. At 1-month follow-up, no differences in depressed mood or alcohol use were found across the conditions; however, moderator effects were present, with the interventions being more effective than controls for those with less severe baseline symptoms.

In response to this gap in evidence-based programs for depressive and alcohol problems among young people, we developed the DEpression-ALcohol (DEAL) Project, a brief, Web-based intervention for young people aged 18 to 25 years based on the SHADE program. Because the program is a self-help intervention, it is primarily aimed at those with moderate symptomatology who may not reach diagnostic cut-offs for disorders but are, nonetheless, experiencing distress and would benefit from early intervention. Such conditions have been associated with substantial impairment [27-29], particularly in young people [30]; these conditions have been shown to escalate into full alcohol use disorder in 17.0% to 38.2% of cases within 5 years [31-33] and full major depressive disorder in 10% to 25% of patients with minor depression within 3 years [27,34].

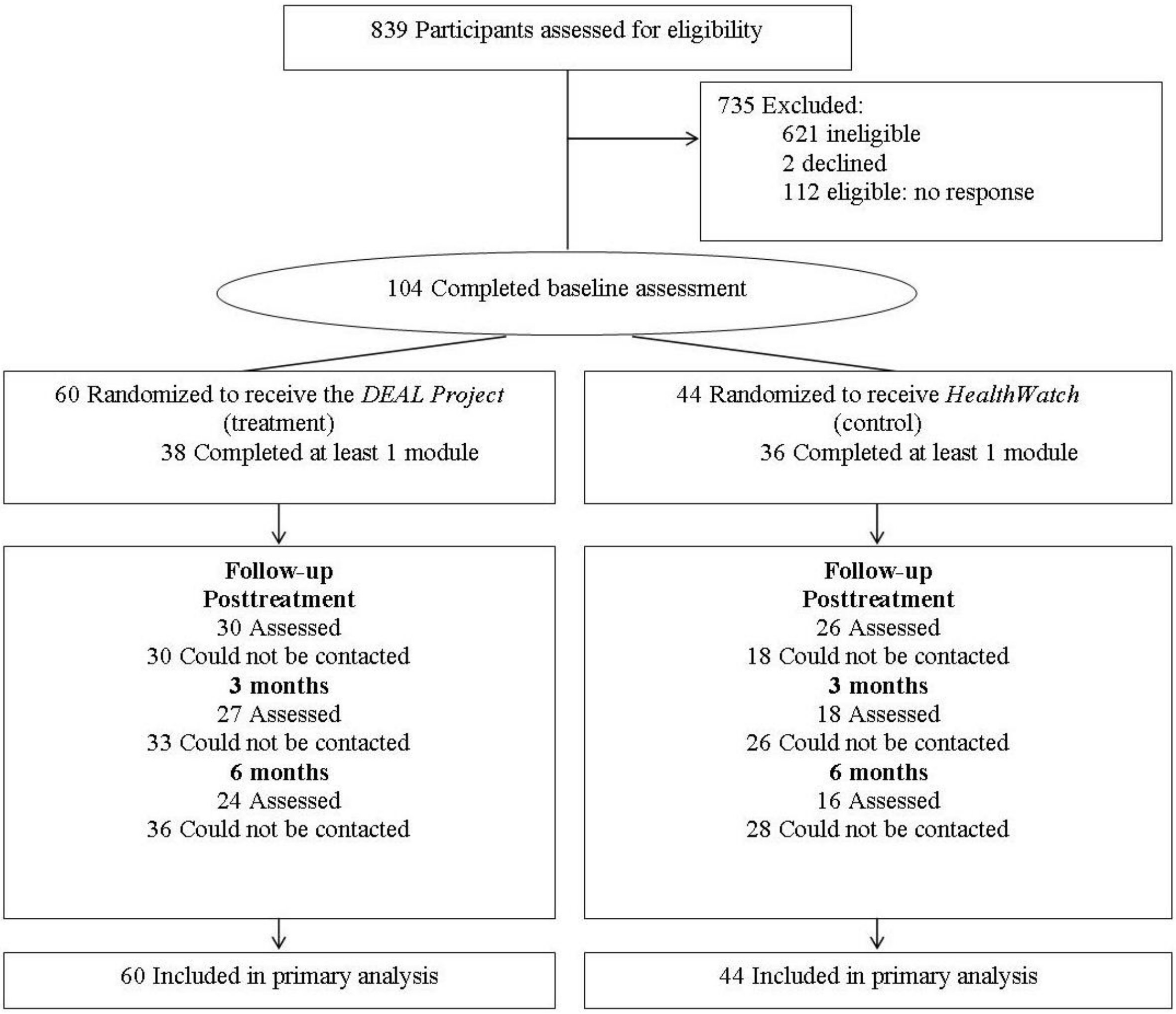
The primary aim of this study was to evaluate the feasibility and preliminary efficacy of the DEAL Project and compare outcomes relative to an attention-control condition (HealthWatch) in a RCT. Specifically, this study aimed to determine whether (1) the DEAL Project produces significantly greater pre- to posttreatment reductions in severity of depression symptoms as well as quantity and frequency of alcohol use relative to HealthWatch and (2) changes observed from pre- to posttreatment are maintained through to 6 months postbaseline.

Methods

Study Design

The study design and flow of participants is shown in Figure 1. Ethical approval was obtained from the University of New South Wales Human Research Ethics Committee and consent was obtained electronically from all participants. The study was conducted entirely online with all contact occurring via automated emails. Following online screening, eligible participants were asked to provide informed consent in order to take part and were randomized to one of two conditions delivered over four weekly sessions: (1) the DEAL Project or (2) HealthWatch. Access to the website for each of the programs was for a period of 10 weeks from the point of randomization. Randomization was automated within the online program; therefore, the trial researcher was blind to randomization. This process occurred immediately after the eligibility screener, consent form, and baseline assessment were completed. Block randomization was conducted with a 1:1 ratio; however, due to a programming error (which included test users within the blocks), a group imbalance occurred resulting in 60 participants being randomized to the DEAL Project and 44 randomized to HealthWatch. Participants then completed a baseline assessment on entry to the study and follow-up assessments at posttreatment (5 weeks), and at 3 and 6 months postbaseline.

Figure 1. Flow of participants through study.



Recruitment

Recruitment took place between July 2013 and February 2014 using extensive media coverage across Australia, including tertiary institution flyers and street press, radio and newspaper stories, treatment services websites, and paid Facebook and Google advertisements. Individuals were eligible for the study if they (1) were aged 18 to 25 years, (2) reported current moderate depression symptomology (score of ≥7 on the Depression Anxiety Stress Scale [DASS-21-Depression]) [35], (3) were drinking at hazardous levels as measured by the Alcohol Use Disorders Identification Test (AUDIT; score of ≥8) [36], (4) had the ability to access the Internet (either in the private residence of the participant or willingness to use the public library/other suitable venue with Internet access), and (5) were Australian residents. Exclusion criteria included (1) a Psychosis Screener score ≥3 [37], (2) an inability to speak English, (3) serious risk of suicide in the past 2 weeks (serious thoughts of suicide and desire to act), and (4) daily use of cannabis/weekly use of amphetamines.

Interventions

The DEAL Project

The DEAL Project [38] consists of four 1-hour modules to be completed over a 4-week period (homework is provided at the conclusion of each module and reviewed at the beginning of the subsequent module). The website tracked participants' completion of each weekly module, with automated email reminders sent to participants' nominated email addresses. As mentioned, the program is based on the SHADE program, which consists of evidence-based cognitive behavioral therapy and motivational interviewing. The modules were as follows:

1. Week 1: Where Are You At? Psychoeducation, assessment, goal setting, mood/activity/alcohol use monitoring (homework: mood/drinking monitoring).
2. Week 2: Getting Moving Again. Behavioral activation, decisional balance (alcohol use), behavior change, activity scheduling (homework: activity planning).
3. Week 3: Taking Charge of your Thoughts. Mood monitoring, cognitive restructuring (homework: thought monitoring).

4. Week 4: Coping with Tough Situations. Mindfulness and relaxation, problem solving, drink reduction and refusal, relapse planning and management (mindfulness/relaxation, problem-solving exercises).

HealthWatch

HealthWatch is a 12-module attention-control condition first developed for the Australian National University WellBeing Study [39] in which participants read information about various health concerns and complete accompanying surveys. The purpose of this condition was to control for time spent interacting with an online program. Four modules deemed to be most relevant to younger people were selected to act as the attention control in this study: environmental health, physical and mental activity, nutrition, and relationships. These were redesigned to match the DEAL Project in appearance.

Assessment and Outcome Measures

A structured online assessment was conducted at each of the four assessment time points. Primary outcomes were (1) depressed mood as measured by the Patient Health Questionnaire-9 (PHQ-9) [40] and (2) quantity and frequency of alcohol use as measured by the TOT-AL [41]. The PHQ-9 is a reliable and valid brief measure of depression severity over the past 2 weeks [42]. The self-report measure utilizes a 4-point Likert scale ranging from 0 (not at all) to 3 (nearly every day). Total scores range from 0 to 27. Scores ≤4 are considered to represent minimal depression, scores 5-9 are considered mild, 10-14 are considered moderate, 16-19 are considered moderately severe, and scores ≥20 are considered indicative of severe depression. The TOT-AL has been found to be a reliable and valid online measure of alcohol consumption [41]. The tool uses a dropdown menu of type, brand, and size of beverages consumed each day for the past week. The TOT-AL calculates the cumulative unit content of the drinks consumed over the previous 7 days (1 unit=approximately 8 g ethanol) to generate an overall consumption score (drinks per week) and frequency score (drinking days per week).

Automatic email prompts to complete online follow-up assessments were sent to participants at baseline, posttreatment (5 weeks), and 3 and 6 months postbaseline. Reminder emails were sent if the participant did not complete an assessment within 6 days (three emails per assessment in total). On completion of assessments, participants received an AU $10 iTunes voucher as reimbursement for time.

Data Analysis

Sample Size Calculation

Power analysis on the primary outcome variables was conducted using Power Analysis and Sample Size Software (PASS) [43]. Taking into account sample attrition, the sample size had 92.9% power to detect a 5-point time-averaged difference between groups (SD 6.80) on the PHQ-9 at $\alpha<.05$ (large effect). There was 75.7% power to detect a time-averaged difference between groups of three drinks per drinking day (SD 5.89) at $\alpha<.05$. A 5-point difference on the PHQ-9 was chosen because this was considered to be clinically significant [44]. No clinical indicators were available for the TOT-AL, but three drinks per drinking day was considered substantial enough to be significant at a public health level.

Statistical Analysis

Data were analyzed using PASW Statistics 18 for Windows (release 18.0.0) [45]. Baseline differences between groups were examined using chi-square (using Yates continuity correction in 2×2 tables to avoid overestimation) and independent-samples *t* tests.

Analysis of outcomes was undertaken based on intention to treat using a series of generalized estimating equations (GEE) [46]. Baseline scores were modeled and controlled for in the GEE analysis. Linear and negative binomial (with log link) GEE were used to examine outcomes with normal and count distributions, respectively. An exchangeable correlation structure was used for all models. An interaction term for the intervention variable and time (group × time) was included in each model to test for differential change over time. When this interaction was nonsignificant ($P\geq.05$), it was removed from the model and the analysis was rerun. Alpha was set at .05 and a least significant difference method was used for pairwise comparisons. Results are reported as the unstandardized mean difference (beta) with Wald-type 95% confidence interval (95% CI) and chi-square for linear models and the risk ratio (RR) with 95% CI for negative binomial models. Furthermore, standardized effect sizes (Cohen’s *d*) were calculated for the primary outcomes [47].

Sample Retention and Missing Data

The follow-up rates at posttreatment and at 3 and 6 months postbaseline were 53.8% (56/104), 43.3% (45/104), and 38.5% (40/104), respectively. Those who completed follow-up assessments were consistently more likely to have completed a session ($\chi^2_1=15.3$, $P<.001$), seen a psychologist in past year at baseline ($\chi^2_1=5.3$, $P=.02$), and were less likely to be a smoker ($\chi^2_1=5.1$, $P=.02$). Importantly, attrition was not related to treatment allocation or any of the outcome variables of interest.

Missing data analysis revealed 35.79% (2866/8008) missing data across all follow-up assessments. According to the results of Little’s missing completely at random test [48], the data could be considered to be missing completely at random ($\chi^2_{711}=652.5$, $P=.94$).

Results

Participant Characteristics

The sample consisted of 104 participants (female: 59.6%, 62/104) with a mean age of 21.74 (SD 2.22) years. The mean PHQ-9 score was 16.32 (SD 5.00) and the mean AUDIT score was 17.39 (SD 6.42). Drinking quantities and frequencies were positively skewed with a median of 15.20 standard alcoholic drinks per week (range 0-97) consumed over a median of 2.00 drinking days per week (range 0-7). There were no statistically significant differences between the groups on baseline characteristics (Table 1).

Table 1. Participant characteristics by group.

Demographics	DEAL Project treatment (n=60)	HealthWatch control (n=44)	Total (N=104)	t_{102}	χ^2 (*df*)	*P*
Age (years), mean (SD)	21.85 (2.32)	21.59 (2.08)	21.74 (2.22)	0.59		.56
Sex (female), n (%)	36 (60)	26 (59)	62 (60)		0.0 (1)	>.99
Rural, n (%)	5 (8)	8 (18)	13 (13)		1.4 (1)	.23
Completed secondary school, n (%)	52 (87)	33 (75)	85 (82)		0.2 (1)	.21
Postschool qualifications, n (%)					3.7 (2)	.15
No postschool	11 (18)	15 (34)	26 (25.0)			
TAFE student/graduate	12 (20)	9 (20)	21 (20)			
University student/graduate	37 (68)	20 (45)	57 (55)			
Employment, n (%)					1.8 (2)	.40
Unemployed	7 (12)	4 (9)	11 (11)			
Full/part time employment	42 (70)	27 (61)	69 (66)			
Student	11 (18)	13 (30)	24 (23)			
Mental health treatment in past year, n (%)						
GP	33 (55)	28 (64)	61 (59)		0.47 (1)	.49
Psychologist	19 (32)	14 (32)	33 (32)		3.19 (1)	.07
Psychiatrist	21 (35)	24 (55)	45 (43)		0.00 (1)	>.99
Other mental health worker	5 (8)	10 (23)	15 (14)		3.17 (1)	.08
Alcohol/drug worker	1 (2)	5 (11)	6 (6)		2.79 (1)	.09
Medication, n (%)	17 (28)	14 (31.8)	31 (30)		0.03 (1)	.87
Doubtful about computer therapy, n (%)	29 (48)	22 (50)	51 (49)		0.00 (1)	>.99
Borderline symptoms (MSI-BPD), mean (SD)	5.80 (2.41)	6.50 (2.02)	6.10 (2.27)	0.59		.56
Depression						
Likely MDD diagnosis (PHQ-9), n (%)	35 (58)	21 (48)	56 (54)		0.76 (1)	.38
Likely other depressive diagnosis, n (%)	8 (13)	5 (11)	13 (13)		0.00 (1)	>.99
Alcohol in past 12 months						
≥1 alcohol abuse criteria met, n (%)	39 (65)	29 (66)	68 (66)		0.00 (1)	>.99
≥3 alcohol dependence criteria met, n (%)	50 (83)	35 (80)	85 (82)		0.06 (1)	.81
AUDIT, mean (SD)	17.02 (6.19)	17.89 (6.76)	17.38 (6.42)	–0.68		.50
Smoker, n (%)	17 (28)	17 (39)	34 (33)		0.80 (1)	.37
Drug use in past month, n (%)						
Cannabis	16 (27)	9 (20)	25 (24)		0.25 (1)	.62
Stimulants	7 (12)	7 (16)	14 (13)		0.11 (1)	.74
Other illicit drugs	3 (5)	2 (5)	5 (5)		0.00 (1)	>.99

Treatment Retention

Compared to those in the control group, those in the treatment group attended fewer sessions (t_{102}=–3.14, *P*=.002). The treatment group completed a mean of 1.50 sessions (SD 1.53), whereas the control group fully completed mean 2.50 sessions (SD 1.69). Overall, 68.3% (71/104) of the sample completed at least one module (treatment: 60.0%, 36/60; control: 79.5%, 21/44). This figure did not statistically differ significantly between groups (χ^2_1=3.4, *P*=.07). In both groups, missing data at follow-up was associated with fewer modules completed (posttreatment: χ^2_4=263.7, *P*<.001; 3 month: χ^2_4=82.5, *P*<.001; 6 month: χ^2_4=102.6, *P*<.001).

Service Use

At each time point, participants reported their use of a range of services for mental health treatment (medication, psychologist, alcohol and drug worker, psychiatrist, general practitioner, other health professional). Although those in the control condition were consistently more likely to use services for mental health problems over the 6-month follow-up, there was no difference in service use over the course of the trial (χ^2_1=3.6, *P*=.55).

Treatment Outcomes

Primary Depression Outcomes

There were no statistically significant differences between the groups on PHQ-9 scores at baseline (see Table 2). There was a statistically significant group × time interaction in relation to depression symptom severity (χ^2_3=11.5, *P*=.009), indicating that the treatment and control groups differed on PHQ-9 scores over time. As shown in Table 2, the treatment group demonstrated a statistically significant reduction in symptom severity from baseline to posttreatment follow-up (beta=–5.94, 95% CI –8.18 to –3.70; *P*<.001), representing a large effect (*d*=1.09). The change in control group PHQ-9 scores over this time was small (*d*=0.18) and not statistically significant (beta=–1.43, 95% CI –3.46 to 0.60; *P*=.17). Overall, the degree of improvement in depression symptom severity between baseline and posttreatment follow-up was 4.51 points greater in the treatment group compared to the control group and the treatment group reported significantly better depression scores relative to control at posttreatment follow-up (beta=–3.89, 95% CI –7.09 to –0.68; *d*=0.71).

The reduction in severity of depression observed for the treatment group persisted from posttreatment to 3-month follow-up (beta=0.01, 95%CI –2.52 to 2.53; *P* <.99) and from the 3- to 6-month follow-ups (beta= –1.59, 95% CI –1.38 to 4.57; *P*=.29; i.e, no statistically significant change). The control group demonstrated a statistically significant reduction in depression symptoms between posttreatment and 3-month follow-up (beta = –2.78, 95% CI –5.33 to 0.23; *P*=.03) that persisted to the 6-month follow-up (beta= –0.61, 95% CI –2.83 to 1.60; *P*=.59).

There was no statistically significant difference in depression scores between groups at either the 3- (beta =–1.10, 95% CI –5.10 to 2.90; *P*=.59; *d*=0.15) or 6-month follow-ups (beta=–2.08, 95% CI –6.45 to 2.29; *P*=.35; *d*=0.39). The within-group effect between baseline and 3-month follow-up for the treatment group was *d*=0.96 and *d*=0.67 for the control group. The within-group effect between baseline and 6-month follow-up was *d*=1.42 for the treatment group and *d*=0.78 for the control group.

Primary Alcohol Outcomes

Drinks Per Week

There was no difference at baseline between the groups for alcohol use quantity as measured by the TOT-AL (see Table 3). There was a statistically significant group × time interaction in relation to number of standard drinks per week (χ^2_3=9.3, *P*=.03). As shown in Table 3, the treatment group demonstrated a significant reduction in drinks per week from baseline to posttreatment follow-up (RR=0.46, 95% CI 0.32-0.65; *P*<.001) representing a large effect (*d*=1.07). The change in drinks per week in the control group over this time was small (*d*=0.03) and not statistically significant (RR=0.97, 95% CI 0.67-1.41; *P*=.88). Overall, the treatment group reported a two-fold greater reduction in standard drinks consumed per week between baseline and posttreatment follow-up compared to the control group (RR=2.13, 95% CI 1.28-3.54; *P*=.02). Consequently, the treatment group reported statistically significantly fewer drinks per week relative to control at posttreatment follow-up (RR=0.62, 95% CI 0.39-1.00; *P*=.05).

Table 2. Unadjusted comparisons between conditions on Patient Health Questionnaire-9.

Time point	DEAL Project			HealthWatch			Between-group difference			
	Mean (95% CI)	Change from t0 (95% CI)	*P*	Mean (95% CI)	Change from t0 (95% CI)	*P*	Mean (95% CI)	*P*	Change from t0 (95% CI)	*P*
t0	16.58 (15.42, 17.75)	—		15.95 (14.36, 17.54)	—		0.63 (–1.34, 2.60)		—	.53
t1	10.64 (8.31, 12.97)	–5.94 (–8.18, –3.70)	<.001	14.53 (12.33, 16.73)	–1.43 (–3.46, 0.60)	.17	–3.89 (–7.09, –0.68)	.02	4.51 (1.49, 7.54)	.003
t2	10.65 (7.99, 13.31)	–5.93 (–8.53, –3.37)	<.001	11.75 (8.76, 14.74)	–4.21 (–7.27, –1.15)	.01	–1.10 (–5.10, 2.90)	.59	–1.73 (–5.74, 2.29)	.40
t3	9.05 (6.21, 11.90)	–7.53 (–10.51, –4.55)	<.001	11.14 (7.82, 14.45)	–4.82 (–8.28, 1.36)	.01	–2.08 (–6.45, 2.26)	.35	–2.71 (–7.28, 1.86)	.24

Table 3. Unadjusted comparisons between conditions on TOT-AL.

Time point	DEAL Project			HealthWatch			Between-group differences, RR (95% CI)			
	Mean (95% CI)	RR[a] (95% CI)	*P*	Mean (95% CI)	RR[a] (95% CI)	*P*	At each time point	*P*	From t0	*P*
Drinks per week										
t0	25.65 (19.52-33.71)	—		19.43 (14.02-26.93)	—		1.32 (1.16-2.02)		—	
t1	11.72 (8.11-16.93)	0.46 (0.32-0.65)	<.001	18.89 (14.00-25.52)	0.97 (0.67-1.41)	.88	0.62 (0.39-1.00)	.05	2.13 (1.28-3.54)	.02
t2	9.79 (4.66-20.54)	0.38 (0.19-0.76)	.006	12.96 (7.65-21.96)	0.67 (0.37-1.22)	.19	0.76 (0.30-1.88)	.55	1.75 (0.70-4.73)	.23
t3	15.81 (9.89-25.27)	0.62 (0.41-0.93)	.02	15.97 (9.87-25.84)	0.82 (0.47-1.42)	.48	0.99 (0.51-1.94)	.98	1.33 (0.67-2.65)	.41
Drinking days per week										
t0	3.00 (2.49-3.60)	—		2.64 (2.05-3.41)	—		1.13 (0.83-1.55)	.43	—	
t1	1.56 (1.18-2.07)	0.52 (0.41-0.67)	<.001	2.48 (1.89-3.25)	0.93 (0.69-1.26)	.67	0.63 (0.43-0.93)	.02	1.79 (1.22-2.64)	.003
t2	1.59 (1.07-2.34)	0.53 (0.37-0.76)	.001	1.90 (1.15-3.13)	0.72 (0.42-1.24)	.23	0.84 (0.44-1.58)	.58	1.35 (0.70-2.61)	.36
t3	2.07 (1.46-3.13)	0.69 (0.50-0.96)	.03	2.67 (1.71-4.15)	1.01 (0.64-1.59)	.97	0.78 (0.44-1.37)	.38	1.46 (0.83-2.55)	.19

[a] From t0.

The reduction observed for the treatment group persisted from posttreatment to 3-month follow-up (RR=0.84, 95% CI 0.46-1.51; *P*=.55). Between the 3- and 6-month follow-ups, the number of drinks per week in the treatment group increased (RR=1.62, 95% CI 0.96-1.90; *P*=.04); however, at 6-month follow-up the number of drinks per week was still significantly lower than baseline (RR=0.62, 95% CI 0.41-0.93; *P*=.02). No statistically significant change in the number of drinks per week was found for the control group between posttreatment and 3-month follow-up (RR=0.69, 95% CI 0.44-1.07; *P*=.10) or between the 3- and 6-month follow-ups (RR=1.23, 95% CI 0.61-2.50; *P*=.56). Similarly, compared to baseline, the number of drinks per week in the control group was no different at the 3- (RR=0.67, 95% CI 0.37-1.22; *P*=.19) or 6-month follow-ups (RR=0.82, 95% CI 0.47-1.42; *P*=.48).

There was no statistically significant difference in the number of drinks per week between the treatment and control groups at either the 3- (RR=0.76, 95% CI 0.30-1.88; *d*=0.13; *P*=.55) or 6-month follow-ups (RR=0.99, 95% CI 0.51-1.94; *d* =–0.09; *P*=.99). The within-group effect between baseline and 3-month follow-up for the treatment group was *d*=0.76 and *d*=0.54 for the control group. The within-group effect between baseline and 6-month follow-up was *d*=0.38 for the treatment group and *d*=0.24 for the control group.

Drinking Days Per Week

There were no statistically significant differences between the groups for alcohol use frequency as measured by the TOT-AL (see Table 3). There was a statistically significant group × time interaction in relation to number of drinking days per week (χ^2_3=9.6, *P*=.02). As shown in Table 3, the treatment group demonstrated a statistically significant reduction in drinking days per week from baseline to posttreatment follow-up (RR=0.52, 95% CI 0.41-0.67; *P*<.001), representing a large effect (*d*=1.06). The change in weekly drinking days in the control group over this time was small (*d*=0.10) and not statistically significant (RR=0.93, 95% CI 0.69-1.26; *P*=.67). Compared to the control group, the treatment group reported a 79% greater reduction in drinking days (RR=1.79, 95% CI 1.22-2.64; *P*=.003). The treatment group also reported significantly fewer drinking days per week relative to control at posttreatment follow-up (RR=0.63, 95% CI 0.43-0.93; *d*=0.76; *P*=.02).

The reduction observed for the treatment group persisted from posttreatment to 3-month follow-up (RR=1.01, 95% CI 0.70-1.47; *P*=.94) and from 3- to 6-month follow-ups (RR=1.31, 95% CI 0.93-1.84). No statistically significant change was observed for the number of drinking days per week in the control group between posttreatment and 3-month follow-up (RR=0.77, 95% CI 0.49-1.20; *P*=.25) or between 3- and 6-month follow-ups (RR=0.71, 95% CI 0.32-1.57; *P*=.40). Similarly, compared to baseline, the number of drinking days per week in the control group was no different at 3- (RR=0.72, 95% CI 0.42-1.23; *P*=.23) or 6-month follow-ups (RR=1.01, 95% CI 0.64-1.59; *P*=.97).

There was no statistically significant difference in the number of drinking days per week between groups at either the 3-

(RR=0.84, 95% CI 0.44-1.58; *P*=.58; *d*=0.22) or 6-month follow-ups (RR=0.78, 95% CI 0.44-1.37; *P*=.38; *d*=0.24). The within-group effect between baseline and 3-month follow-up for the treatment group was *d*=0.89 and *d*=0.45 for the control group. The within-group effect between baseline and 6-month follow-up was *d*=0.42 for the treatment group and *d*=0.04 for the control group.

Discussion

This RCT evaluated the feasibility and preliminary efficacy of the DEAL Project, a Web-based program that aims to reduce depression and alcohol use in 18- to 25-year-olds. The program demonstrated statistically significant greater reductions in depression and alcohol use compared to a control group at posttreatment. Furthermore, the positive outcomes observed among those randomized to the DEAL Project were maintained at 3- and 6-month follow-ups. However, between-group differences at these later time points disappeared because of statistically nonsignificant shifts in both control and treatment groups. There is evidence to suggest that in brief intervention trials, assessment alone may result in improved outcomes either as a consequence of assessment on subsequent self-report (known as the Hawthorne effect) [49] or as a catalyst to mobilize individuals into actual behavioral change [25]. As such, there is the potential that those in the HealthWatch condition may have derived benefit from not only the assessments, but also the thought involved in completing the surveys. Alternately, because this was a sample that sought out this treatment, the control condition may have been intensive enough for some change to be observed when combined with participant motivation for change. Participants may have also accessed other treatments. However, this was not borne out in our data on service utilization over the follow-up period. Treatment deterioration effects may also have led to this lack of between-group differences at 6 months. Finally, natural recovery cannot be disregarded as an alternative explanation for disappearance of differences between the two groups. Nevertheless, it would appear that the DEAL Project was associated with more rapid improvement in depression and alcohol outcomes compared with control.

Overall, mean PHQ-9 depression scores in the treatment group dropped from the “moderately severe” range to just outside the range for “mild depression” at 6 months. This was a clinically significant change [44]. At baseline, the treatment group were drinking, on average, 3 days per week and consuming more than 25 drinks per week. At 3-month follow-up, drinking occasions had halved and participants were drinking just over nine drinks per week. Although this reduced figure is still considered above the recommended range for short-term harm [50], it has potentially large public health implications (especially considering the automated nature of the program), including a reduction in risk of harm to the individual and the societal costs associated with heavy alcohol use, including violence, hospital and emergency department visits, road safety and drunk driving, and lost productivity [51]. The posttreatment effect sizes observed in this study were considerably stronger than previous research; however, at 3- and 6-month follow-ups, effect sizes looked similar to the small and moderate effects found in previous Internet-based trials for single disorder interventions [14,16,19,52,53]. Similarly, the overall effects of the DEAL Project program at 3- and 6-month follow-ups were similar to those of the SHADE program trial [24]. The DEAL Project is briefer, unguided, and delivered completely online, which is likely to increase cost-effectiveness and accessibility for youth.

Despite these various strengths, this study is not without its limitations. Although there was significant interest at the recruitment level (with more than 900 individuals beginning—and 839 completing—the screener over a 6-month period), the recruitment rate was low. However, this was unsurprising considering this was an opportunistic sample (not treatment-seeking). Consequently, on average, individuals randomized to the DEAL Project fully completed less than half of the four sessions offered to them. Of those who completed one session, approximately one-third went on to fully complete the program. This issue with adherence is unsurprising given the unguided nature of the program [54,55]. Despite considerable efforts in the program development stage to optimize adherence [56], this raises some questions around program acceptability and feasibility. Interestingly, the mean number of DEAL Project modules completed was equivalent to the number of modules completed by the younger participants in the previous SHADE trial [57], suggesting that adherence may be a generalized issue for this demographic. The DEAL Project’s brief structure allows for exposure to more key strategies before dropout. Although only one-third of the treatment group completed at least half of the program, module completion refers to full completion and does not account for participants sampling from different modules in a nonlinear way. Furthermore, the reasons for selective attrition are difficult to interpret because they may reflect the contradictory possibilities of dropout due to dissatisfaction versus dropout due to a sense that the individual feels their needs have been met [58]. Further research is needed to examine methods to improve engagement and retention within online programs. Nevertheless, despite the lack of adherence the positive results are encouraging for the utility of brief interventions. Similarly, although not dissimilar to previous studies without therapist/administrative guidance of participants [59,60], the follow-up rates were low. This may limit the generalizability and conclusions that may be drawn from this study. Telephone or face-to-face contact during online trials has been shown to increase adherence; however, this reduces real-world applicability [61]. Nevertheless, the GEE analysis used is robust to this level of loss to follow-up [62] and missingness was found to be at random.

Due to difficulties diagnosing disorders online, the sample was nondiagnostic. Nevertheless, the mean baseline PHQ-9 score was in the moderately severe range and the mean baseline AUDIT score indicated high-risk/harmful levels of use. According to the PHQ-9, more than half the sample had a likely depression diagnosis, whereas two-thirds endorsed at least one alcohol abuse diagnostic criterion and three-quarters endorsed more than two dependence diagnostic criteria. Thus, this was not a clinically insignificant sample. Furthermore, subthreshold conditions have been associated with comparable negative outcomes to full-disorder syndromes, especially in younger populations [63,64], and provide an opportunity for early intervention.

Additionally, this Australian sample may not generalize internationally. The programming error in randomization is a possible study limitation. Nevertheless, few differences were found between the groups at baseline. Finally, as with any study of this kind, there is the potential for self-report bias; evidence suggests self-report provides useful and accurate estimates when conditions are designed to maximize response accuracy [65]. Studies have shown that self-reports of alcohol use correlate with behavioral observations [66]. Furthermore, the anonymity provided by online assessment is likely to be more accurate than other forms of self-report [67].

Overall, the DEAL Project was associated with significant improvements in both depression symptoms and alcohol use among young people with these co-occurring conditions relative to control at posttreatment. However, although within-group improvements were maintained over the 6-month follow-up period, the significant between-group differences were no longer present at long-term follow-up. This study adds useful evidence to both the eHealth and comorbidity treatment fields. Further studies are required to better understand these long-term outcomes and address the program adherence and trial attrition issues that were present in this study.

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Conflicts of Interest

M Deady and the other authors also worked to develop the DEAL Project website, but derive no personal or financial benefit from its operation.

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Abbreviations

DASS: Depression Anxiety Stress Scale
AUDIT: Alcohol Use Disorders Identification Test
GEE: generalized estimating equations
MSI-BPD: McLean Screening Instrument for Borderline Personality Disorder
PHQ-9: Patient Health Questionnaire
RCT: randomized controlled trial
RR: risk ratio
SHADE: Self-Help for Alcohol and other drug use and DEpression

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Original Paper

Toward a Mixed-Methods Research Approach to Content Analysis in The Digital Age: The Combined Content-Analysis Model and its Applications to Health Care Twitter Feeds

Eradah O Hamad[1,2], BPsych (Hons), MSc (Health and Rehab); Marie Y Savundranayagam[3], PhD; Jeffrey D Holmes[4], OT, PhD; Elizabeth Anne Kinsella[4], OT, PhD; Andrew M Johnson[3], PhD

[1]Department of Psychology, Faculty of Arts and Humanities, King Abdulaziz University, Jeddah, Saudi Arabia

[2]Health and Rehabilitation Sciences Graduate Program, Faculty of Health Sciences, Western University, London, ON, Canada

[3]School of Health Studies, Western University, London, ON, Canada

[4]School of Occupational Therapy, Western University, London, ON, Canada

Corresponding Author:
Andrew M Johnson, PhD
School of Health Studies
Western University
Room 1004, Elborn College
1201 Western Road
London, ON, N6G 1H1
Canada
Phone: 1 519 661 2111 ext 80312
Fax: 1 519 661 2111
Email: ajohnson@uwo.ca

Abstract

Background: Twitter’s 140-character microblog posts are increasingly used to access information and facilitate discussions among health care professionals and between patients with chronic conditions and their caregivers. Recently, efforts have emerged to investigate the content of health care-related posts on Twitter. This marks a new area for researchers to investigate and apply content analysis (CA). In current infodemiology, infoveillance and digital disease detection research initiatives, quantitative and qualitative Twitter data are often combined, and there are no clear guidelines for researchers to follow when collecting and evaluating Twitter-driven content.

Objective: The aim of this study was to identify studies on health care and social media that used Twitter feeds as a primary data source and CA as an analysis technique. We evaluated the resulting 18 studies based on a narrative review of previous methodological studies and textbooks to determine the criteria and main features of quantitative and qualitative CA. We then used the key features of CA and mixed-methods research designs to propose the combined content-analysis (CCA) model as a solid research framework for designing, conducting, and evaluating investigations of Twitter-driven content.

Methods: We conducted a PubMed search to collect studies published between 2010 and 2014 that used CA to analyze health care-related tweets. The PubMed search and reference list checks of selected papers identified 21 papers. We excluded 3 papers and further analyzed 18.

Results: Results suggest that the methods used in these studies were not purely quantitative or qualitative, and the mixed-methods design was not explicitly chosen for data collection and analysis. A solid research framework is needed for researchers who intend to analyze Twitter data through the use of CA.

Conclusions: We propose the CCA model as a useful framework that provides a straightforward approach to guide Twitter-driven studies and that adds rigor to health care social media investigations. We provide suggestions for the use of the CCA model in elder care-related contexts.

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KEYWORDS

health care social media; Twitter feeds; health care tweets; mixed methods research; content analysis; coding; computer-aided content analysis; infodemiology; infoveillance; digital disease detection

Introduction

Overview

In the digital age, social networking sites such as Twitter are increasingly turned to as an information source, as they offer a large amount of digital text and are readily available to multisite apps (eg, personal computers, mobile phones, and tablets). Health discussions, for example, occur regularly on Twitter, with online discussions and content sharing among a variety of populations, including health care professionals, patients with chronic conditions, and their caregivers. Some efforts have emerged to investigate the content of health care-related posts on Twitter, constituting a new area for researchers to investigate using content analysis (CA). These approaches are also known as infodemiology, infoveillance, or digital disease detection research. In many of these research initiatives, quantitative and qualitative Twitter data are combined, but there are few clear guidelines for researchers or reviewers to follow when collecting and evaluating this content. An explanation for this could be that contemporary CA is best described as a juxtaposition of quantitative (eg, frequency analysis to count words in a text and represent them statistically) and qualitative (eg, nonfrequency analysis for in-depth hermeneutic interpretations of a text) methodological dimensions [1]. Whether CA should be approached quantitatively or qualitatively has been debated in the literature since modern CA originated in the 1930s [2]. However, these approaches (quantitative and qualitative [3,4]) to CA have common features, including the sampling and data collection strategy (defining the source and amount of content to be collected for analysis), the coding process (defining the units of analysis, training coders, and establishing the coding scheme), and validation of study results (assessing reliability and validity or trustworthiness of study results). These key features of CA may vary according to research aims [1,4-8].

Research using social media platforms (eg, Facebook, Twitter, or LinkedIn) is in the early stages, and despite the great potential for the application of CA to Twitter-based health care content, there are few guidelines for the collection, analysis, and evaluation of the various types of Twitter data. Thus, the aim of our study was to use criteria available in the CA literature, specifically literature on the use of CA in health care research, to identify and evaluate published studies that used Twitter as a primary source of data and CA as a method of analysis and interpretation. Based on our analysis, we propose the combined content-analysis (CCA) model as an organizing framework to guide the application of integrated methods (quantitative and qualitative) and modes (manual and computer assisted) of CA, and to address the varied nature of Twitter feed data (eg, textual, numerical, audio, and video material) within single or multiple-phase studies.

In this paper, we first discuss the position of CA in previous research and then illustrate how CA has been used in health care research. Building on common characteristics of CA found in the literature, we evaluate 18 studies published between 2010 and 2014. Finally, we propose the CCA model of CA along with mixed-methods research approaches. We suggest how to apply the CCA model and offer supporting resources drawing on elder care-related examples.

Background

Positioning of CA

CA is a research methodology or set of methods to analyze content collected from written (eg, open-ended surveys, personal communications, letters, diaries, short stories, newspapers or magazines, and theoretical or methodological trends in journal papers), verbal (eg, interviews, focus groups, radio programs, and folk songs), or visual (eg, films, videos, and TV programs) materials, from printed and electronic resources [2,7,9]. In the digital age, CA may also be used to analyze digital texts (eg, Web-published news, Internet forums, and social media discussions). Once the research aim is stated and the source of data (content components) is identified, data may be sampled and subjected to either qualitative or quantitative analysis, or both. The process of CA consists of coding raw data (eg, papers, interview transcripts, or images) according to a developed or predefined classification scheme (a coding manual). Both qualitative and quantitative approaches can be applied to analyze targeted material. The appropriate method(s) to collect, analyze, and classify content is a critical choice that needs to take careful account of many methodological considerations based on the intended application of CA to the proposed study.

Between the 1930s and 1950s, CA was called “symbol analysis” and was a scientific method of recording the frequency of certain keywords found in newspapers [2]. Cartwright [10] was the first to propose CA and coding as interchangeable terms. When understood this way, CA is viewed as a quantitative approach, whereby text data are coded into categories (code frequencies) based on pre-existing knowledge or hypotheses and then described using codebooks and statistical techniques that allow for future inferences [3,7]. According to Berelson [11], CA is an objective and systematic description of the manifest content. Quantitative concepts have historically been essential to CA. These concepts include objectivity, systematicity, generalizability, transferability, validity, and reliability. In addition, this view of CA requires well-defined samples and units of analysis and stability of results across coders and over time [3]. The quantitative perspective of CA emphasizes the “objective” and consistent quantification or classification of categorical (“subjective”) data [12]. However, some scholars deemed this approach simplistic, arguing that it was not conducive to detailed statistical analysis [7]. Restricting CA to numerical values and the frequency of symbols and other units may create theoretical and practical problems [9,13,14].

As CA spread to other disciplines in the social sciences, such as sociology, psychology, business, and health research, the qualitative approach to CA was developed and was recognized as an approach for data analysis in many research disciplines [7,15,16]. Researchers using qualitative CA may go beyond counting the frequency of words in a text and focus more on the context, including the analyst's assumptions, preunderstandings, or constructions of reality, the conceptual environment, and where the text is situated in relation to other studies. Context can be construed in relation to the personal or social constructs that support researchers' questions [17]; thus, qualitative CA may differ across fields of study and from one content analyst to another. In contrast, some researchers argue that CA is insufficiently qualitative and presents some methodological obstacles [9,13,16]. Still others argue that the reading of a text may not differ between researchers and nonresearchers (eg, public readers or study participants). The importance of the description of context related to qualitative CA can also be applied to Twitter as a public data source of social networking and communication, where richness of data, such as user information and biographies and social networking communication (eg, information about "following" and "number of followers", Twitter chat managers, and community), is as important as the exploration of the content of tweets.

CA researchers such as Holsti [9], Krippendorff [7], and Schreier [6] are generally in agreement that qualitative and quantitative CA are not discrete classifications, but rather fall along a continuum. Consequently, moving back and forth between these approaches affords a greater opportunity to gain insight into the meaning of data [9]. Similarly, Pool [18] suggested that these seemingly opposite approaches to CA exist within a feedback loop in which each approach provides new insights upon which the other can feed. Accordingly, one should not assume that qualitative methods are insightful or that quantitative methods are merely mechanical methods to check hypotheses. By definition, CA is a research approach that can be situated at the intersection of quantitative and qualitative methods, a place where both methods can meet [2] and that quantifies and qualifies the manifest and latent meanings of the data [19]. However, we argue that researchers need to consider combining this understanding of CA with a solid mixed-methods design, especially with the massive growth of digital texts and multimedia data.

CA in Health Care Research

CA has come into widespread use in health care research in recent years because of its sensitivity and flexibility as a research technique concerned with meanings, intentions, consequences, and context [15,20]. A review of health studies literature using the Cumulative Index to Nursing and Allied Health Literature shows that the use of CA increased, being mentioned in 97 papers in 1991 and rising to 601 in 2002 [20]. A similar review of nursing studies by Elo and Kyngäs [15] found that the analysis process remains challenging for health care researchers regardless of the flexibility of CA, because there are no clear guidelines for its use. Elo and Kyngäs [15] highlighted the heterogeneity of CA research, noting that it has been mostly used as a general qualitative method for research on psychiatry (713 papers), health care (627 papers), nursing (625 papers), gerontologic care (441 papers), public health (389 papers), and occupational therapy (165 papers).

Hsieh and Shannon [20] divide qualitative CA into three distinct approaches: conventional CA or the "inductive approach" [15]; directed CA or the "deductive approach" [15]; and summative CA or the "manifest approach" [20]. According to Hsieh and Shannon [20], all three approaches adhere to the naturalistic paradigm and can be used to interpret meaning from the content of text data. In addition, the three approaches require a similar analytical process consisting of 7 steps: (1) formulating the research questions, (2) selecting the sample for analysis, (3) defining the categories to be applied, (4) outlining the coding process and training the coders, (5) implementing the coding process, (6) determining trustworthiness, and (7) analyzing the results of the coding process ([20], p 1285). The key differences between these approaches are the initial codes developed by the coder(s), which are generally determined according to the purpose of the study. The intended approach can guide coding schemes and affect the study's trustworthiness (the quality criteria of qualitative research).

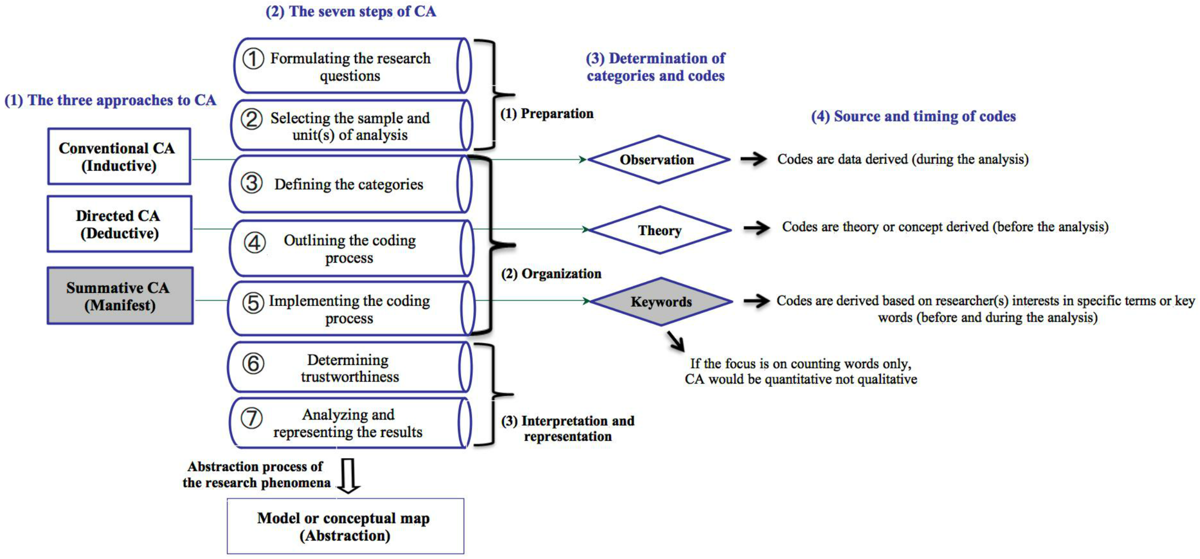
In conventional CA, it is assumed that because there is insufficient or fragmented knowledge about a phenomenon [15], categories and their content are data driven [1]. In this case, the researcher starts the analysis without predetermined categories (eg, theory or concept driven) and derives categories inductively during data analysis. Using this approach, the researcher gains a rich understanding of the phenomenon under investigation, as new insights emerge from the study results. Elo and Kyngäs [15] suggested that a CA approach based on inductive data can be used if the researcher aims to develop a theory, as this approach allows him or her to move from specific details to the general picture of the phenomenon. For example, in Juvani and colleague's [21] qualitative study, they developed two categories inductively from participants' interviews to describe the threats and supportive aspects of the physical environment for the well-being of adults over the age of 65 years.

Deductive or directed CA can be used when the purpose of the study is to test a theory or extend an existing theory or prior research [1,15,20]. In a directed approach, categories are determined prior to data analysis. The researcher's role is to examine and code the data according to these corresponding categories. Thus far, the qualitative deductive approach has been applied infrequently in health research; as such, studies are typically based on an earlier review of the literature, theory, or model, moving from the general to the specific [15]. For example, Latvala et al [22] applied a deductive CA to examine three predefined categories related to psychiatric patients' participation in their care in a hospital environment. However, Kondracki et al [1] argued that inductive and deductive approaches to CA are not mutually exclusive and can be mixed in a single study. According to Kondracki et al [1], one way to accomplish this integration is to augment quantitative CA by conducting an initial qualitative analysis. Alternatively, the results of qualitative CA can be used to refine quantitatively derived categories and, if necessary, create new variables to capture new aspects of content.

The third type of CA used in health care research is the summative approach. Rather than the data being analyzed as a whole, as in the previous two approaches, the text is searched for particular words or content in relation to a particular topic.

For example, the summative approach was used to examine content related to end-of-life care in 14 critical care nursing textbooks [23] and 50 best-selling medical textbooks [24]. Hsieh and Shannon [20] held that if the analysis were to stop at this point it would be quantitative and focused only on the manifest content. A summative approach to qualitative CA goes beyond counting words to include the latent content, the process of interpreting the content, and the discovery of the underlying meaning and alternative terms for the words. Figure 1 summarizes the three approaches to CA in health care research and their steps.

Figure 1. Content analysis (CA) in health care research. Adapted from Hsieh & Shannon (2004, p 1286, Table 4) with permission of SAGE Publications, Inc.



Methods

To locate current trends in health care social media studies and studies using CA to analyze data from the most popular social media tool, Twitter, we conducted a PubMed search of the years 2010 to 2014. Keyword sets combined “content analysis” AND one of the following: “healthcare social media,” “social networking websites,” “Twitter-driven content,” “Twitter feeds,” OR “healthcare tweets.” The primary research questions were “How is CA used in health care social media studies?” and “Does it follow the common features of CA literature identified in CA research, in general, and health care-related research, in particular?” Paper selection was based on the title and the abstracts. In case of uncertainty, we read the entire text of a paper. In addition, we manually searched the reference lists of all included studies. From the 21 studies found, we selected 18 for examination (see Table 1 [25-42] for the list of studies of health-related tweets published between 2010 and 2014). We based the evaluation of these papers on the narrative review of CA methodological textbooks [6-9,11,17,18,43,44] and CA in published literature [1-5,13-16,20,45,46]. After examining the papers, we constructed the CCA model, which we explained in detail in the Discussion section.

Results

Our results show that, in the 18 studies examined (in English), Twitter was used as a public and real-time source for textual health data where users tried to disseminate health information from formal sources (eg, academic journals or news websites) and informal sources (eg, personal opinions or actual experiences). In these studies, researchers analyzed Twitter messages using CA as a sole technique or with other research techniques, such as the infoveillance approach (eg, [25,26]), the cross-sectional survey approach (eg, [27-29]), and discourse analysis (eg, [30]). Our review of these studies showed that the quantitative approach was the most common approach to CA (eg, [25-28,31-38]). In addition, it is clear that researchers neither follow a particular procedural model of data analysis and interpretation, nor use straightforward guidelines that would lead other researchers in their evaluation of social media-driven content. In all studies shown in Table 1, the qualitative summative (manifest CA) approach [20] was used as an initial step to track, archive, or retrieve tweets related to the topic of interest (eg, elder care). By identifying and quantifying certain words (eg, elder care, dementia, or Alzheimer) or hashtags (eg, #eldercare, #dementia, or #Alzheimer) using Twitter’s search function or a Twitter archive software program (see Table 2 for a list of software used in the analyzed studies to archive tweets), researchers were able to access hundreds, thousands, or millions of tweets based on the availability of the target topic, time frame (eg, hours, days, or weeks), and frequency of discussions on Twitter at the time of data collection. Through this process, researchers formed a Twitter database for each topic, generating a data pool from which to select their samples. Because the quantitative approach was the leading approach in most studies, the random sampling technique was commonly used, even when CA was used as a qualitative research technique (eg, [39,40]).

Table 1. Studies analyzing health-related Twitter posts (2010–2014).

Author(s)	Keywords and hashtags (#)	Sampling and data collection	Data analysis (coding process)	Validation and presentation of results
Chew & Eysenbach (2010) [25]	"swine flu", "swine-flu", and "H1N1"	Random sample of 5395 tweets for 9 days (each 4 weeks apart) generated from 2 million archived tweets over 8 months. Tweets were posted between May 1 and December 31, 2009 (n=600 tweets/per day were collected for analysis).	Infoveillance approach (statistical classifier) for tracking flu rate (longitudinal text mining and analysis). This approach includes in-depth qualitative manual coding, automated CA[a]using a triaxial coding scheme, and sentiment analysis.	Pilot coding (1200 tweets), ICR[b]for a subset of 125 tweets using kappa statistic (κ>.70), Pearson correlations between manual and automated coding, and chi-square to test changes over time, frequency tables, and text matrices with quotes illustrating the categories.
Scanfeld et al (2010) [27]	"antibiotic" and "antibiotics"	Random sample of 52,153 tweets. Tweets were posted weekly between March 13 and July 31, 2009 (n=1000 tweets were collected for analysis).	Cross-sectional survey approach using Q-methodology and CA (frequencies).	Pilot coding of 100 tweets, ICR for a random sample of 10% of the analyzed tweets using kappa statistic (κ=.73), frequency tables, and text matrices with quotes illustrating the categories.
Heaivilin et al (2011) [28]	"toothache", "tooth ache", "dental pain", and "tooth pain"	Random sample of 4859 tweets over 7 nonconsecutive days (n=1000 tweets were collected for analysis).	Cross-sectional survey approach and CA (frequencies and descriptive statistics).	Pilot coding of 300 tweets, ICR using kappa statistic (κ=.96), frequency tables, and continuous text with quotes illustrating the categories.
Signorini et al (2011) [31]	"flu", "swine", "influenza", "vaccine", "tamiflu", "oseltamivir", "zanamivir", "relenza", "amantadine", "rimantadine", "pneumonia", "h1n1", "symptom", "syndrome", and "illness" and additional keywords (eg, travel, trip, flight, fly, cruise, and ship)	Two large data sets for tracking flu rate over time and location. The first data set consists of 951,697 tweets selected from the 334,840,972 tweets. Tweets were posted between April 29 and June 1, 2009. The second data set consists of 4,199,166 tweets selected from roughly 8 million tweets. Tweets were posted between October 1, 2009 and December 2009.	Quantitative CA (descriptive and advanced statistics).	Regression analysis and frequency graphs with respect to time.
McNeil et al (2012) [39]	"seizure", "seizures", "seize", "seizing", and "seizuring"	Random sample of 10,662 tweets from a period of 7 consecutive days. Tweets were posted between April 15 and April 21, 2011 (n=1504 tweets were collected for analysis).	Prospective qualitative CA.	Pilot coding of a 48-hour preliminary data set and interrater agreement (85.4%), frequency tables, and text matrices with quotes illustrating the categories.
Sullivan et al (2012) [40]	"concussion", "concussions", "concuss", "concussed", "#concussion", "#concussions", "#concuss," and "#concussed"	Random sample of 3488 tweets over 7 consecutive days. Tweets were posted between 12:00 GMT[c]on July 23 and 12:00 GMT on July 30, 2010 (n=1000 tweets were collected for analysis).	Prospective observational study using qualitative CA.	Pilot coding of 100 tweets from a sample collected over a 24-hour period and interrater agreement, frequency tables, and text matrices with quotes illustrating the categories.
Donelle & Booth (2012) [41]	"#health" and "health" as a single word, part of a word (eg, health care)	Purposeful cross-sectional sample of 36,042 tweets. Tweets were collected over 4 consecutive days, from June 16, 2009 at 19:32 GMT until June 20, 2009 at 12:02 GMT (n=2400 tweets were collected for analysis; the first 100 tweets from the end of each hour of June 19, 2009, starting at 05:00 GMT for a 24-hour period).	Qualitative (directed and deductive) CA [20] guided by the Public Health Agency of Canada's Determinants of Health framework.	Trustworthiness and validation of findings (interrater agreement, systematic data analysis, analyst triangulation, and verbatim data collection, and basic descriptive statistics). Data were presented through frequency graphs, text matrices, and continuous text with quotes illustrating the categories.

Author(s)	Keywords and hashtags (#)	Sampling and data collection	Data analysis (coding process)	Validation and presentation of results
Robillard et al (2013) [29]	“dementia” and “Alzheimer”	Random sample of 9200 tweets for a period of 24 hours (starting February 15, 2012 at 3:35 pm) (n=920 tweets were collected for analysis in addition to a subsample containing 100 tweets generated by the top users).	Cross-sectional survey using CA [25,27] Statistical analysis (descriptive statistics) was used to characterize the composition of the sample.	Pilot coding of an initial set of 100 random tweets and frequency graphs and tables.
Lyles et al (2013) [42]	“pap smear” and “mammogram”	Cross-sectional sample of top tweets during a 5-week period. Tweets were posted between April and early May 2012 (n=474 tweets were collected for analysis).	Exploratory qualitative CA.	Pilot coding of 20% of collected tweets, ICR of 40% of collected tweets, interrater agreement, frequency graphs, text matrices, and continuous text with quotes illustrating the categories.
Bosley et al (2013) [32]	“cardiac arrest”, “CPR”, “AED”, “resuscitation”, “heart arrest”, “sudden death”, and “defib”	All identified resuscitation-related tweets from the keyword search. Tweets were posted between April 19 and May 26, 2011 (n=15,475 tweets were collected for analysis).	Quantitative CA (descriptive statistics).	Pilot coding of 1% of identified tweets, ICR using kappa statistic (κ=.78), frequency graphs and text matrices with quotes illustrating the categories.
Hanson et al (2013) [33]	“prescription drugs”	Random set of tweets posted by 25 identified social networks or circles. Tweets were posted between November 29, 2011 and November 14, 2012 (up to 3200 tweets per user were collected for analysis).	Quantitative CA of identified social circles	Pearson correlation coefficient of user interactions. Frequency tables and social network graphs.
Henzell et al (2013) [30]	“braces”, “orthodontist”, and “orthodontics”	Convenience sample of consecutive tweets posted over a 5-day period. Tweets were posted between September 3 and 7, 2012 (n=131 tweets were collected for analysis).	Qualitative (discourse) CA.	Continuous text with quotes illustrating the categories.
Myslín et al (2013) [26]	“cig*”, “nicotine”, “smoke*”, “tobacco”, “hookah”, “shisha”, “waterpipe”, “e-juice”, “e-liquid”, “vape”, and “vaping”	Random sample of tweets at 15-day intervals. Tweets were posted between December 5, 2011 and July 17, 2012 (n=7362 tweets were collected for analysis).	Infoveillance methodology [25], which includes iterative (manual) content and sentiment analysis.	Pearson correlations between manual and automated coding, chi-square to test changes over time, frequency graphs, and text representation diagrams.
Rui et al (2013) [34]	Not stated	Random sample of tweets posted by 58 health organizations (chosen randomly) within 2 months. Tweets were posted between September and November 2011 (n=1500 tweets were collected for analysis).	Quantitative (deductive) CA guided by the classic categorization of social support.	Descriptive statistics, ICR of 200 random tweets using Krippendorff alpha (.74), frequency tables, and continuous text with quotes illustrating the categories.
Zhang et al (2013) [35]	113 physical activity keywords generated from lists of published physical activity measures	A random sample of 30,000 tweets selected from a pool of one million tweets. Tweets were posted between January 1 and March 31, 2011 (n=4672 tweets were collected for analysis in addition to 1500 collected from this sample for further coding).	Quantitative CA (descriptive and advanced statistics).	Pilot coding of 100 tweets (separate from the final 1500 tweets) to calculate ICR (ranges from 0.83 to 0.98) using Holsti’s [9] method and frequency graphs and tables.
Park et al (2013) [36]	“health literacy”	Random sample of 1044 tweets. Tweets were posted during the time following time periods to construct a composite month: October 25–31, 2009; November 7–14, 2009; December 15–23, 2009; and January 4–10, 2010 (n=571 tweets were collected for analysis).	Quantitative CA based on Web reports on key Twitter features and previous literature in health communication and media studies.	Pilot coding, ICR of a subsample of 111 tweets using Holsti [9] reliability coefficient (.91), Krippendorff alpha (.85), and statistical analysis (frequencies and chi-square analyses and tables).

Author(s)	Keywords and hashtags (#)	Sampling and data collection	Data analysis (coding process)	Validation and presentation of results
Love et al (2013) [37]	"vaccine", "vaccination", and "immunization"	Random sample of 6827 English-language tweets. Tweets were posted between January 8 and 14, 2012 (n=2580 tweets were collected for analysis).	Quantitative CA.	Statistical analysis (frequencies and chi-square analyses and tables).
Jashinsky et al (2013) [38]	Keywords and phrases created from suicide risk factors (12 identified factors)	All tweets (1,659,274 tweets) posted by 1,208,809 unique users over a 3-month period. Tweets were posted between May 15, 2012 and August 13, 2012 (n=37,717 tweets from 28,088 unique users were collected for analysis).	Quantitative CA (descriptive and advanced statistics).	ICR using kappa statistic (κ=.48), Spearman rank correlation coefficient, vital statistics, and text matrices with quotes illustrating the categories.

[a] CA: content analysis.

[b] ICR: intercoder reliability.

[c] GMT: Greenwich mean time.

Table 2. Twitter archive software used in the studies analyzing health-related Twitter posts (2010–2014).

Author(s)	Archive software used
Chew & Eysenbach (2010) [25]	Infoveillance system and Twitter API[a]
Scanfeld et al (2010) [27]	Twitter search engine
Heaivilin et al (2011) [47]	Twitter search engine
Signorini et al (2011) [31]	JavaScript application and Twitter's API
McNeil et al (2012) [39]	Twitter search engine
Sullivan et al (2012) [40]	Twitter search engine
Donelle & Booth (2012) [41]	The Archivist (MIX Online, 2011) data collection software program
Robillard et al (2013) [29]	Twitter's API
Lyles et al (2013) [42]	Twitter search engine
Bosley et al (2013) [32]	Twitter search engine
Hanson et al (2013) [33]	Twitter's API
Henzell et al (2013) [30]	Twitter search engine
Myslín et al (2013) [26]	Twitter's API
Rui et al (2013) [34]	ActivePython v2.7.2
Zhang et al (2013) [35]	Twitter's API
Park et al (2013) [36]	Twitter's API
Love et al (2013) [37]	Twitter's API
Jashinsky et al (2013) [38]	Twitter's API

[a] API: application programming interface.

The qualitative approaches to sampling techniques, such as purposeful and convenience sampling, were used in only 2 studies ([30,41]). The focus of most of these studies situated tweets as a primary source of information. The context of the tweets (eg, events or other Web-based information attached to tweets, if any, such as pictures, videos, user biographies, characteristics of active users, and social network communities related to that topic) was rarely mentioned. In 1 study [41], major world events were reviewed and summarized over the month of data collection, and an explanation of how those events related to the analyzed tweets was provided. However, the authors recommended the collection of a larger data set in order to examine the proposed inferences from world events in more detail. In another study [29], the characteristics of top users were described as frequencies in statistical graphs. Furthermore, when studies used CA with a cross-sectional survey design [27-29], they included mixed components of analyzed data, integrating quantitative data (quantitative strings or classifiers) with categories (codes or themes) developed inductively from the tweets. Units of analysis were inadequately described, and a single tweet was mentioned as a coding unit in only a few studies. For all studies, only publicly available data were used with no attempt to contact users.

Among the reviewed studies, all used a form of CA that was neither purely quantitative nor purely qualitative. Despite the fact that these two types of data were combined, no formal approach to mixing methods was described within any of the methods sections. With either approach chosen by the researchers there were mixed modes of analysis. Data were either imported and coded automatically (computer assisted) or imported automatically and coded manually (with human-assisted analysis). While the manual mode of CA can be used to qualify small amounts of coded data, the automatic mode may be used for large samples of either categorical or more quantifiable words or texts. The validation of results in these studies was based mostly on the pilot coding (also called trial coding [6]) or intercoder reliability (ICR) using Cohen kappa coefficient (kappa statistic) or Krippendorff alpha, which is more frequently used in both quantitative and qualitative studies. Descriptive statistics (mean, standard deviation, or correlation) or advanced statistics (regression analysis or chi-square) were used to validate the studies if the study's primary approach was quantitative.

We propose that a blended research methodology that considers quantitative and qualitative perspectives in the study design and coding procedure would be fruitful for the advancement of CA methodologies. Further, an approach that allows for a combination of manual and computer-assisted coding through the most suitable supported software for the methodological approach of the study would be beneficial. A robust approach of this kind was not explained explicitly in these studies; we describe our proposed model for such studies is in the Discussion section.

Discussion

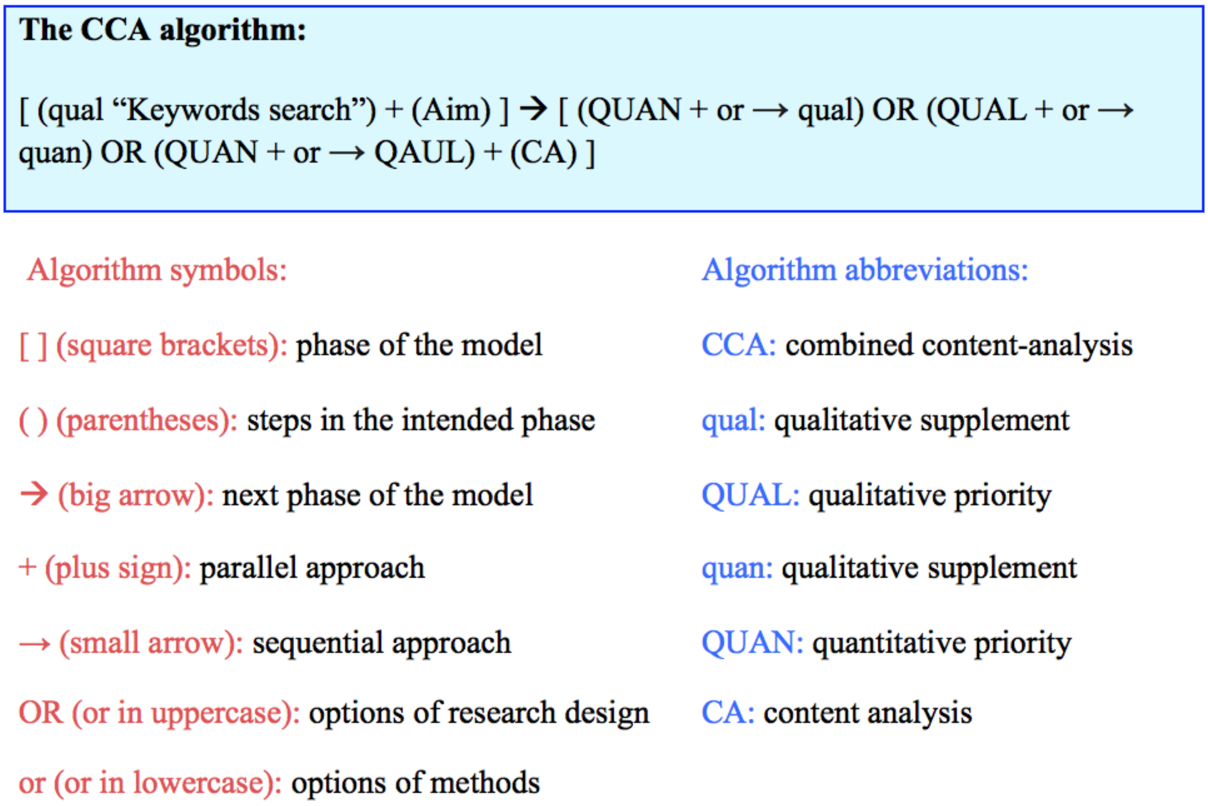
Model Development

Building on our review of the literature for key concepts, components, and data collection and analysis procedures of CA, and our appraisal of 18 health care social media studies, we propose the CCA model as a solid model for combining methods (quantitative and qualitative), coding procedures (inductive and deductive), and analytic modes (manual and automated) of CA. Our model is designed to address the mixed (quantitative and qualitative) nature of Twitter feed data in single or multiple-phase studies depending on the research aim of the phenomena under investigation. The model enables researchers to integrate methods and blend data in a single study—or a series of studies—using Twitter as a primary data source for analysis; it is a mixed-methods approach to CA research in the age of digital data. The CCA model integrates the major designs of mixed-methods research—the convergent, sequential, embedded, and transformative designs [48]—with the main features of each phase of CA. Our model can be divided into 3 phases: (1) preparation phase: research aim and keyword search and direction of the CCA model, (2) organization phase: sampling and data collection and coding procedure, and (3) interpretation and presentation phase: validation of study results and quality criteria and the use of computer software in CA.

Because text is always qualitative to begin with and the quantification of text alone is insufficient for successful understanding of content [7], quantitative and qualitative methods offer a more flexible alternative and dialectic integration of inductive (working from the data level) and deductive (working form the theoretical or hypothetical level) approaches. Given the nature of Twitter feeds, such an approach is more suitable than using CA without a clearly laid out and adapted methodology. The CCA model considers quantitative and qualitative perspectives either simultaneously (through a convergent parallel design) or sequentially, with either perspective serving as the predominant approach (through an explanatory or exploratory sequential design). Both quantitative and qualitative methods are embedded or nested within the predominant approach (through an embedded design). Those who are interested in ideology, political approaches, or theoretical frameworks (eg, critical theory, advocacy, or participatory research) aimed explicitly at societal change can use a transformative design with CA. The CCA design is useful when the researcher has more than 1 question best addressed through the use of multiple methods, or when the aim is to gain the best from each method by combining them to address a particular question. We propose an algorithm for the CCA model (see Figure 2).

When referring to potential mixed-methods design, in the CCA algorithm we used the most common notations (abbreviations) used in mixed-methods literature [48]. For example, 4 letters indicate the quantitative "quan/QUAN" and qualitative "qual/QUAL" methods of the model. The relative priority of the two methods within a particular study or research project is indicated through the use of uppercase and lowercase letters. In addition, within the mixed-methods design, the plus sign indicates methods that occur at the same time, and a small arrow indicates methods that occur in sequence. "OR" in uppercase letters refers to potential options of mixed-methods designs, and "or" in lowercase letters refers to options regarding priority of methods (see Figure 3 for the CCA model). More details about the model are discussed in the next sections.

Figure 2. The combined content-analysis (CCA) algorithm.



The CCA algorithm:

[(qual "Keywords search") + (Aim)] ➔ [(QUAN + or → qual) OR (QUAL + or → quan) OR (QUAN + or → QAUL) + (CA)]

Algorithm symbols:

[ ] (square brackets): phase of the model

( ) (parentheses): steps in the intended phase

➔ (big arrow): next phase of the model

+ (plus sign): parallel approach

→ (small arrow): sequential approach

OR (or in uppercase): options of research design

or (or in lowercase): options of methods

Algorithm abbreviations:

CCA: combined content-analysis

qual: qualitative supplement

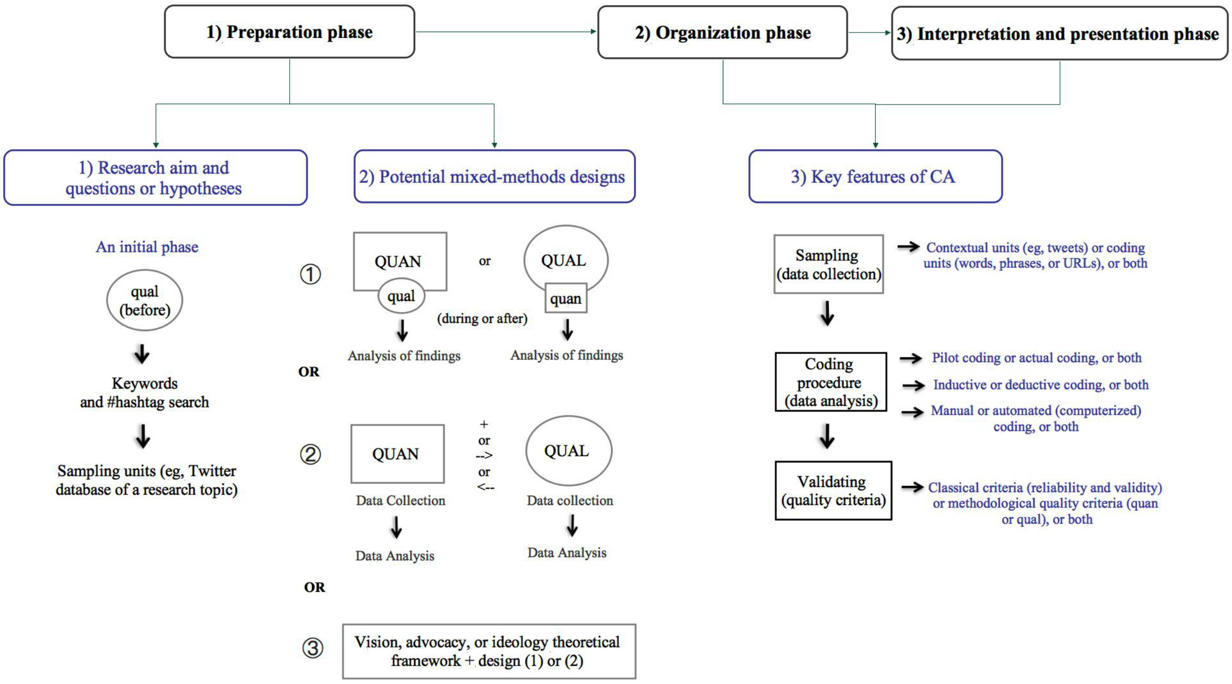
QUAL: qualitative priority

quan: qualitative supplement

QUAN: quantitative priority

CA: content analysis

Figure 3. The combined content-analysis (CCA) model. CA: content analysis; qual: qualitative supplement; QUAL: qualitative priority; quan: quantitative supplement; QUAN: quantitative priority.



Phase 1: Preparation

Researchers interested in health care social media-driven data can use Twitter as a rich and useful data source to generate information related to their health topic. This way of collecting data may go beyond traditional data collection methods (eg, observations, interviews, or focus groups), and researchers may have a large amount of textual data that is shared by a diverse group of people in a social and natural platform. Analyzing Twitter-driven content such as tweets can be a productive way not only to analyze text, but also to evaluate discourses surrounding health and disease-related issues [25,27]. Unless a Twitter account is protected by its user, Twitter content is largely public and freely accessible through the Twitter website or mobile and tablet apps (see Multimedia Appendix 1A for a Twitter overview).

Twitter features a search function (eg, keyword or hashtag search) to filter status updates that meet particular search criteria. Archive software is also available to search, track, store, and retrieve targeted health topics from collected tweets by date, time, and possible geographic location. Because reading any form of text, even using a technical search, is fundamentally an interpretive process regardless of its numerical outcomes [7], there is a need for a flexible model that takes into account qualitative as well as quantitative data to respond to multiple research aims. In the CCA, identifying the research aim, including the qualitative keyword search, and identifying the research direction are the 2 initial steps of the preparation phase of the model.

Research Aim and Keyword Search

Before conducting a study on health tweets, several factors are important for researchers to consider in deciding what CA approach to use. First, it is essential to confirm that data on their topic have been tweeted (preliminary search for data) and to determine the time frames or periods of time when this has occurred. Some Twitter databases may be created in response to a specific event (eg, an Alzheimer awareness day or month); the data cannot be interpreted well if that event (the context of the data) is not taken into account in the analysis. Discussions on specific health topics may not be established yet, and the number of tweets may be insufficient to facilitate analysis. Searching for health-related keywords in Twitter is the first step for any Twitter-driven study using CA. This step is common to traditional summative CA studies and mirrors the first part of the CCA model equation ([(qual "Keywords search") + (Aim)] →), which is usually qualitative in nature because it is done manually. However, the Twitter database itself may be collected directly from Twitter (eg, Twitter's advanced search), downloaded from chat recaps (eg, Twitter chat transcripts) using particular health care social media websites (eg, the Healthcare Hashtag Project [49]; see Multimedia Appendix 1B for examples of elder care tweet chats), or captured through an automatic mode using a Twitter archive software package (eg, Analytics for Twitter in Excel, Microsoft; or NCaptur in NVivo, QSR International). More advanced automated approaches that use algorithms and dictionaries or machine-learning approaches can be used to filter tweets. We briefly describe the use of software in assessing CA below. This step of the CCA model should also include establishing a clear plan and study objectives (eg, hypotheses or questions) that would meet the needs of the research, which is an important factor in the next step: choosing the appropriate methodology for conducting the research.

Direction of the CCA Model

Availability of data and worded objectives will help researchers choose the study, data collection, and analysis approaches to use. To make a final decision on study approach, it is important for researchers to consider which CA approach will be helpful in achieving their desired results. For example, researchers might ask the following questions. Should we test hypotheses by counting words (a single word), the co-occurrence of words (word-to-word), or text as a whole in the targeted tweets? Should we explain counted results using descriptive or inferential statistics and then integrate additional qualitative information (eg, QUAN + or → qual)? Should we try to understand the environment surrounding tweets (text and related context) by asking questions and seeking answers within the data and then support the answers using descriptive statistics (eg, QUAL + or → quan)? Are both numbers or hypotheses and words or questions equally important in understanding the big picture (eg, QUAN + or → QAUL)? Are we interested in an interpretive analysis of the content and, if so, what qualitative methods can best inform the design and analysis? By considering all of these factors researchers can choose an appropriate direction (and potential assisted software) for CA as per the second part of the CCA algorithm [(QUAN + or → qual) OR (QUAL + or → quan) OR (QUAN + or → QAUL) + (CA)].

Phase 2: Organization

The last part of the equation, "+ (CA)", includes the key feature of successful CA, which moves from selecting the sample of content, establishing the coding process, and developing or testing category schemes to determining the quality criteria of study results. We provide these steps and explanations of how combined mixed-methods approaches to CA (as shown in the CCA algorithm) can be applied to the analysis of Twitter feed content in this section.

Sampling and Data Selection

Although in all potential approaches—that is, "(QUAN + or → qual) + (CA)", "(QUAL + or → quan) + (CA)", and "(QUAN + or → QAUL) + (CA)", —researchers sample the text or "universe" [2,7] from a Twitter database or transcript of written tweets with or without attached material, such as pictures, URLs, or videos, there is no previous research on a validated sampling method for Twitter data [25]. This methodological gap poses a challenge for researchers in selecting the appropriate sample of tweets and defining its related context. Furthermore, there is a need for translation of Twitter texts into CA sampling terminology. On the basis of Neuendorf's [43] typology of CA texts, CA researchers should take into consideration the number of participants or setting of the messages. Twitter posts can be individual messages (for 1 user or between 2 or more users), interpersonal (group) messages, or organizational messages [50]. All three kinds of messages can help to define the appropriate context of collected tweets. In addition, Twitter posts consist of three types of CA units: sampling units (units of selection), contextual units (the largest textual units of analysis in a category), and coding or recording units (the smallest units of analysis or units of description). All three units need to be conducted within a suitable multistage sampling frame that differentiates CA from other methods of data collection. For example, the extracted Twitter database or selected transcripts of Twitter chats on a specific topic within a limited time frame can be identified as sampling units that identify the population and establish the basis for inclusion and exclusion criteria. The content of a single tweet can serve as a contextual unit. The recording or coding units can include different levels of units in a single tweet, such as words, phrases, URLs, pictures, or videos, that are the basis for establishing the coding schemes. A suitable selection and precise description of the different kinds of CA units can help with the evaluation of reported results in later steps of CA [4,8].

Despite the gap in the social media methodology literature about sampling, the CA literature follows the general direction of research paradigms [5,7]. Cohen et al [8] argue that the rules of sampling human subjects can be applied to sampling documents. Building on their argument, the same rules can be applied to social media data taking into account the nature of massive Web-based content and the sampling frame of CA. Based on existing paradigms, the number of tweets (many or few) in a Twitter database that are purposefully tracked or retrieved (using specific keywords or hashtags) and chosen for analysis, the method of selecting the tweets (probability or nonprobability sampling) within the database, and the time period of tweets (cross-sectional or over time) all affect the subsequent steps of CA. As a result, the “(QUAN + or → qual) + (CA)” approach would be appropriate for evaluating a random (representative) sample (thousands or millions) of tweets that are randomly selected, where each tweet has an equal chance of selection. In this case, there is a chance for generalizability, reproducibility, and making valid inferences from the text (the manifest content of analyzed tweets) to the universe (a broader representation of tweets) based on valid statistical conclusions with less focus on the context of the tweets. With random samples, it is also essential that researchers know all units (the universe) in the population (all Twitter database or potential sample of tweets related to the topic). Other probability sampling techniques, such as stratified sampling, can also be applied, when a range of dates or points in time may be set to focus on a random subsample of tweets. Contextual units and analysis units can be the same (tweets) in some cases (eg, when there is no material attached to the tweets and the whole tweet is used to establish categories); however, a unit of analysis cannot be larger than the unit of context. It is important to carefully define all three kinds of units, because different levels of units may influence the credibility of CA [4] and require different levels of reliability [7,8]. In addition, the sample can be completely randomized before initiating the coding process; however, the supplemental or sequential “qual” part in this approach can work, and, if needed, collecting a small (purposeful) subsample (eg, tweets of top or active users or chat managers) can assist in refining the codes developed from the random sample during or after the dominant “QUAN” analysis.

On the other hand, with the “(QUAL + or → quan) + (CA)” approach, the focus is on the transferability rather than the generalizability of results. As such, researchers can purposefully collect a sample of tweets (hundreds) within the tweets database that is unique to specific users (eg, regular users or chat managers of a specific topic identified by an elder care-related hashtag), events (eg, an elder care-related event), or researchers’ assumptions about such tweets. Nonprobability samples, such as purposeful, convenience, and other types of qualitative samples, allow for the collection of important interpretive data and for the consideration of research questions that acknowledge the contexts, meanings, emphasis, and thematic dimensions of the topic. For example, a researcher might select his or her purposeful sample based on selected tweets of a popular health care community on Twitter (eg, #AlzChatUS). The selection of data may continue throughout the coding phase. Once the researcher establishes a rationale for specific tweets (which are likely to involve purposive, convenience, or other nonrandom sampling methods), the dominant direction of the study will no longer be quantitative, unless the rationale is combined with a random sampling method for the inclusion of tweets in the study. For instance, if researchers choose to analyze the random tweets of top users on an Alzheimer awareness month or day, the “(QUAN + or → QAUL) + (CA)” approach might lead the study, because the tweets, their environment, and specific (top) users are important. Regular tweets about Alzheimer disease from users tweeting on this subject may differ from tweets and users on Alzheimer awareness month or day. If researchers want to choose their sample purposefully (tweets of Alzheimer awareness month or day) but also want to track the changes of tweets over time (eg, in 2010, 2012, and 2013), this also means that the two approaches lead the study equally, because the aim is to track changes over time related to a specific event or Twitter context. It is important, however, to note that there is a potential for rich data within the structure of the social network from which the textual information is derived—information that may best be understood through an application of social network analysis. Such analyses are, however, beyond the scope of this paper. Further information may be found in Gruzd and Haythornthwaite [51].

Coding Procedure and Data Analysis

Establishing coding categories is one of the most fundamental steps in CA, especially for checking the quality criteria of the study, such as trustworthiness [4]. As explained in Figure 1, while coding in the “(QUAL + or → quan) + (CA)” approach can be inductive or deductive, “(QUAN + or → qual) + (CA)” is always deductive, and researchers may rely on coding schemes devised by other researchers or theories. Categories provide the structure for grouping the recording or coding units and can be considered the heart of CA, because when there is a large amount of textual data, text can be reduced into fewer and more abstracted categories or concepts [8] either to develop a theory or to support an existing theory. Therefore, categories must relate to the research goal and be designed to truly respond to the research questions [2,46]. As Berelson [11] pointed out, successful CA is seen in studies with well-structured categories that are strongly related to the research goal of the analyzed content. To systematize and organize CA, structured and well-defined categories are important. Categories that are exhaustive, mutually exclusive [9], and independent allow all relevant items (eg, scientific information, news, and personal statements) in a tweet to be placed into a single category. With deductive approaches to coding, the coding scheme is developed before the coding begins in order to test hypotheses or retest models or theories (eg, [41]). If adjustments are made during coding, items already coded must be recoded with the revised scheme. In contrast, in inductive coding the coding scheme is usually guided by the study questions and developed in the process of close and iterative reading (and sometimes sampling new tweets) to identify significant concepts and patterns (eg, [42]). Furthermore, researchers can record memos of their comments during the analysis, and these memos can be used in the inductive coding process. The overall process of inductive coding may suggest new questions that were unanticipated at the start of the analysis and that can be added to the study questions. In addition, inductive coding can be guided by more specific qualitative approaches, such as discourse analysis, rhetorical analysis, or ethnography [7]. For example, using qualitative coding with discourse analysis can take the analysis of tweets to a more advanced level than just coding the words to include symbols and related emotions (eg, [30]). These qualitative approaches can be modified to fit the purpose of collecting digital data. The integration of both the inductive and deductive procedures is sometimes called abduction [44], in which theory-oriented and data-oriented categories are generated simultaneously or sequentially.

Phase 3: Interpretation and Presentation

It is suggested that CA has the potential to be a valid and reliable tool to summarize extensive content if it is conducted carefully with clear and understandable results and well-described categories. This strength of the research is enhanced when researchers explain how they matched the reported results in their study with the study's aim, questions, and hypothesis. This matching can be done with the use of quality criteria of CA. When considering the evaluation of CA results, there are two ways to ensure the rigor of a CA study: (1) using classic criteria to determine valid and reliable CA, and (2) using specific criteria to assess quality within the dominant research paradigm used. With the first way, while validity and reliability concepts can be used with quantitative CA, QUAN-dominant study and results can be presented through basic and advanced statistics (eg, percentages, probability, or inferences) that allow for objectivity and replication. Credibility, transferability, dependability, conformability, and other areas for ensuring trustworthiness [52] can be used in QUAL-dominant studies [5], and a group of these concepts can be used if the QUAN and QUAL approaches are used equally in the study. In the next sections, we discuss the issues associated with the validation of CA results. Furthermore, we discuss how the use of computer software can help with the preparation, analysis, interpretation, and validation of CA results.

Validation of Study Results and Quality Criteria

Schreier [6] claimed that in validating the results of CA, there are no clear divisions between approaches. Terms such as rigor, reliability, and validity are usually used with either the qualitative or quantitative approach to CA, despite their positivistic origin from quantitative research or constructivist origin from qualitative analysis. Therefore, reliability, in particular ICR, is often used as a classic quality criterion for both qualitative and quantitative CA. The use of ICR is consistent with the most common use of CA to evaluate study results in the literature. With ICR, at least two coders usually conduct the analysis, especially if the deductive procedure is used for either QUAN or QUAL as the predominant approach. ICR reliability is one type of reliability that is often used to insure the reproducibility of a coding matrix in deductive coding of data [7], that is, the likelihood that all coders under different circumstances will code the same group of items the same way (consistency and agreement between coders). This ensures that categories are sufficiently defined so that all coders reach the same conclusion.

Another way to test ICR reliability is to use reliability checks before conducting the analysis, which often entails pilot coding (trial coding) or pretesting categories several times before the actual coding. Pilot coding involves coding a small portion of the tweets to be analyzed or all tweets generated before selecting the sample (all retrieved sampling units). Such a pretest can enable researchers to determine whether the categories are clearly specified and meet the requirements, that the coding instructions are adequate, and that coders are familiar with the data and are suitable for the job. It is recommended that with a QUAN-dominant study, the sample of pilot coding should be different from the sample of actual coding. In contrast, if the QUAL-dominant approach is used, the sample of pilot coding should be a subset of the sample of actual coding [6]. Once high reliability standards of the pilot phase are met (all categories are pretested and critically examined and modified), the actual coding can begin. High ICR reliability can strengthen the validity of the coding procedure; however, reliability is not guaranteed [9]. With a large amount of text, the comparison of results between coders becomes more difficult. Therefore, both ways of testing ICR are needed to ensure reproducibility and reliability as a way of producing stability of results over time [7].

With an inductive coding procedure, on the other hand, reliability checks between coders may not be helpful when an in-depth (line-by-line) analysis and iterative process is required. According to Elo et al [4], qualitative coding takes time and requires going back and forth with the data several times to ensure credibility and confirmability of findings. Therefore, it is suggested that 1 researcher can code the data, and experts in the targeted topic, participants, or readers can evaluate the coded data. This quality criterion may be referred to as intracoder reliability or member checking. As a requirement for intracoder reliability, the coding scheme should have clear definitions, straightforward instructions, and unambiguous examples or quotes to help assess the quality of results [4].

Validity with CA may refer to the representation of the intended concept [43] and that the data of the study has good face validity [4]. Construct validity is also significant to CA, meaning that categories truly test the proposed hypotheses or answer the study questions. In addition, mutually exclusive categories should be maintained to ensure validity and proper statistical inferences in QUAN studies. In a "(QUAN + or → qual) + (CA)" study, sampling validity is strongly related to the selected sample [7]. A biased and unrepresentative sample would hurt the study. Although with a "(QUAL + or → quan) + (CA)" study all decisions regarding sampling must be justified and the sampling strategy must be explicitly described (systematic sampling procedure), in qualitative CA research the important criterion is not numeric, but conceptual consistency between observation and conclusion. Findings are confirmed by looking at the data, not the sample or coder(s), to determine validity. If the data support the conclusions, the study is valid. Thus, validity checks are more important than reliability checks in this case [6].

Representing the results linked to the quality criteria of CA, particularly showing the connection between the aim of the study and the reported data [4], is important. Difficulties in structuring the data are related to unsuccessful CA analyses or to challenges that researchers face in the abstraction process. In contrast, clear and systematic representation of the data corresponds to successful analysis [15]. Conceptualization of coded results may differ according to the CA design used. For example, researchers may use numbers or percentages, either in simple tabulations or in cross-tabulations, to show relationships, but they may also rely on the gradual accretion of details within the textual presentation without resorting to numbers. While represented quotations, figures, and flowcharts of coded concepts are recommended in the QUAL approach to CA [4], frequency tables, percentages, and more advanced statistical values are recommended for the QUAN approach to CA [7].

Using Computer Software in CA

This section summarizes how technology can be used to facilitate different approaches of CA. As mentioned, the main idea behind CA is to break down a large amount of text into small codes, nodes, categories, themes, or concepts by making links between those concepts to support an emergent theory or test an existing theory [8]. The use of software for CA depends on many factors that can only be decided based on each individual project [1]. The number of researchers and their level of experience with the chosen methodology, the amount of coded text, the study's financial plan, and the availability of and preferences for computers are important factors in determining the mode of CA. In the CA literature, software packages have been used to assist the process of coding [7,44], saving time and handling the hard work associated with manual coding of textual data (eg, highlighting sentences, writing analytical memos, and retrieving and connecting codes). Another reason is that computerized CA may enhance the validity and reliability of the coded data by filtering tweets, classifying codes, managing the sampling of text, and producing the same results across human coders each time they run the data [1,7,44].

In aiding CA, the software can be classified into two types: (1) computational software packages, such as text mining and statistical software packages [43], and (2) qualitative analysis software, such as computer-assisted/aided qualitative data analysis software (CAQDAS) packages [44]. Under each classification there are various types of packages and different analysis techniques. The role of software used may vary according to the aim and methodological plan of the study. For example, the role of software in a qualitative CA study is not to perform the analysis; rather, it is limited to the facilitation of data management and the analytical process carried out by the researcher. In contrast, the software for quantitative CA can do a lot more than aid in the analysis, as it can automatically code the words that have been decided in the dictionary of key terms created by the researcher [6]. Table 3 provides a nonexhaustive list of available software packages and their reference websites. It is recommended that researchers compare and contrast software features, examining the utility of software based on the study methodology and type of data gathered for analysis. In addition, training sessions for computerized coding is required for coders to deal with the complexity of data analysis, to reduce coding errors, and to ensure that the produced results answer the research questions [8].

Table 3. Selected software to aid content analysis.

Software (source)	Web address
Computational software packages	
Analytics for Twitter for Excel (Microsoft)	www.microsoft.com/en-us/download/details.aspx?id=26213
twitteR (The Comprehensive R Archive Network)	cran.r-project.org/package=twitteR
Tweet Archivist (Tweet Archivist)	www.tweetarchivist.com
Twitter Analytics (Twitter)	analytics.twitter.com/about
Qualitative and integrative software packages	
CAQDAS[a,b]Networking Project (University of Surrey)	www.surrey.ac.uk/sociology/research/researchcentres/caqdas/support/choosing/
Other	
Text Analysis Info (Social Science Consulting)	textanalysis.info/pages/text-analysis-software---classified.php

[a] CAQDAS: CAQDAS (computer assisted qualitative data analysis) networking project.

[b] For example, ATLAS.ti, NVivo, MAXQDA, Dedoose, HyperRESEARCH.

In addition to the benefits of computerized coding listed above, software can be used to capture multiple types of data, such as multimedia data (eg, sounds and videos). On Twitter, for example, tweets can be coded manually or by data-analysis software depending on the leading approach chosen, length and format of the text (tweets), and the researchers' aims. It is suggested that with limited qualitative data, manual coding provides a better understanding of the meanings between the lines [15]. CAQDAS software programs (eg, ATLAS.ti, NVivo, and MAXQDA) can be used for larger texts to make CA more manageable and ordered. On the other hand, Twitter's application programming interface streaming [53] and quantitative statistical software (eg, R or Analytics for Twitter Excel add-ins) can be used with more advanced statistical analysis of tweets, such as multivariate analysis and factor analysis. With the use of the research approach suggested through the CCA model, numerous software packages can be used to aid the collection and analysis of data, especially when applying algorithmic approaches to CA (eg, machine-learning approaches [54]), where, for instance, software (eg, Python packages [53]) can be used to specify models and identify patterns to extract the content computationally based on a certain classification and categorizing of highest probability (statistical classification). Other software (eg, CAQDAS packages) can be used to code the gathered contextual content with support of human coders (eg, [55]).

Conclusions

CA is a prevalent methodology used to analyze health care social media-driven content, such as Twitter feeds. With the digital revolution of social networking platforms, Twitter has become a common source for online discussions on health issues; thus, health researchers need to become familiar with a structured model of CA that can respond to the nature of the retrieved digital data and the varied purposes of their studies. This paper reviews the general and health care literature of CA and evaluates how CA was used in Twitter-driven studies between 2010 and 2014. The CCA model is suggested as a new research framework that takes into account the various dimensions of the CA research methodology in a way that allows for mixing methods, procedures, and modes and components of CA. Thus, the CCA model will be useful in designing new studies (as a structured model) and evaluating existing studies (as an outline or checklist) that require or use various types or multiple modes of information within a single coherent model. The model integrates the main features of CA with the most common designs of mixed-methods research to facilitate the application and evaluation of studies that intend to use CA to analyze social media-driven content related to the researched phenomenon.

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Authors' Contributions

This manuscript was a part of EH's doctoral comprehensive exam. EH designed the study, reviewed related literature, and drafted the first version of the manuscript. MS, JH, and AJ contributed to the quantitative perspective of the study. EK contributed to the qualitative perspective of the study. All authors discussed the study design and contributed to the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

(A) Twitter overview. (B) Examples of eldercare tweet chats [51].

[PDF File (Adobe PDF File), 221KB - jmir_v18i3e60_app1.pdf]

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Abbreviations

CA: content analysis
CAQDAS: computer-assisted/aided qualitative data analysis software
CCA: combined content analysis
ICR: intercoder reliability
QUAL: qualitative priority
qual: qualitative supplement
QUAN: quantitative priority
quan: quantitative supplement

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Original Paper

Finding the Patient’s Voice Using Big Data: Analysis of Users’ Health-Related Concerns in the ChaCha Question-and-Answer Service (2009–2012)

Chad Priest[1], RN, MSN, JD; Amelia Knopf[2], RN, MPH, PhD; Doyle Groves[2], BS; Janet S Carpenter[2], RN, PhD, FAAN; Christopher Furrey[2], RN, BSN; Anand Krishnan[3], MS; Wendy R Miller[2], RN, PhD; Julie L Otte[2], RN, OCN, PhD; Mathew Palakal[3], PhD; Sarah Wiehe[4], MPH, MD; Jeffrey Wilson[5], PhD

[1] Social Network Health Research Laboratory at the Indiana University School of Nursing, School of Medicine, Department of Emergency Medicine, Indiana University, Indianapolis, IN, United States

[2] Social Network Health Research Laboratory at the Indiana University School of Nursing, School of Nursing, Indiana University, Indianapolis, IN, United States

[3] Social Network Health Research Laboratory at the Indiana University School of Nursing, School of Informatics and Computing, Indiana University, Indianapolis, IN, United States

[4] Social Network Health Research Laboratory at the Indiana University School of Nursing, School of Medicine, Indiana University, Indianapolis, IN, United States

[5] Social Network Health Research Laboratory at the Indiana University School of Nursing, School of Liberal Arts, Indiana University-Purdue University at Indianapolis, Indianapolis, IN, United States

Corresponding Author:
Chad Priest, RN, MSN, JD
Social Network Health Research Laboratory at the Indiana University School of Nursing
School of Medicine, Department of Emergency Medicine
Indiana University
Suite 3100
410 W 10th St
Indianapolis, IN, 46202
United States
Phone: 1 317 278 4048
Fax: 1 317 274 0787
Email: cspriest@iu.edu

Abstract

Background: The development of effective health care and public health interventions requires a comprehensive understanding of the perceptions, concerns, and stated needs of health care consumers and the public at large. Big datasets from social media and question-and-answer services provide insight into the public’s health concerns and priorities without the financial, temporal, and spatial encumbrances of more traditional community-engagement methods and may prove a useful starting point for public-engagement health research (infodemiology).

Objective: The objective of our study was to describe user characteristics and health-related queries of the ChaCha question-and-answer platform, and discuss how these data may be used to better understand the perceptions, concerns, and stated needs of health care consumers and the public at large.

Methods: We conducted a retrospective automated textual analysis of anonymous user-generated queries submitted to ChaCha between January 2009 and November 2012. A total of 2.004 billion queries were read, of which 3.50% (70,083,796/2,004,243,249) were missing 1 or more data fields, leaving 1.934 billion complete lines of data for these analyses.

Results: Males and females submitted roughly equal numbers of health queries, but content differed by sex. Questions from females predominantly focused on pregnancy, menstruation, and vaginal health. Questions from males predominantly focused on body image, drug use, and sexuality. Adolescents aged 12–19 years submitted more queries than any other age group. Their queries were largely centered on sexual and reproductive health, and pregnancy in particular.

Conclusions: The private nature of the ChaCha service provided a perfect environment for maximum frankness among users, especially among adolescents posing sensitive health questions. Adolescents’ sexual health queries reveal knowledge gaps with serious, lifelong consequences. The nature of questions to the service provides opportunities for rapid understanding of health concerns and may lead to development of more effective tailored interventions.

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KEYWORDS

social meda; health information seeking; adolescent; sexual health; patient engagement; ChaCha; big data; question-and-answer service; infodemiology; infoveillance

Introduction

The development of effective health care and public health interventions requires a comprehensive understanding of the perceptions, concerns, and stated needs of health care consumers and the public at large [1,2]. Clinical and behavioral interventions are most successful when aimed at improving outcomes that are important and relevant to patients. Interventions targeted at these patient-centered outcomes are most effectively developed when patients are engaged in the research process, particularly regarding the identification of salient problems. Funders of health care research increasingly expect proposals to include substantial evidence of attention to patient-centered outcomes through public engagement in the research process, including the process of developing and framing research questions [1-3].

There are many successful models of engaging the public in research, ranging from long-term engagement models such as community-based participatory and action research to the use of focus groups, interviews, and specific designs to elicit stakeholder feedback [4,5]. However, there are substantial challenges associated with these approaches. First, these approaches require a significant investment of time and resources, valued commodities that may not be available to researchers and their teams, nor to communities and their members [6]. Second, in traditional research geographic constraints often limit the number and diversity of individuals who can be included in a single project. Third, most of these methods begin with an a priori research question relevant to the community but often generated by the researcher, which restricts public involvement in the framing of research priorities [7]. In order to overcome the aforementioned limitations and develop relevant and effective patient-centered health interventions, new methods of patient and public engagement are needed.

The Internet has changed the ways in which people seek out and share health-related information [8,9]. Research shows that 35% of Americans report having used the Internet, including social media platforms, to determine what medical condition they or someone they know might have [9,10]. Advances in mobile phone technology make searching the Internet for health-related issues even easier. A recent poll found that 62% of mobile phone owners have used their phone in the past year to look up information about a health condition [11]. Researchers have increasing access to anonymized data from these sites, which have thus far been used to research and disseminate information about disease and disease processes [12]. More recently, social media and other Web-based data sources have been used to facilitate early outbreak detection [13-15]. These datasets can also be used as a point of entry for public involvement in health research. Social media data provide insight into the public's health concerns and priorities without the financial, temporal, and spatial encumbrances of more traditional community-engagement methods. While these newer methods cannot replace the more traditional ones, social media methods may prove a useful starting point for public engagement in the health research enterprise.

In 2014, the Indiana University Social Network Health Research Laboratory developed a partnership with ChaCha (ChaCha Search, Inc, Carmel, IN, USA) [16], a US-based company that operates a human-guided question-and-answer service that provides free, real-time answers to any question through its website, text messaging, or mobile apps. The data provide a powerful and unique opportunity to listen to the authentic health concerns of individuals. Other Internet-based platforms also provide opportunities to assess population health concerns. Social media platforms have been widely discussed in the literature [17-20]. These platforms, while valuable, are designed for users to communicate with a broad audience of friends or the public at large (eg, Twitter, Facebook), and posts are part of social identity presentation [21]. Conversely, ChaCha queries are a private exchange between an anonymous user and anonymous human guides or a computer. The private nature of the exchange allows users to put forth questions that may be stigmatizing in other settings.

Through our partnership with ChaCha, our laboratory is examining the use of Internet-based question-and-answer services to elicit the patient's voice and develop health interventions that resonate with public concern. The purpose of this paper is to describe ChaCha user characteristics and health-related queries, and to discuss how this big dataset may be used to better understand the perceptions, concerns, and stated needs of health care consumers and the public at large.

Methods

In early 2015 we conducted an automated retrospective textual analysis of 1.9 billion anonymous queries submitted to ChaCha by 19.3 million unique users between January 2009 and November 2012. Because we analyzed only existing, de-identified data, the Indiana University Institutional Review Board determined that the study did not meet definitions of human subject research.

We aggregated queries by year in tabulated ASCII text files, in which each line contained 16 data fields representing 1 ChaCha query and 16 associated descriptors (Table 1). Each year's file was imported to a Linux machine with 64 GB of RAM. Perl scripts were used to parse and summarize the raw data for cleaning and subsequent analyses. A total of 2.004 billion queries were read, of which 3.50% (70,083,796/2,004,243,249) were missing 1 or more data fields, leaving 1.934 billion complete lines of data for these analyses.

Table 1. Description of data fields in queries submitted to the ChaCha question-and-answer service.

Field	Description
1	Date and time (eastern time) of query
2	Full category path
3	Auto-detected category
4	Auto-detected subcategory
5	Source type (voice, text message)
6	System used to route and answer question
7	City in which user lives (user reported)
8	State in which user lives (user reported)
9	Region in which user lives (derived from state given in field 8)
10	Country in which user lives
11	Area code of user’s phone number (user reported)
12	Zip code in which user lives (user reported)
13	User’s sex (user reported)
14	User’s age (user reported)
15	User unique identifier (machine generated)
16	Text of query

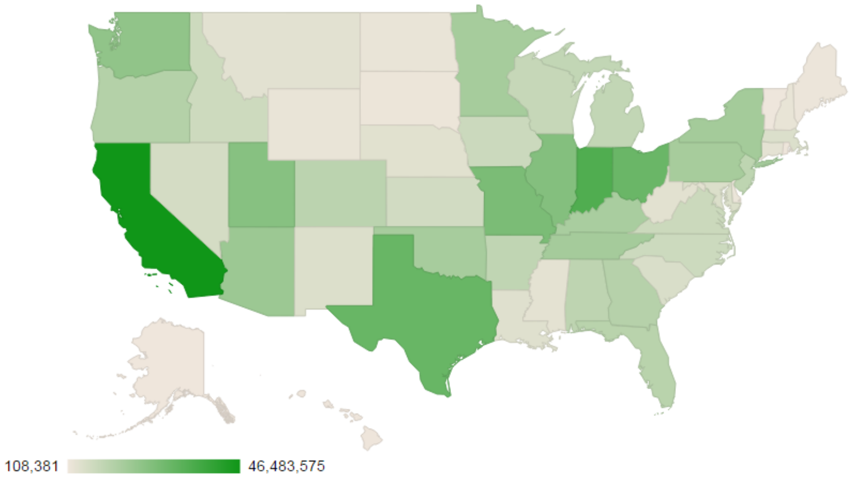
Results

User Characteristics

There were 19.3 million unique ChaCha users who submitted at least one query during the dates under study. The median user age was 17 years, and approximately 68.35% (5,431,866/7,947,118) of users were younger than age 20 years. There were roughly equal numbers of male (4,367,538/8,875,704, 49.21%) and female (4,508,166/8,875,704, 50.79%) users. The median number of queries per user was 16, with a range of 1–1128 (99th percentile). Approximately 75.93% (1,468,646,207/1,934,159,453) of queries had user profiles from which we could derive the user’s sex, and similarly age from 74.41% (1,439,144,291/1,934,159,453) of queries. A little more than half (800,109,775/1,468,646,207, 54.48%) of these queries were submitted by females. The majority (987,749,753/1,439,144,291, 68.63%) were submitted by users between 12 and 19 years of age. Among these adolescent users, more queries were submitted by females (603,941,883/1,053,718,318, 57.32%) than by males (449,776,435/1,053,718,318, 42.68%). In total, 74.26% (1,436,399,307/1,934,159,453) of queries were made via short message service text message, and the rest from a mix of Web interface, other mobile apps, and voice calls to an automated system. User location (place of residence) was missing for about 73.56% (1,422,701,099/1,934,159,453) of queries. The vast majority of queries were made from the United States (1,933,171,565/1,934,159,453, 99.95%), and approximately 0.05% (987,887/1,934,159,453) of queries originated from the United Kingdom. Figure 1 depicts the user’s location in the United States for the 26.44% (511,458,354/1,934,159,453) of queries for which this information was available.

Service use peaked in 2011, during which there were nearly 672 million queries. Monthly service use fluctuated between 10 million queries in January 2009 and a peak of approximately 60 million queries in May 2011. There were no noteworthy service use trends by month or day of the week. Users most often submitted their questions between 9 PM and 12 AM.

Figure 1. Number of queries posted to ChaCha by user location within the United States, 2009-2012.



Content of Queries

All incoming queries were initially filtered a by proprietary ChaCha algorithm that identifies keywords to sort 75.45% (1,459,279,135/1,934,159,453) of queries into 12 broad categories (Table 2) that are further divided into 129 subcategories. Excluding ChaCha customer service-related questions, the queries we analyzed most commonly fell into 5 ChaCha-described categories: (1) Entertainment & Arts, (2) Language & Lookup, (3) Society & Culture, (4) Science & Technology, and (5) Health. Of a total of 106 million health queries, 78.17% (83,056,248/106,254,243) were generated by users who specified their sex and age. We focus here on the subset of those queries (n=68 million) that passed a proprietary ChaCha algorithm that looks for sentence structure, interrogative words, and other factors to filter out “bad questions” that lack sufficient information to be answered.

Table 2. Queries submitted to ChaCha: question counts by category and sex (n=1,459,279,135).

Category	Total number of questions	Questions per male user	Questions per female user	% male users, this category	% female users, this category	% of categorized questions (n=1,459,279,135)
Entertainment & Arts	391,911,144	40.2	42.4	49.36% (3,850,766/7,801,869)	50.64% (3,951,103/7,801,869)	26.86% (391,911,144)
Language & Lookup	226,403,804	19.4	25.9	48.49% (3,786,865/7,809,778)	51.51% (4,022,913/7,809,778)	15.51% (226,403,804)
Customer Service	174,889,683	17.5	19.0	49.27% (3,727,948/7,566,817)	50.73% (3,838,869/7,566,817)	11.98% (174,889,683)
Society & Culture	136,908,800	12.5	17.2	48.62% (3,354,359/6,899,650)	51.38% (3,545,291/6,899,650)	9.38% (136,908,800)
Science & Technology	109,703,527	11.1	10.5	49.97% (3,437,238/6,878,206)	50.03% (3,440,968/6,878,206)	7.52% (109,703,527)
Health	106,247,678	11.7	16.4	47.17% (2,847,543/6,036,379)	52.83% (3,188,836/6,036,379)	7.28% (106,247,678)
Sex	89,136,284	15.7	12.6	51.09% (2,587,600/5,064,404)	48.91% (2,476,804/5,064,404)	6.11% (89,136,284)
Lifestyle	74,829,194	8.1	9.5	48.87% (3,095,517/6,334,749)	51.13% (3,239,232/6,334,749)	5.13% (74,829,194)
Politics & Government	47,119,373	6.7	6.6	50.26% (2,436,934/4,848,274)	49.74% (2,411,340/4,848,274)	3.23% (47,119,373)
Sports	46,741,475	9.7	5.1	55.51% (2,617,724/4,715,548)	44.49% (2,097,824/4,715,548)	3.20% (46,741,475)
Business	29,509,62	4.4	4.3	49.60% (2,148,975/4,332,832)	50.40% (2,183,857/4,332,832)	2.02% (29,509,621)
Travel	25,878,552	3.7	4.2	47.93% (2,190,337/4,569,614)	52.07% (2,379,277/4,569,614)	1.77% (25,878,552)

We examined whole-sentence health queries, first those that were generated by roughly equal proportions of males and females, then those that were predominately (≥90%) submitted by females, and finally those predominately (>80%) submitted by males. Among the sex-balanced queries, questions about pregnancy were by far the most prevalent, such as the following: “How are babies made?” “Can you get pregnant on your period?” “What are the signs of pregnancy?” The only other health query frequently submitted by both males and females was about the length of time that alcohol remains in the body.

The queries submitted predominately by females focused on signs and symptoms of reproductive and urinary tract infections, ovulation, and pregnancy. The most common query was about signs and symptoms of yeast infection, followed by inquiries about how to treat, get rid of, or cure a yeast infection. Females more commonly than males asked about the menstrual cycle and its relationship to pregnancy: “When do you ovulate?” “When are you most likely to get pregnant?” “Am I pregnant?” Toxic shock syndrome was frequently mentioned by females, who wanted to know more about its symptoms. Other predominately female user queries included body image questions such as “How can you make your butt bigger?” “How do you get rid of cellulite?”, and 1 relational question: “How do you get over a guy?”

Whole-sentence queries submitted predominately by males focused on body image, particularly penis size and methods for increasing it: “Does ExtenZe work?” “How to make your penis bigger?” “How do I get a six-pack?” Marijuana was the next most-common subject of health queries submitted by males: “What is the best kind of marijuana?” “How many grams in an ounce?” “Why is marijuana illegal?” This was followed by queries related to women’s anatomy and physiology: “How deep is a vagina?” “How do you get a girl pregnant?” Personal health queries focused on testicular discomfort (pain, itching), whether creatine use is safe, and physical fitness goals.

Next we examined smaller word groups, of 2- and 3-word phrases, sorted by sex. Table 3 presents the 10 most prevalent 3-word phrases submitted by males, and Table 4 shows those submitted by females. Findings mirrored the whole-word analysis with the addition of weight-loss questions arising in queries submitted by both male and female users. Figures 2 and 3 illustrate the most prevalent 2-word phrases submitted predominately by males and females, respectively. Figure 4 shows the most prevalent 2-word phrases submitted by both males and females.

Table 3. The most prevalent 3-word phrases submitted to ChaCha by males.

3-word phrase	Total queries where sex indicated	No. submitted by males	% from males
girl pregnant period	31,670	20,892	65.97% (20,892/31,670)
pass drug test	84,231	55,328	65.69% (55,328/84,231)
stay ur system	24,880	15,944	64.08% (15,944/24,880)
fail drug test	20,372	12,823	62.94% (12,823/20,372)
urine drug test	16,183	10,075	62.25% (10,075/16,183)
kill brain cells	22,120	13,477	60.92% (13,477/22,120)
marijuana stay system	23,891	13,765	57.61% (13,765/23,891)
long marijuana stay	30,325	17,410	57.41% (17,410/30,325)
long-term effects	24,048	13,623	56.65% (13,623/24,048)

Table 4. The most prevalent 3-word phrases submitted to ChaCha by females.

3-word phrase	Total queries where sex indicated	No. submitted by females	% from females
symptoms yeast infection	36,158	32,177	88.99% (32,177/36,158)
15 year girl	33,139	28,245	85.23% (28,245/33,139)
early signs pregnancy	49,749	40,368	81.14% (40,368/49,749)
urinary tract infection	91,179	72,242	79.23% (72,242/91,179)
birth control pills	101,851	79,706	78.26% (79,706/101,851)
birth control pill	69,488	53,437	76.90% (53,437/69,488)
help lose weight	79,265	59,683	75.29% (59,683/79,265)
lose weight fast	52,361	39,264	74.99% (39,264/52,361)
pregnant birth control	48,347	33,946	70.21% (33,946/48,347)

Finally, we examined patterns in queries by age groups. The most prevalent 2-word phrases in queries from users aged 13–19, 20–39, and ≥40 years are depicted in Figures 5-7, respectively.

Among adolescents younger than 19 years, more females than males submitted queries, whereas among young adults aged 19–29 years, more males than females submitted queries. Age patterns were also sex-related patterns, as reflected in the most prevalent 3-word phrases (Table 5).

Table 5. Use of 3-word phrases when submitting queries to ChaCha, by sex and age.

Age in years	Males	Females
13–19	average weight 17	17 year girl
	weight 17 year	weight 17 year
	16 year olds	18 year girl
20–39	pill white oblong	pill oblong white
	pill oblong white	pill white oblong
	side blank side	white oblong pill
≥40	white oblong pill	congestive heart failure
	congestive heart failure	side blank side
	13 year girl	small round white

Figure 2. The most prevalent 2-word phrases submitted to ChaCha predominately by male users.

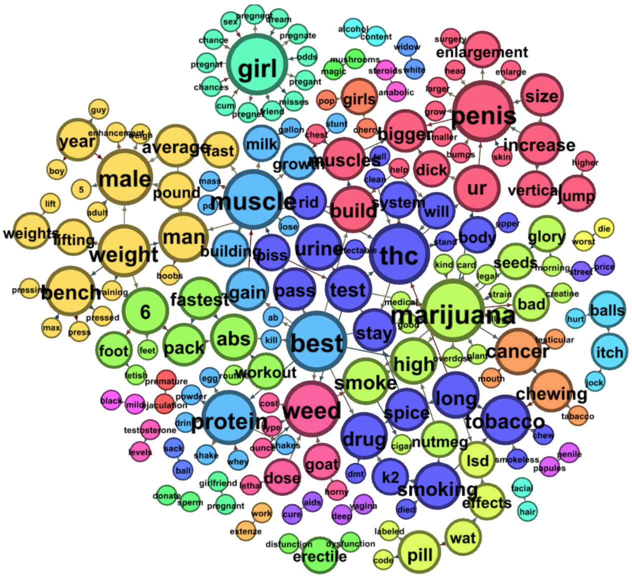


Figure 3. The most prevalent 2-word phrases submitted to ChaCha predominately by female user.

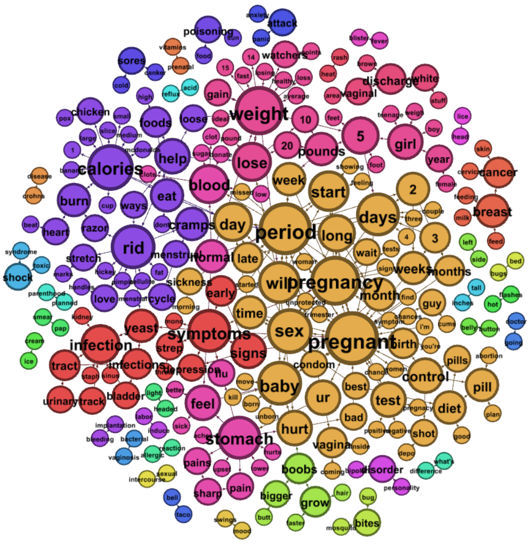


Figure 4. The most prevalent 2-word phrases submitted to ChaCha by both males and females.

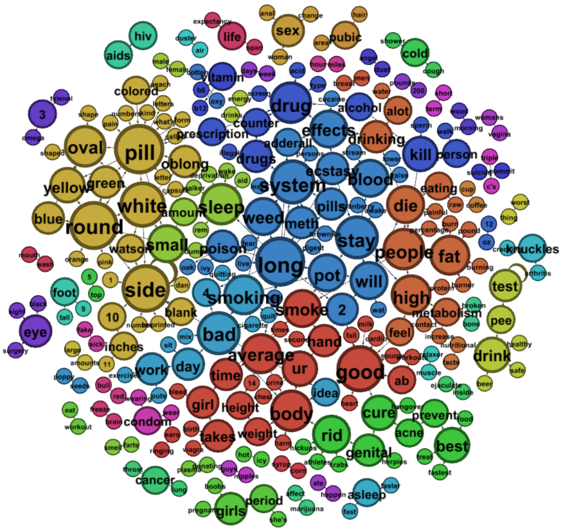


Figure 5. The most prevalent 2-word phrases submitted to ChaCha by users aged 13â€“19 years.

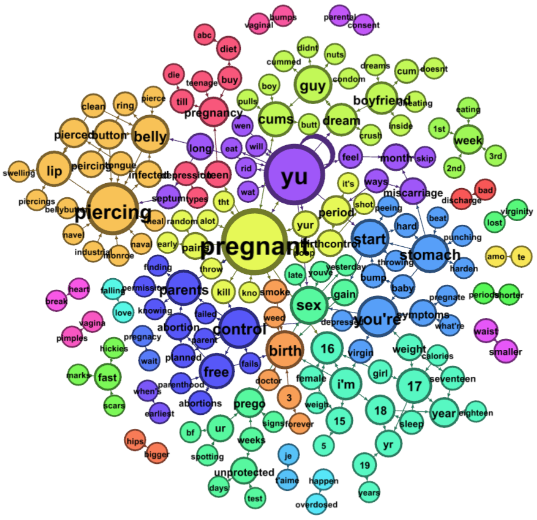


Figure 6. The most prevalent 2-word phrases submitted to ChaCha by users aged 20â€“39 years.

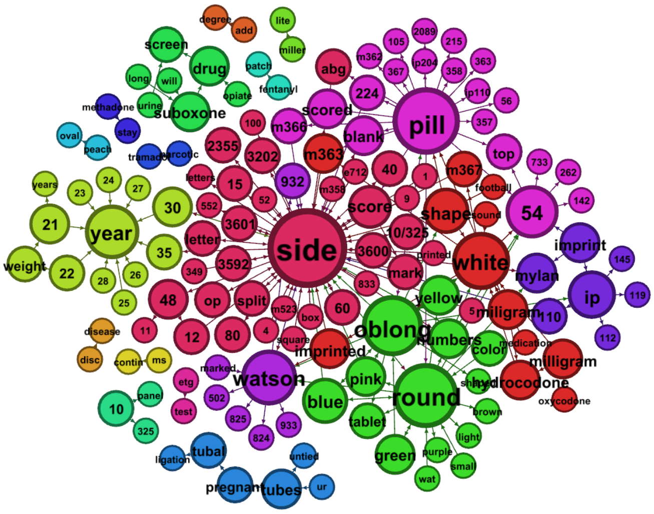
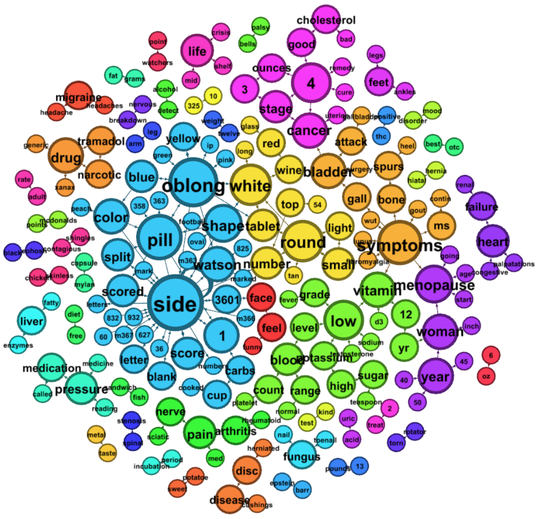


Figure 7. The most prevalent 2-word phrases submitted to ChaCha by users aged â‰¥40 years.



Discussion

Exploring the ways in which consumers use the Internet to seek health information can also aid Internet-based recruitment for research studies of various types, to improve communication between consumers and health care providers, and to inform the content and geographic scope of marketing for evidenced-based interventions using Internet-accessible platforms. To our knowledge, this is the first analysis of ChaCha data, and these initial results provide valuable methodological and content insights. Methodologically, the results of this initial query affirm our a priori assumption, and the findings of other studies examining Internet health information seeking, that big-data analytical techniques applied to these datasets allow for highly efficient identification of health concerns of users and provide substantial opportunities to develop interventions focused on patient-centered outcomes. Consider that our team analyzed 68 million health-related queries among 1.9 billion overall, generated by 19 million unique users, in less than 5 months and with a total cost of less than $15,000.00. Our entire team working full-time using traditional patient-engagement strategies would have been unable to generate this volume of data in our collective lifetimes, and the cost would be untenable. The ability to analyze such a large volume of user-generated health information-seeking data in such a short time has the potential to fundamentally change patient-centered outcomes research. Patient-engagement strategies are at the heart of effective health outcomes research but are costly and time intensive. Big-data analytic strategies have the potential to make widespread adoption of patient-centered engagement strategies possible at a fraction of the cost.

Several significant content findings from this initial analysis of the ChaCha dataset are consistent with the literature regarding adolescents’ use of social media (eg, Twitter) for seeking health information. The first is that the majority of health-related queries were submitted by adolescent users, which suggests that adolescents are comfortable using an anonymous text-based question-and-answer service for health information seeking, and a similar platform could be useful for interventions targeted to adolescents. The second is that adolescents’ health queries reveal potential knowledge gaps that have serious, lifelong consequences. The vast majority of health questions submitted by adolescents were focused on sexual and reproductive health. They frequently asked about when and how a girl could become pregnant, the signs and symptoms of pregnancy, and the effectiveness and adverse-effect profile of birth control. There were also a large number and proportion of adolescent user-generated queries about the detection and treatment of reproductive tract infections (primarily yeast and urinary tract infections), the length of time that marijuana remains detectable in the blood or urine, weight loss, and wisdom tooth removal. The content of adolescents' queries indicates their interest in and need for real-time, anonymous answers to questions about their sexual and reproductive health.

As with most studies that analyze social media data, this study had several limitations. First, we do not know whether users were searching for their own knowledge or on behalf of a friend or family member. Second, demographic data were self-reported by anonymous users, who may have misrepresented their city, state, sex, or age. Third, our research team was not provided access to this data until 2014, rendering the data 3–6 years old at the time of analysis. As a result, it is possible that the terminology used to describe health concerns, especially among adolescents, may be slightly outdated. However, we are less focused on *how* people talk about health concerns than on *what issues* cause them enough concern to prompt health information seeking. We believe it is unlikely that the core health concerns raised by users of the ChaCha services have changed dramatically in the last 3–6 years. Importantly, had we applied traditional methods to collect these data, the time lag between collection and analysis would have been substantially longer than the 3- to 6-year gap in our study. Finally, given that this is a proprietary dataset, as are many other social media datasets, it is not convenient for other investigators to replicate this work.

While other question-and-answer services exist, and many are more popular than ChaCha, the ChaCha service has several unique features that make it appealing for patient-centered research. First, ChaCha use is completely anonymous. Users of other question-and-answer sites, such as Quora, are required to sign up for the service using potentially traceable information such as email or Facebook profile. While Quora may be a secure site, the requisite entry of identifiable information in order to use the site may limit the pool of users and the types of questions they are willing to ask. Popular search engines such as Google or Bing provide a greater sense of privacy, but they leave a searchable history, which may also promote self-censorship. Moreover, ChaCha was specifically designed as a question-and-answer service, in which users understood there was a human curating the answers on the other end of the line. This simulates the health care encounter more closely than a Web search, in which the curating is done by the information seeker.

Additional research with these and other social media data are needed to develop a deeper understanding of spatial and temporal patterns in health information seeking that can inform patient-centered research. The ChaCha service provided a perfect environment for maximum frankness, especially around sensitive health questions. Just below the surface of this massive dataset are the quietly whispered questions, both banal and extraordinary, that represent the hopes, fears, dreams, and concerns of millions of people. Without compromising their anonymity in any way, we can listen in, to improve the health and wellbeing of millions more.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

The most prevalent 2-word phrases submitted to ChaCha predominately by male users. View interactive graph at http://www.jmir.org/ojs/public/graphs/male/.

[ZIP File (Zip Archive), 173KB - jmir_v18i3e44_app1.zip]

Multimedia Appendix 2

The most prevalent 2-word phrases submitted to ChaCha predominately by female user. View interactive graph at http://www.jmir.org/ojs/public/graphs/female/.

[ZIP File (Zip Archive), 176KB - jmir_v18i3e44_app2.zip]

Multimedia Appendix 3

The most prevalent 2-word phrases submitted to ChaCha by both males and females. View interactive graph at http://www.jmir.org/ojs/public/graphs/both/.

[ZIP File (Zip Archive), 177KB - jmir_v18i3e44_app3.zip]

Multimedia Appendix 4

The most prevalent 2-word phrases submitted to ChaCha by users aged 13â€“19 years. View interactive graph at http://www.jmir.org/ojs/public/graphs/age_1/.

[ZIP File (Zip Archive), 172KB - jmir_v18i3e44_app4.zip]

Multimedia Appendix 5

The most prevalent 2-word phrases submitted to ChaCha by users aged 20â€“39 years. View interactive graph at http://www.jmir.org/ojs/public/graphs/age_2/.

[ZIP File (Zip Archive), 170KB - jmir_v18i3e44_app5.zip]

Multimedia Appendix 6

The most prevalent 2-word phrases submitted to ChaCha by users aged â‰¥40 years. View interactive graph at http://www.jmir.org/ojs/public/graphs/age_3/.

[ZIP File (Zip Archive), 173KB - jmir_v18i3e44_app6.zip]

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Original Paper

Patterns of Treatment Switching in Multiple Sclerosis Therapies in US Patients Active on Social Media: Application of Social Media Content Analysis to Health Outcomes Research

Valéry Risson[1], PhD, MBA; Deepanshu Saini[2], MBA; Ian Bonzani[3], PhD; Alice Huisman[1], BSC; Melvin Olson[1], PhD

[1]Novartis Pharma AG, Basel, Switzerland
[2]IMS Health, Haryana, India
[3]IMS Health, London, United Kingdom

Corresponding Author:
Valéry Risson, PhD, MBA
Novartis Pharma AG
Postfach
Basel, CH-4002
Switzerland
Phone: 41 61 324 6036
Fax: 41 61 324 8001
Email: valery.risson@novartis.com

Abstract

Background: Social media analysis has rarely been applied to the study of specific questions in outcomes research.

Objective: The aim was to test the applicability of social media analysis to outcomes research using automated listening combined with filtering and analysis of data by specialists. After validation, the process was applied to the study of patterns of treatment switching in multiple sclerosis (MS).

Methods: A comprehensive listening and analysis process was developed that blended automated listening with filtering and analysis of data by life sciences-qualified analysts and physicians. The population was patients with MS from the United States. Data sources were Facebook, Twitter, blogs, and online forums. Sources were searched for mention of specific oral, injectable, and intravenous (IV) infusion treatments. The representativeness of the social media population was validated by comparison with community survey data and with data from three large US administrative claims databases: MarketScan, PharMetrics Plus, and Department of Defense.

Results: A total of 10,260 data points were sampled for manual review: 3025 from Twitter, 3771 from Facebook, 2773 from Internet forums, and 691 from blogs. The demographics of the social media population were similar to those reported from community surveys and claims databases. Mean age was 39 (SD 11) years and 14.56% (326/2239) of the population was older than 50 years. Women, patients aged 30 to 49 years, and those diagnosed for more than 10 years were represented by more data points than other patients were. Women also accounted for a large majority (82.6%, 819/991) of reported switches. Two-fifths of switching patients had lived with their disease for more than 10 years since diagnosis. Most reported switches (55.05%, 927/1684) were from injectable to oral drugs with switches from IV therapies to orals the second largest switch (15.38%, 259/1684). Switches to oral drugs accounted for more than 80% (927/1114) of the switches away from injectable therapies. Four reasons accounted for more than 90% of all switches: severe side effects, lack of efficacy, physicians' advice, and greater ease of use. Side effects were the main reason for switches to oral or to injectable therapies and search for greater efficacy was the most important factor in switches to IV therapies. Cost of medication was the reason for switching in less than 0.5% of patients.

Conclusions: Social intelligence can be applied to outcomes research with power to analyze MS patients' personal experiences of treatments and to chart the most common reasons for switching between therapies.

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KEYWORDS

Internet; multiple sclerosis; outcomes assessment; drug switching

Introduction

The Internet is rapidly becoming the first source of general and specific information on illnesses and treatments for a large number of people worldwide. Surveys have reported that between 70% and 75% of online users in the United States and Europe search for health care information [1-4]. Social media platforms are commonly used by patients seeking to connect with others with the same disease and as a source of medical information. In the United Kingdom, Facebook is reported as the fourth most popular source of health information [5]. In the United States, 42% of respondents to a recent survey said that they had used social media to find out about a health care issue, 25% had discussed a health-related experience, and 20% had joined a health community or forum [6].

For researchers, this explosion of online activity has generated a treasure trove of digital data that can be mined for insights into various aspects of health-seeking behavior and treatments. In the areas of infectious disease and public health, social network messages have been analyzed (eg, syndromic surveillance, disease sentiment analysis, or studies of drug abuse epidemiology using social media) [7-9]. Social media are a well-established source of patient-reported information on pharmacovigilance. Beyond media managed by pharmaceutical companies, microblogs such as Twitter have been used as a source of information about adverse events from a variety of medications [10] or to assay opinions about treatments [11].

In recognition of this value of the Internet and digital media, the European Medicines Agency in its guideline on good pharmacovigilance practices recommends that marketing authorization holders should regularly screen Internet or digital media (Web sites, Web pages, blogs, vlogs, social networks, Internet forums, chat rooms, health portals) under their management or responsibility for potential reports of suspected adverse reactions [12].

Despite this intense activity, social media analysis has rarely been applied to the study of specific questions in outcomes research. To test the validity of social media information and the applicability of social intelligence to outcomes research, we developed a comprehensive process that blends automated listening with the filtering and analysis of data by life sciences-qualified analysts and physicians. The process was designed to combine the advantages of purely manual and purely automated analyses. Manual coding in content analysis studies is superior to automatic content analysis in capturing complex semantic relationships between concepts or recognizing irony or sarcasm, which are frequently used in the informal conversation typical of social media. Automated analysis systems are superior in their sheer computing power, required to scan large datasets for relevant lexical entities, coding, and statistical analysis.

The mix of manual and automatic content analysis has been applied in other settings [9], but to our knowledge the applicability of the method to social media and health outcomes research has not been evaluated.

In this pilot study, we validated our social intelligence process by analyzing the representativeness of the social media population with multiple sclerosis (MS). To apply the analysis to outcomes research, we then used the collected data to study patterns of treatment switching to and from oral therapies in the MS population.

Methods

Social intelligence analysis combines automated listening to social media conversations with the filtering and analysis of data by human experts. As such, it is a noninterventional, retrospective database analysis of data available in the public domain.

The population was patients with MS from the United States. Patients who did not mention their location country or mentioned their location as not in the United States were excluded from the switchover analysis. Data sources for user-generated content were Facebook, Twitter, blogs, and online forums. The sites were selected because they are highly active, with a large number of users, and the content is publicly available and not redacted. Only publicly available social media conversations were included in the listening process and no password-restricted information was accessed. No patient-identifiable information available on social media was collected. Age, sex, and geographic location of social media users were collected when available.

Social Intelligence Process

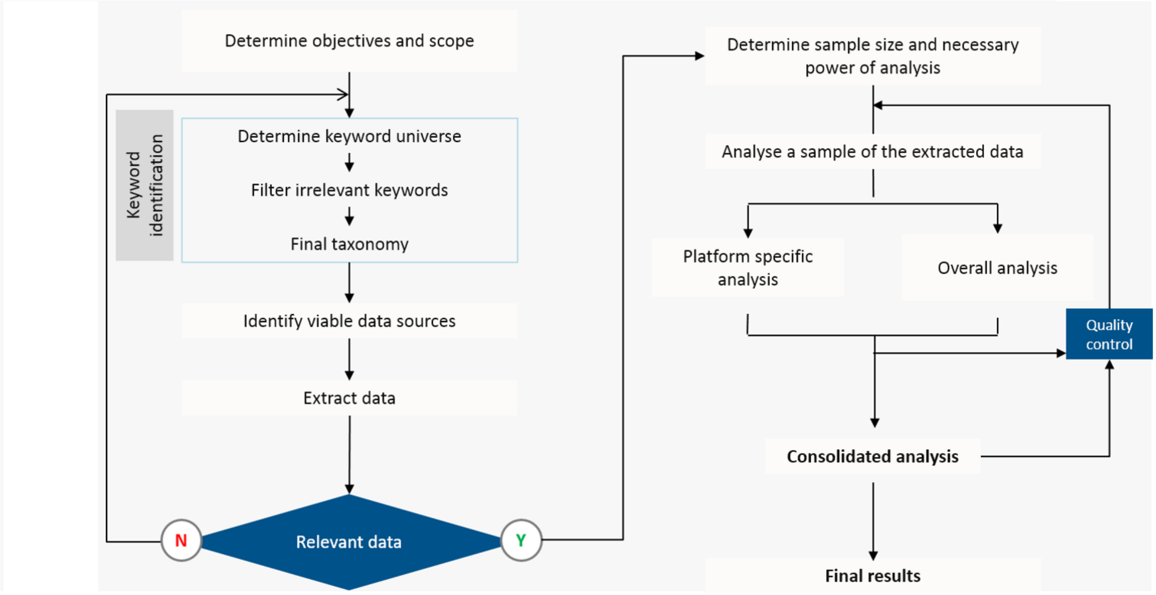
The overall process is illustrated in Figure 1. Data were collected from social media by monitoring the sources automatically and extracting semantic information. The system identified lexical entities in conversations related to the objectives of switching patterns between oral and injectable therapies for MS. Switchovers were identified through a set of keyword patterns, such as “switched from [brand A] to [brand B],” “moving from [brand A] to [brand B],” “stopping [brand A] starting [brand B],” and similar expressions. As proxies for oral therapies, the trade names Tecfidera (dimethyl fumarate), Gilenya (fingolimod), and Aubagio (teriflunomide) were used as terms. Proxies for subcutaneously and intramuscularly injectable therapies were the common BRACE therapies: Betaseron (interferon beta-1b), Rebif (interferon beta-1a), Avonex (interferon beta-1a), Copaxone (Glatiramer acetate), and Extavia (interferon beta-1b). In addition, Tysabri (natalizumab) and Novantrone (mitoxantrone) were included as representatives of intravenous (IV) infusion treatments. Search terms also included common misspellings of brand names.

The identification of potential switches was performed by the automatic system based on a set of predefined categories: potential switches; category of conversations as information sharing or information seeking; themes of conversation as cost, efficacy, side effects, or adherence; and conversation sentiment as positive or negative. For potential switches, the system was trained to recognize conversations containing switching patterns, terms, brands involved in a switch, and the potential reason for the switch. The data were filtered for relevance to the study objectives. The identification and grouping of content was done by the automated system. The automatic identification was followed by manual analysis of the complete set of records to eliminate errors and record the involved brands and reasons for switchovers.

The objectives of the analysis were (1) to explore the feasibility of using social media analysis to address outcomes questions in health care that focus on a population of MS patients; (2) to validate the representativeness of the social media population by comparing the characteristics of the database population with data on MS patients obtained by other methods, such as medical records, patient advocacy groups, or general practitioners; and (3) to use the validated database to analyze switching patterns and reasons for switching between oral and injectable classes of MS therapies.

This study was designed, implemented, and reported in accordance with the Guidelines for Good Pharmacoepidemiology Practices of the International Society for Pharmacoepidemiology [13], the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines [14], and with the ethical principles laid down in the Declaration of Helsinki [15]. The secondary data source used for the analysis meets all the US Health Insurance Portability and Accountability Act (HIPAA) compliance standards, ensuring patient anonymity. As such, approval from an Institutional Review Board was not necessary.

Figure 1. Flowchart of the social intelligence analysis process. The system was trained to identify switchovers through a set of keyword patterns such as “switched from [brand A] to [brand B],” “moving from [brand A] to [brand B],” “stopping [brand A] starting [brand B],” and similar expressions.



Statistical Analysis

The information extracted by the automated system was organized by social platform (ie, Twitter, Facebook, online discussion forums, and blogs). The data were further stratified monthly for each platform. To generate representative samples for the population dataset for manual review, random samples were extracted for each month and for each platform based on a 95% confidence interval with a 5% margin of error. These data were subjected to manual analysis by life sciences-qualified analysts, who were guided by a physician, to confirm the representativeness of the samples. After the review of these samples, validation sample sets were generated for three random months for each platform using the preceding methodology to cross-validate the findings derived from the sample set.

Results

Social media conversations were monitored between October 1, 2013 and October 31, 2014. A total of 49 forums and 152 blogs were used for the analysis. All publicly available Facebook pages were searched for the relevant semantic information. The automated system extracted 25,073 social media data points (unique posts on any specific media platform) in this time period. A total of 22,887 relevant data points were identified: 8672 from Twitter, 6919 from Facebook, 6505 from Internet forums, and 791 from blogs. Of these, 10,260 data points were sampled by the analysts for a detailed manual review: 3025 from Twitter, 3771 from Facebook, 2773 from Internet forums, and 691 from blogs.

The demographics of the population are shown in Table 1. Mean age was 39 (SD 11) years and 14.56% (326/2239) of the population was older than 50 years. The mean time since diagnosis was 6.8 (SD 4.5) years, but one-third of the population reported more than 10 years since diagnosis. Women, patients aged between 30 and 49 years, and those diagnosed for more than 10 years were represented by more data points than other patients were. Women also accounted for a large majority (82.6%, 819/991) of reported switches. Mean time since diagnosis in patients who switched medication was 7.5 (SD 4.3) years and two-fifths of switching patients had lived with their disease for more than 10 years since diagnosis.

Table 1. Demographics of the analyzed population.

Variable	All patients N=3911	Switching patients n=991
Sex (female), n (%)	3001 (76.73)	819 (82.6)
Age (years), mean (SD)	39 (11)	40 (12)
Age distribution (years), n (%)	n=2239	n=515
<20	11 (0.49)	7 (1.4)
20-29	442 (19.74)	102 (19.8)
30-39	602 (26.89)	139 (27.0)
40-49	858 (38.32)	167 (32.4)
50-59	210 (9.38)	57 (11.1)
60-69	113 (5.05)	43 (8.3)
>70	3 (0.13)	0
Years since diagnosis, mean (SD)	6.8 (4.5)	7.5 (4.3)
Distribution of time since diagnosis, n (%)	n=992	n=429
0-6 months	97 (9.8)	8 (1.9)
6-12 months	38 (3.8)	7 (1.6)
1-3 years	198 (20.0)	106 (24.7)
4-8 years	239 (24.1)	97 (22.6)
9-10 years	88 (8.9)	38 (8.9)
>10 years	332 (33.5)	173 (40.3)

As a validation of the representativeness of the social media population, the characteristics were compared with those from a survey in three US communities in Texas, Ohio, and Missouri [16]. As shown in Table 2, the sex ratios and age distributions were numerically similar across all populations. There were minor differences in age distribution between the populations, most notably the greater percentage of patients younger than 30 years in this study population compared with the community survey populations. Overall, the identified social media population corresponded well to those in the communities used as comparator. A further comparison with published data confirmed that the percentage of women in the study population (76.73%, 3001/3911) was numerically similar to published rates from three large US administrative claims databases: MarketScan (76.4%), PharMetrics Plus (76.5%), and Department of Defense (76.4%) [17].

Table 2. Comparison of characteristics of the study population with those of MS populations from three US communities [16].

Variable	Study population N=3911	Texas (Lubbock and 19-County surrounding area) N=182	Missouri (Independence and Sugar Creek) N=106	Ohio (Lorain County) N=320
Sex (female)	76.73%	80.1%	81.1%	74.1%
Age distribution (years)	N=2239			
<30	20.23%	10.4%	3.8%	3.1%
30-39	26.89%	32.4%	12.3%	10.6%
40-49	38.32%	26.9%	37.7%	30.3%
50-59	9.38%	9.3%	32.1%	31.9%
60-69	5.05%	2.2%	10.4%	12.5%
>70	0.13%	0.5%	3.8%	11.6%

A total of 1684 data points were identified as treatment switches. Switches were most frequent among patients on injectable therapies who were represented by 1114 of 1684 (66.15%) data points for switches (Figure 2). The largest proportion of reported switches (55.05%, 927/1684) were from injectable medications to oral drugs. The second largest single switch (15.38%, 259/1684) was from IV therapies to orals. Overall, switches to oral drugs accounted for 78.74% (1326/1684) of all switches. Switches from oral therapies to other drug classes were described in 9.50% (160/1684) of the data points.

Relative rates of switches away from oral, injectable, and IV therapies, respectively, are shown in Figure 3. The largest percentages of switches in both groups were to oral therapies. Switches to oral drugs accounted for more than 80% (927/1114) of switches away from injectable therapies. There was a less clear trend among switches away from orals. Although in this group, as in the others, the most common single switch was to other oral therapies, such switches accounted for less than half of the total. There seemed to be no clear preference for injectable compared to IV drugs in terms of switches. Switches away from IV therapies were overwhelmingly (97.7%, 259/265) to orals, with a small number of switches to injectable therapies.

By monitoring conversations, it was possible to identify a number of reasons for drug switching discussed among patients. Four reasons accounted for more than 90% (1130/1234) of all switches: severe side effects, lack of efficacy, physicians' advice, and greater ease of use (Table 3). The three most frequent reasons for switching in each of the therapeutic classes are shown in Figure 4. Overall, as well as in all individual drug classes, side effects and lack of efficacy were the two most frequent reasons to switch to a different medication. Side effects were the largest single reason for switches to oral or injectable therapies and search for greater efficacy was the most important factor driving switches to IV therapies. The third most frequent reason overall for switches was physicians' advice (Table 3). However, in driving switches from injectable to oral therapies, greater ease of use was a more common reason (Figure 4). Physicians' advice played a greater role in switches from oral to IV infusion therapies and from IV infusion to injectable therapies than in other switches. Unspecified safety concerns (without reported side effects) were reported as a reason to switch by 3.08% (38/1234) of patients. Costs of medication were given as reason for switching by less than 1% (7/1234) of patients.

Table 3. Frequency of reasons for switching away from MS treatments.

Reason	Frequency, n (%)
Severe side effects of previous drug	464 (37.60)
Lack of efficacy of previous drug	310 (25.12)
Physician's advice	193 (15.64)
Ease of use of new drug	163 (13.21)
Worsening quality of life	39 (3.16)
Safety concerns	38 (3.08)
Insurance issues	13 (1.05)
High cost	7 (0.57)
Other	7 (0.57)

Figure 2. Percentages of all switches representing switches from oral, injectable, and IV therapies, respectively.

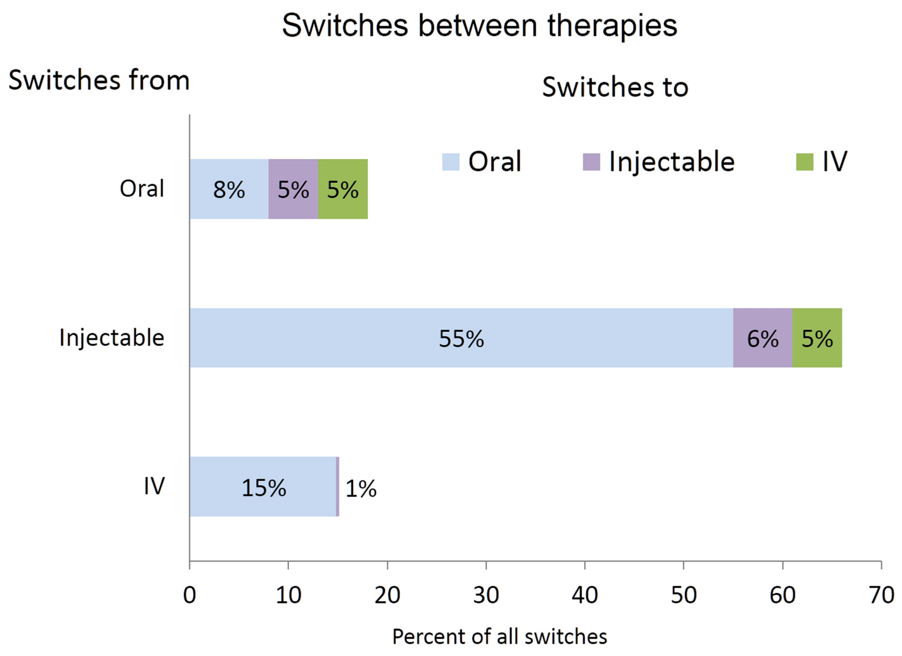


Figure 3. Percentages of switches from oral, injectable, and IV therapies, respectively, to other therapies.

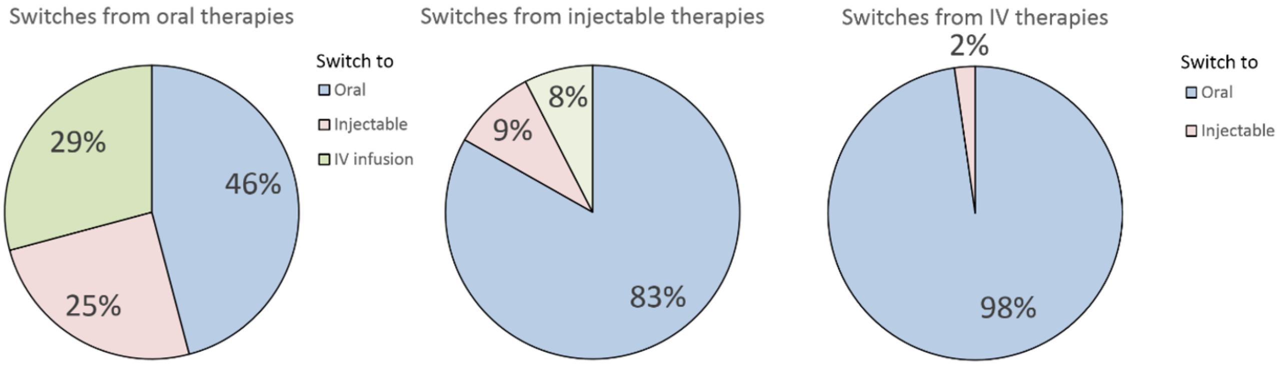
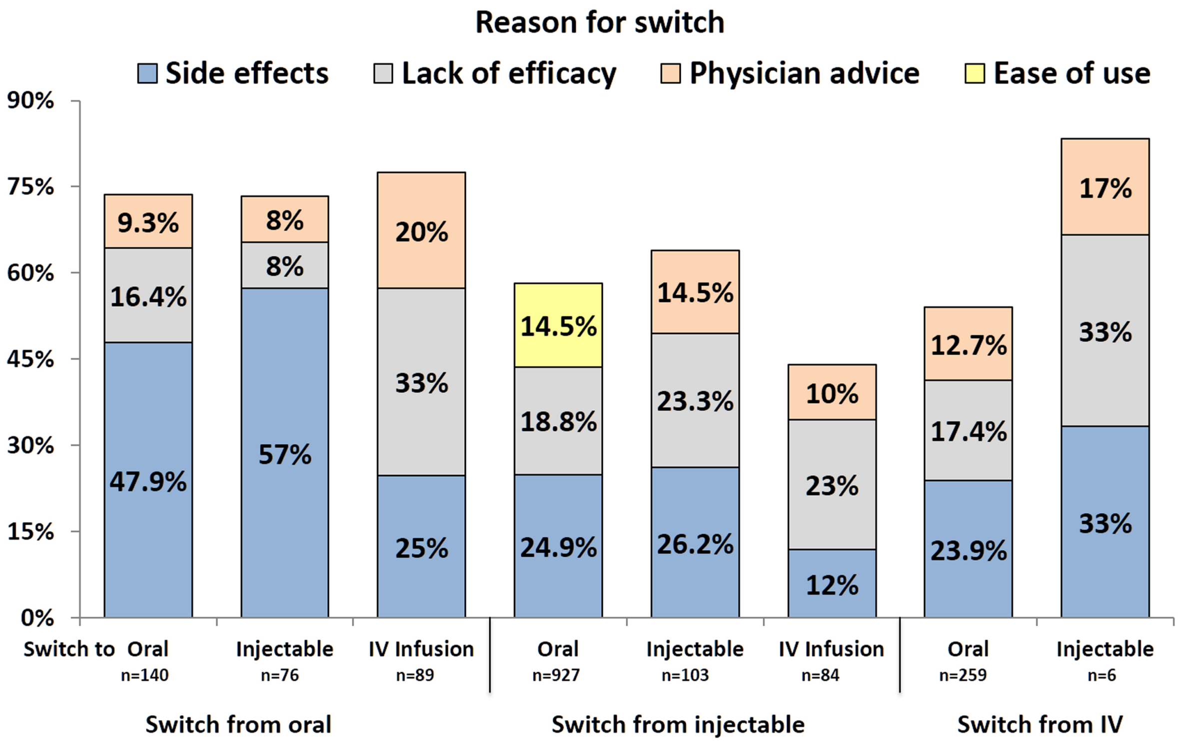


Figure 4. Three most frequent reasons for switching according to starting therapy, expressed as percentages of the total number of each kind of switch. Percentages do not sum up to 100% because only the top three switches in each group are displayed.



Discussion

The results from this pilot study indicate that social intelligence can be applied to outcomes research with the power to tease out facts not available by other analyses, such as retrospective analyses of claims databases, commonly employed in outcomes research. Using a combination of automated listening and filtering and analysis of data by life sciences-qualified analysts and physicians, it was possible to obtain data on MS patients' personal experiences of their treatments and to generate a map of the most common reasons for switching between therapies.

The study had three objectives. The first was to test the applicability of social intelligence in outcomes research. Use of the Internet for medical information varies with the condition: patients with MS have among the highest rates of use at 60% to 80% of (US) patients compared with 35% of (Canadian) patients with spinal cord injury [18,19]. In a survey of information-seeking behavior among patients with MS, the Internet (unspecified sites) was considered one of the most reliable sources of information, second only to doctors [2]. Government health agencies and media scored worse.

Although published data are likely to lag behind the rapid increase in Internet use fed by the mobile revolution, choosing MS as the condition for our analysis was expected to provide a large dataset to analyze which could be assumed to represent a varied population and reduce the potential for bias. The large number of data points related to MS included in our sample shows that there is an extensive and active social media population generating sufficiently large datasets with relevant information to enable analysis of questions typically posed in outcomes research.

The second objective of the study was to validate the representativeness of the social media population for MS. A comparison of the characteristics of the social media population with other MS patient cohorts characterized in community surveys or by analysis of large US administrative claims databases showed strong similarities between populations identified with different methods. Likewise, the analysis of switching patterns yielded similar results to those from other sources: market analyses by Novartis (data on file) indicate that most switches in real life are from injectable to oral therapies, including a not negligible percentage of patients on IV drugs. The similarities between these results from different sources indicate that the risk of bias in online data is no greater than that in acceptable and validated analyses of clinical reality in populations identified and characterized using other methods.

Most patients in the social media population had been living with their disease for several years and the age distribution corresponds to the means for MS patients on therapies. That a large majority of the population were women is a reflection of the demographics of the MS population because the disease is several times more prevalent in women [20]. Our rate of 76.73% women is similar to published proportions of female-to-male incidence rates in a number of populations including the United States [16], Sweden [21], and Canada [22]. There are molecular data in support of sex differences in responses to MS treatments [23]. Thus, the social intelligence population appears to be representative of those patients in real life who are mostly active in switching between therapies.

The third objective was to apply the social intelligence approach to the study of patterns of treatment switching between oral, injectable, and IV therapies for MS. For the purpose of the analysis, oral therapies were represented by the drugs Tecfidera, Gilenya, and Aubagio. In the time period covered by the data, these three compounds represented all available oral medications on the US market. Because the treatments represent different molecular entities, there is a reduced risk of potential bias from social media discussions of drug-specific characteristics not directly related to the oral or injectable nature of the different treatments. Injectable drugs were represented by five common BRACE therapies that together cover the majority of injectable MS medications in the United States. This pilot analysis did not attempt to tease out drug-specific reasons for switching, although the performance of the analysis indicates that such an exercise would be possible with the methods employed in this analysis.

There are few published data on patients' reasons for switching between MS therapies. Most investigators have focused on efficacy comparisons in patients switching from one treatment to another, using observational data from registries to approach the real-world situation [24]. Our findings indicate that patients experience injectable therapies as associated with more side effects than oral medications or at least that patients were more willing to try oral drugs than to switch to other injectable or IV alternatives. The switches to IV drugs were mostly motivated by a desire for greater efficacy, with a small percentage of patients on oral medications apparently willing to risk a less favorable safety profile for greater efficacy with IV drugs. That physicians' advice was a greater factor in switches involving IV therapies than in other switches is a reasonable finding, given the novelty and limited experience with these drugs [25]. However, because 80% of all switches were to oral therapies, the sample size for other switches may be too small to avoid selection bias or chance findings. There were very few switches to injectable drugs from other classes.

The strength of the method lies in the combination of automated and manual analysis. Manual analysis alone is too labor-intensive to be feasible in social media analysis of large datasets. Automated tools for content analysis will not capture the varieties of human expression, such as irony or the use of nonstandard abbreviations, nor will they identify complex semantic relationships between concepts or process information expressed in colloquial language typical of social media [26,27]. The blend of automated listening and human content analysis used in this research was designed to overcome these limitations and reduce the risk of misinterpretation.

The study has a number of limitations. First, all social media are susceptible to misinformation (eg, user experiences or unverifiable data sources), which may be difficult to identify even for the human analysts and guiding physicians [28]. There is a potential for bias in that certain types of patients may be more motivated to interact on social media than others, even if the huge size of the US social media population and the representativeness of our study population argue against this for this study. Because the data originate from public forums, medication-specific discussions on confidential websites, such as physician/patient discussion forums, have not been captured. A further limitation to analyses of social networks is the relative lack of socioeconomic and demographic information available [29]. There is a risk of duplication of data among our population because patients were identified by their screen names and the same patient may have used different screen names on different social media. It is also unclear how well social media data are representative of populations for other diseases than MS.

Although these limitations should be acknowledged, our analysis shows that when applied to appropriate questions that are frequently discussed openly by patients, social intelligence can be a powerful tool for outcomes research, providing information on specific factors driving patient's health-seeking behavior that may not be obtainable by other means.

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Conflicts of Interest

This study was funded by Novartis Pharma AG, Basel, Switzerland. VR, AH, and MO are employees of Novartis.

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Abbreviations

BRACE: Betaseron, Rebif, Avonex, Copaxone, Extavia
HIPAA: United States Health Insurance Portability and Accountability Act
IV: intravenous
MS: multiple sclerosis
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

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Original Paper

Internet Searching About Disease Elicits a Positive Perception of Own Health When Severity of Illness Is High: A Longitudinal Questionnaire Study

Kai Sassenberg[1,2], Dipl.-Psych., Dr. rer. nat.; Hannah Greving[1], MSc, Dr. rer. nat.

[1]Leibniz-Institut für Wissensmedien, Social Processes Lab, Tübingen, Germany
[2]Faculty of Science, University of Tübingen, Tübingen, Germany

Corresponding Author:
Kai Sassenberg, Dipl.-Psych., Dr. rer. nat.
Leibniz-Institut für Wissensmedien
Social Processes Lab
Schleichstrasse 6
Tübingen, 72076
Germany
Phone: 49 7071979220 ext 220
Fax: 49 7071979200
Email: k.sassenberg@iwm-tuebingen.de

Abstract

Background: The Internet is one of the primary sources for health information. However, in research, the effects of Internet use on the perception of one's own health have not received much attention so far.

Objective: This study tested how Internet use for acquiring health information and severity of illness influence patients with a chronic disease with regard to the perception of their own health. Negative psychological states are known to lead to preferential processing of positive information. In particular, the self-directed nature of Internet use provides room for such biases. Therefore, we predicted that patients experiencing negative health states more frequently, due to more frequent episodes of a chronic illness, will gain a more positive perception of their health if they use the Internet frequently to gain health information, but not if they use the Internet rarely. This effect was not expected for other sources of information.

Methods: A longitudinal questionnaire study with two measurement points—with a 7-month time lag—tested the hypothesis in a sample of patients with chronic inflammatory bowel disease (n=208). This study assessed patients' frequency of Internet use, their participation in online social support groups, their use of other sources of health information, and several indicators of the participants' perceptions of their own health. A structure equation model (SEM) was used to test the predictions separately for Internet searches and other sources of information.

Results: Data analysis supported the prediction; the interaction between frequency of health-related information searches and frequency of episodes at the first measurement point (T1) was related to participants' positive perceptions of their own health at the second measurement point (T2) (B=.10, SE=.04, *P*=.02) above and beyond the perceptions of their own health at T1. When participants used the Internet relatively rarely (-1 SD), there was no relationship between frequency of episodes and positive perceptions of their own health (B=-.11, SE=.14, t_{203}=-0.82, *P*=.41). In contrast, when participants used the Internet relatively often (+1 SD), the more frequently they had those episodes the more positive were the perceptions of their own health (B=.36, SE=.15, t_{203}=2.43, *P*=.02). Additional SEM analyses revealed that this effect occurs exclusively when information is searched for on the Internet, but not when other sources of information are consulted, nor when online social support groups are joined.

Conclusions: The results of this study suggest that patients might process information from the Internet selectively, in an unbalanced, biased fashion, with the formation of a self-serving (ie, positive) perception of own health. At the same time, this bias contributes to the ability of patients to cope psychologically with their disease.

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KEYWORDS

health information; Internet search; threat; perception of own health; chronic inflammatory bowel disease

Introduction

Background

The Internet provides lay people with access to health information that was in earlier days available only to physicians and other health care professionals. Already in 2001, about 40% of Internet users searched online for health information [1]. Meanwhile, Internet use in the health domain has become so popular that, based solely on search engine query data, influenza epidemics can be detected [2]. Access to health information through the Internet has the potential to create better-informed patients and to enable them to become engaged in caring for their health; at the same time, health information on the Internet is often inaccurate or incomplete [3-5].

The risks and benefits associated with the availability of health information on the Internet do not result only from the content of this information, but also from how patients process it (see Kalichman et al [6]). Current research aims to test the impact of severity of illness, as a factor that is likely to affect information processing, and the frequency of Internet use for health information acquisition on the perception of one's own health.

A Preference for Positive Over Negative Information

Health information is processed in a biased fashion. Positive or self-serving information (eg, suggesting own good health state) is, for instance, more easily accepted and less avoided than negative self-relevant information (eg, suggesting own illness) [7]. Preferential processing of self-serving information has been demonstrated at different stages of information processing, such as attention, encoding, and recall; for an overview, see De Hoog et al [8] and Shepperd et al [9]. Other results suggest that individuals have a strong tendency to prefer positive over negative information about their own health [10].

There are, however, reasons to assume that the extent to which the positive, or self-serving, bias occurs depends crucially on individuals' health states and their psychological states resulting from them [10,11]. Research across domains has revealed a stronger positive bias in individuals in a negative state (ie, a state experienced as aversive, such as feeling uncertain, threatened, or bad), which is likely experienced by ill individuals. To be more precise, studies have shown that in negative psychological states as compared to positive states (ie, states experienced as enjoyable or neutral states), positive information receives more attention than negative information. This is particularly true when individuals are focusing on losses rather than gains [12], when they are experiencing negative rather than positive emotions [13], or when they are reminded of negative rather than positive experiences [14,15]. In addition, experiencing low control over one's current and future situation (ie, another negative state) elicits a positive bias [16,17]. Moreover, being in a negative state does not only lead to a positive bias regarding attention, but also regarding decision-making [18]. This process is called counter-regulation [19] because a negative state is counteracted by attention to positive stimuli [12]. Taken together, negative psychological states that are likely to come along with periods of illness have been shown to result in a positive bias in information processing.

We believe that during Internet searches, a positive bias in information processing is very likely to occur because searching and surfing the Internet is completely self-directed (ie, not guided by external restrictions). Also, it can be done via multiple paths due to the hypertext structure and the virtually unlimited amount of information available [20]. Other sources of health information usually provide participants with more guidance. In social interactions, doctors or other health professionals communicate information to patients based on their own aims; ideally, they provide patients with balanced and unbiased information to empower them to autonomously make informed decisions [21]. Even on television, in newspapers, or in books (ie, noninteractive sources), information about an illness is usually designed in a way such that readers get a certain unbiased set of information (eg, Anderson and Nottingham [22]). In comparison, information acquisition on the Internet is completely self-directed because users can stop reading a text and "surf on" at any given point in time. This is due to the large quantity and the heterogeneous mass of information with regard to content being available online. Therefore, when the available information allows for several interpretations and a self-directed information search [23,24], as is the case on the Internet, negative psychological states are more likely to guide information processing (ie, influence the behavioral steps of the Internet search process) toward preferential processing of positive information. This is due to the fact that internal negative and positive states can only exert influence on information processing if the search process is self-directed, as it is during Internet searches, but not if the information search is externally guided, as in the case of other sources. In other words, the Internet provides optimal degrees of contextual freedom, which Rothermund [19] named to be the prime precondition for the occurrence of counter-regulation.

Indeed, experimental research [25,26] has shown that a negative psychological state influences Internet search behavior. In a series of experiments with healthy participants, threat was induced based on either providing participants with an ostensible diagnosis [7] or asking them to think and write about a threat they were currently experiencing. Participants then searched for information in a health domain (ie, either information related to the diagnosis or about living organ donation). Under threat, compared to a no-threat control condition, more positive search terms were generated, more positive links were selected from a link list, more positive information was recalled, and the search topic was evaluated as more positive. Positive search terms, links, and information—in the case of searches about living organ donation— focused, for example, on the fact that organ donations give a "second life" to patients or on the circumstances under which donated organs are in good condition. These studies suggest that patients using the Internet to acquire information about their own illness and health will likewise apply a positive bias, because patients' actual health states potentially induce negative psychological states. Patients with a chronic illness—a group that frequently uses the Internet [27]—will, for instance, suffer not only physically but also feel bad (ie, experience a negative psychological state) when they go through an episode of their illness. This, in turn, forms the basis for a positive bias during health-related Internet searches [25,26].

What are the long-term consequences of such a positive bias during Internet searches? As mentioned above, research on the immediate outcomes of Internet searches has shown that negative states lead to better memory for positive information and more positive attitudes toward the target around which the search centers [25,26]. Therefore, in the long run, the perception of the illness and a patient's own health should become more positive the more often Internet searches are conducted by individuals in a negative psychological state. Hence, we predict that patients with chronic illnesses, who use the Internet frequently to search for health-related information, will have a more positive perception of their health the more frequently they experience episodes of their illness. In contrast, this relationship between the frequency of episodes and positive perception of their own health will not occur in patients who rarely use the Internet to search for health-related information.

Methods

Overview and Study Design

A longitudinal study with two measurement points and a time lag of 7 months was conducted with patients who suffer from chronic inflammatory bowel disease to test this hypothesis. We focused on this chronic disease as it is characterized by infrequently occurring acute episodes of illness, which substantially restrict patients in their ability to cope with everyday demands; the episodes are, thus, likely to elicit negative psychological states. Moreover, patients with chronic diseases rely particularly on the Internet as an informational source because their illnesses strongly restrict them in their daily and social activities, which is why they are often unable to leave the house [27]. This also applies to patients with inflammatory bowel disease. These patients, thus, formed an appropriate group of patients for our study.

We used three indicators for the positive perception of own health that captured the immediate outcome of the positive bias—the perception of the risks resulting from the disease—as well as how it affects participants personally—health-related stress and health-related self-esteem. As information about their health and their disease is self-relevant to patients, we expected that our hypothesis would apply to all three indicators of perception of own health.

Participants were recruited and data were collected via the Internet in order to gain a sample of patients who were experienced in using the Internet for health-related purposes. To be able to test whether the predicted frequency of Internet searches by frequency of episodes interaction occurs for all sources of information or just for health-related Internet searches, we assessed online social support group participation and the consultation of offline sources of health-related information (ie, interactive and noninteractive sources). No frequency of episodes by source of information interaction was expected for sources other than Internet searches because these other sources do not provide the degree of self-directedness required to provide room for counter-regulation and the preferential processing of positive cues.

Participants

Patients with chronic inflammatory bowel disease participated in an open, online questionnaire study with two measurement points that were 7 months apart. Participants were recruited via the German Association for Crohn's Disease and Ulcerative Colitis, which has more than 20,000 members and is, thus, the biggest organization of patients with chronic inflammatory bowel disease in German-speaking countries. The association advertised the study in their members' journal, on their website, via email, and on social networking sites.

When following the link in the advertisement, participants first had to provide informed consent online. After receiving information about the duration, the content, and the aims of the study, as well as the data storage policy, each participant had to actively check a box and, thereby, indicate informed consent. Participation was completely voluntary. To get access to the survey, participants had to enter their email address into a Web form. Email addresses were stored separately from the other data and were only accessible to the system administrator (ie, not to the researchers), who deleted them after the second wave of data collection was completed. Participants received an email with a link to the actual questionnaire.

The reported study was ethically approved by the ethics committee of the Faculty of Medicine at the University of Tübingen, Germany. As compensation, participants who completed questionnaires from both waves received a gift voucher of €10—approximately US $11—to be redeemed at an online sales platform.

Main Questionnaire

All measures of the survey at the first measurement point (T1) and the second measurement point (T2) were assessed via the online survey program, Questback. Items were presented in a fixed order. First, participants answered demographic questions (ie, gender, age, and education) and general questions about their health and illness (ie, type of diagnosis, time since receipt of diagnosis, time since occurrence of symptoms, number of episodes, current acute episode, and severity of acute episode). These questions included the assessment of the key predictor, frequency of episodes. Within a larger battery of measures, participants' health-related self-esteem, health-related stress, and health-related risk perceptions were assessed and served as the key dependent measures. Finally, participants answered questions about their Internet use—the second key predictor—the Internet services they used, which online social support group they joined, and which offline sources of information they used. The functionality and readability of the questionnaire was pretested by healthy participants. The questionnaire contained up to 14 items. Returning to already completed pages of the questionnaire was not possible. It was mandatory to complete the items assessing key concepts. Participants were contacted via email about 7 months after they had completed the questionnaire from the first wave. Those who did not reply within a week received a reminder. All measures at T2 were exactly the same as at T1.

Measures

Frequency of episodes was assessed with an item asking participants to indicate how many acute episodes of illness they had had during the last year. Participants reported a mean of 1.93 episodes (SD 2.10). This indicator was *Z*-standardized for all analyses reported below because the raw values were skewed, as is often the case for frequency counts.

Health-related information searches on the Internet was assessed with an item that requested participants to report the frequency of their Internet use for this purpose. Participants provided the answer on a 7-point scale with the following options: *rarely or never* (1), *two to six times per year* (2), *one to two times per month* (3), *one time per week* (4), *two to five times per week* (5), *one time per day* (6), and *several times per day* (7). This item served as a measure of health-related information searches on the Internet.

In the next passage, questions on the use of health information sources had to be answered by checking or not checking boxes. Possible information sources were search engines, forums, encyclopedias, patient association websites, Internet portals, scientific search engines, newsletters, and social networks.

Online social support group participation was also assessed by one item—"How often do you visit online social support groups?"—which participants answered again on the 7-point scale used for health-related information searches.

For *other sources of health information,* participants indicated by checking or not checking a box whether they made use of the following offline sources of health information: doctors, family and friends, psychologists or advisory centers, books, presentations, newspapers and journals, and television or radio. We created two indices from these answers by counting the number of checked boxes, separately for social interactive sources (ie, doctor, friends and family, and psychologists or advisory centers) and noninteractive sources (ie, books, presentations, newspapers and journals, and television or radio).

The positive perception of own health was, as mentioned above, captured by using three different indicators: health-related self-esteem, health-related stress (reversed), and health-related risk perception (reversed). Health-related self-esteem was measured by five items adopted from the social state self-esteem subscale of the State Self-Esteem Scale [28]: "Due to my chronic illness, I feel self-conscious," "Due to my chronic illness, I feel displeased with myself," "Due to my chronic illness, I feel inferior to others at this moment," "Due to my chronic illness, I am worried about what other people think of me," and "Due to my chronic illness, I feel concerned about the impression I am making." All of these items were reverse coded as in the original scale (T1 alpha=.86, T2 alpha=.87). The health-related stress that participants experienced due to their illness was assessed by seven items adopted from different stress appraisal measures [29,30]; for example, "I feel totally helpless with my chronic illness," "I feel that my chronic illness is beyond my control," and "My chronic illness impacts me greatly" (T1 alpha=.88, T2 alpha=.91). Finally, participants' health-related risk perception in relation to their disease was measured with five self-developed items. We developed these items because, to the best of our knowledge, no available scale captures the perceived risks associated with inflammatory bowel diseases: "Inflammatory bowel diseases may result in bowel cancer after a long time," "Inflammatory bowel diseases greatly restrict social life," "Inflammatory bowel diseases often come along with intestinal incontinence," "Inflammatory bowel diseases make you feel constantly ill," and "Inflammatory bowel diseases come along with many adverse effects" (T1 alpha=.54, T2 alpha=.56). The internal consistencies of this scale were not as high as one would have wished, which could unfortunately not be substantially improved by excluding single items. As the scale was approximately normally distributed, we chose to average the items into a single index. Ratings for all three scales were on a 5-point Likert scale ranging from 1 (*does not apply at all*) to 5 (*completely applies*).

Inclusion and Exclusion Criteria

Participants had to be 18 years of age or older and have chronic inflammatory bowel disease. The only exclusion criterion was that the answers to the two main disease-related variables—time since receipt of diagnosis and number of episodes per year—had to be within a plausible range: < 60 years and < 20 episodes, respectively.

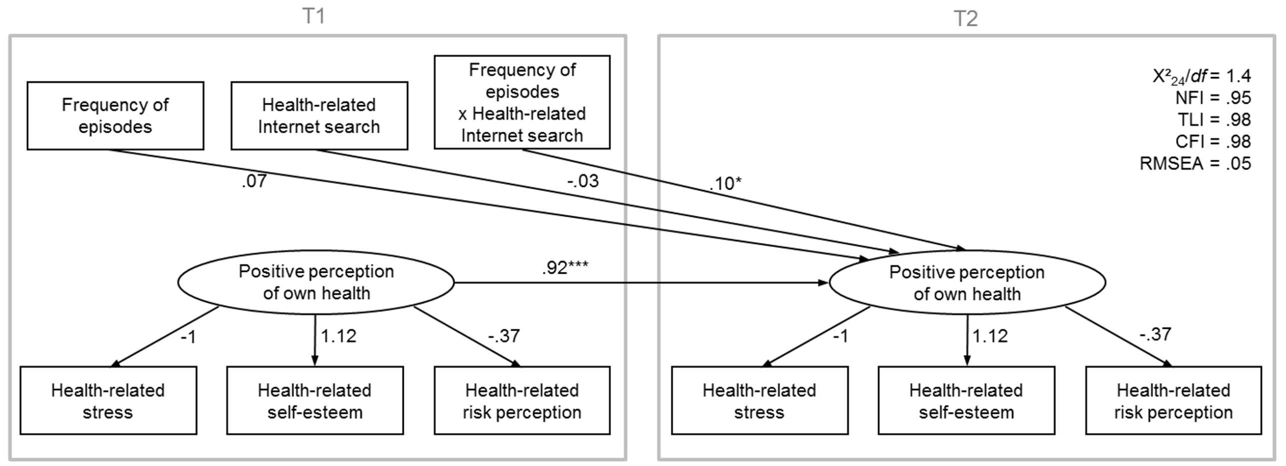
Data Analysis

To test the hypothesis, a structure equation model (SEM) was applied using SPSS Amos version 22 (IBM Corp). In this model, the three manifest indicators of the positive perception of own health were summarized as a latent variable, separately for T1 and T2. Relationships between the assessed indicators and the latent variables were set equally across both time points. The model regressed the perception of own health at T2 on the same variable at T1, as well as on frequency of health-related information searches, frequency of episodes, and their interaction (see Figure 1). Before the interaction was computed, both variables were *Z*-standardized.

The correlation between the measurement error of frequency of episodes at T1 and the error term for positive perception of own health at T1 was set free as it was likely that both were related. Moreover, measurement errors of health-related stress, health-related self-esteem, and health-related risk perception at T1 were allowed to covary with their respective measurement errors at T2. This was done because we assumed that components of these indicators that are not part of the latent variable of positive perception of own health might still be stable. The model did not include any further covariates. To test for the opposite causal relationship, we also computed a model in which the perception of own health at T1 predicts the interaction between frequency of episodes and health-related Internet searches at T2.

Finally, additional models were tested to find out whether Internet searches alone or also other types of information searches interact with the frequency of episodes in their impact on the perception of own health. These alternative models replaced health-related information searches on the Internet by social interactive sources, by noninteractive sources, or by participation in online social support groups. Except for this change in the predictor and its interaction with frequency of episodes, the alternative models did not exhibit any changes in comparison to the main model. We did not expect to find an interaction between the respective information sources and the frequency of episodes on positive perception of own health in these models.

Figure 1. Structure equation model (SEM) for the effects (unstandardized regression coefficients, B) of frequency of episodes, frequency of health-related information searches, and their interaction from the first measurement point (T1) on the latent variable, positive perception of own health, and from the second measurement point (T2), controlling for positive perception of own health from T1. NFI: normed fit index; TLI: Tucker-Lewis index; CFI: comparative fit index; RMSEA: root mean square error of approximation; ns: not significant; *P<.05; ***P<.001.



Results

Sample Description

A total of 8 out of 216 participants (3.7%) who completed both questionnaires were excluded from the analyses reported below based on the exclusion criteria: time since receipt of the diagnosis (> 60 years) and number of episodes during the last year (> 20 episodes). Thus, 208 participants were included in the analyses: 154 women (74.0%), 54 men (26.0%), mean age 37.77 years (SD 11.51, range 18-63). Out of these participants, 0.5% (1/208) had not finished school, 8.7% (18/208) had a certificate of secondary education after 9 years of schooling (German: Hauptschulabschluss), 26.4% (55/208) had a general certificate of secondary education after 10 years of schooling (German: Mittlere Reife), 30.8% (64/208) had a high school degree (ie, a certificate of general university maturity after 12 years of schooling), 10.1% (21/208) had a polytechnic degree, and 23.6% (49/208) had a university degree. Thus, the sample was well educated.

The self-report about participants' diseases revealed that 57.7% (120/208) of the participants had Crohn's disease, 40.4% (84/208) had ulcerative colitis, 1.0% (2/208) had indeterminate colitis, and 1.0% (2/208) reported to have a disease different from the aforementioned ones. The participants received the diagnosis an average of 11.79 years (SD 10.01) ago and had had symptoms for an average of 13.61 years (SD 10.83).

Participants reported using the following online sources of health information: search engines (196/205, 95.6%), forums (154/205, 75.1%), encyclopedias (109/205, 53.2%), patient association websites (108/205, 52.7%), Internet portals (68/205, 33.2%), scientific search engines (eg, Google Scholar and PubMed) (53/205, 25.9%), newsletters (51/205, 24.9%), and social networks (44/205, 21.5%). Out of 208 participants, 3 (1.4%) did not answer this question. In addition, they indicated using the following offline sources of health information: doctors (187/204, 91.7%), family and friends (108/204, 52.9%), psychologists or advisory centers (52/204, 25.5%), books (131/204, 64.2%), presentations (113/204, 55.4%), newspapers and journals (90/204, 44.1%), and television or radio (67/204, 32.8%). Out of 208 participants, 4 (1.9%) did not answer this question.

Dropout Analysis

The first page of the questionnaire had 319 hits. A total of 258 patients with inflammatory bowel disease completed the whole questionnaire at T1 (258/319, 80.9%) and 216 patients completed the questionnaire at T2 (216/319, 67.7%): dropout rate of 16.3% (42/258) from T1 to T2. These subsamples did not differ with respect to the following variables: gender (χ^2_1=0.1, P=.85), type of diagnosis (χ^2_3=1.5, P=.67), age, time passed since receipt of diagnosis, time since occurrence of first symptoms, and number of episodes during the last year (t<1.5, P>.13). Those participants who dropped out of the study used the Internet slightly more often for health-related purposes (mean 4.70, SD 1.32) than the participants who completed the questionnaire at both measurement points (mean 4.25, SD 1.47; t_{258}=1.84, P=.07). As the dropout rate was very small and as we found only one marginal deviation between both subsamples, we considered the remaining sample as suitable for testing our prediction.

Basic Analysis

The correlations between variables and their means and standard deviations are displayed in Table 1.

Table 1. Correlation of all variables.

Number	Variables	Mean	SD	1	2	3	4	5	6	7	8	9
1	Health-related Internet search T1[a]	4.24	1.46									
2	Frequency of episodes T1	1.95	2.11	.07								
3	Health-related stress T1	2.63	0.95	.19[b]	.22[b]							
4	Health-related self-esteem T1	3.42	1.06	-.16[c]	-.23[b]	-.66[d]						
5	Health-related risk perception T1	3.30	0.65	.17[c]	.20[b]	.38[d]	-.30[d]					
6	Health-related Internet search T2[e]	4.07	1.48	.61[d]	.04	-.01	.05	.08				
7	Frequency of episodes T2	1.64	1.98	.16[c]	.53[d]	.23[b]	-.16[c]	.21[b]	.04			
8	Health-related stress T2	2.58	0.99	.18[b]	.12	.75[d]	-.55[d]	.26[d]	.08	.25[d]		
9	Health-related self-esteem T2	3.49	1.08	-.19[b]	-.15[c]	-.62[d]	.72[d]	-.32[d]	-.07	-.17[c]	-.73[d]	
10	Health-related risk perception T2	3.17	0.66	.10	.18[b]	.32[d]	-.28[d]	.57[d]	.19[b]	.14[c]	.35[d]	-.40[d]

[a] T1: first measurement point.

[b] *P*<.05.

[c] *P*<.01.

[d] *P*<.001.

[e] T2: second measurement point.

Test of Predictions

We predicted that frequency of episodes and health-related information searches on the Internet interact in their impact on patients' positive perceptions of their own health. To be more precise, we expected that in patients using the Internet frequently, but not in patients using it rarely, more frequent episodes should lead to a more positive perception of their own health. Multi-colinearity is often an issue when computing interactions between variables assessed in one source. Yet, our predictors—frequency of episodes and frequency of health-related information searches—were not correlated (r=.07, n=208, *P*=.33).

The predicted model showed a good fit to the data (see Figure 1)—χ^2_{24}=35.0, *P*=.07; normed fit index (NFI)=.954; Tucker-Lewis index (TLI)=.977; comparative fit index (CFI)=.985; root mean square error of approximation (RMSEA)=.046. When the measurement errors at T1 were not allowed to correlate, the model nevertheless showed a satisfactory, though not excellent, fit to the data—χ^2_{23}=49.7, *P*=.001; NFI=.934; TLI=.942; CFI=.963; RMSEA=.074.

Frequency of health-related information searches at T1 did not predict the perception of own health at T2 (B=-.03, SE=.04, *P*=.50), whereas there was a trend for an effect of frequency of episodes at T1 on perception of own health at T2 (B=.07, SE=.04, *P*=.07). More importantly, we found the predicted interaction between frequency of health-related information searches and frequency of episodes at T1 on positive perception of own health at T2 (B=.10, SE=.04, *P*=.02). As depicted in Figure 2, when participants used the Internet relatively rarely (-1 SD) to search for health-related information, there was no relationship between frequency of episodes and positive perception of own health (B=-.11, SE=.14; t_{203}=-0.82, *P*=.41). In contrast, when participants used the Internet relatively often (+1 SD) to search for health-related information, the more frequently they experienced episodes the more positive was their perception of their own health (B=.36, SE=.15; t_{203}=2.43, *P*=.02).

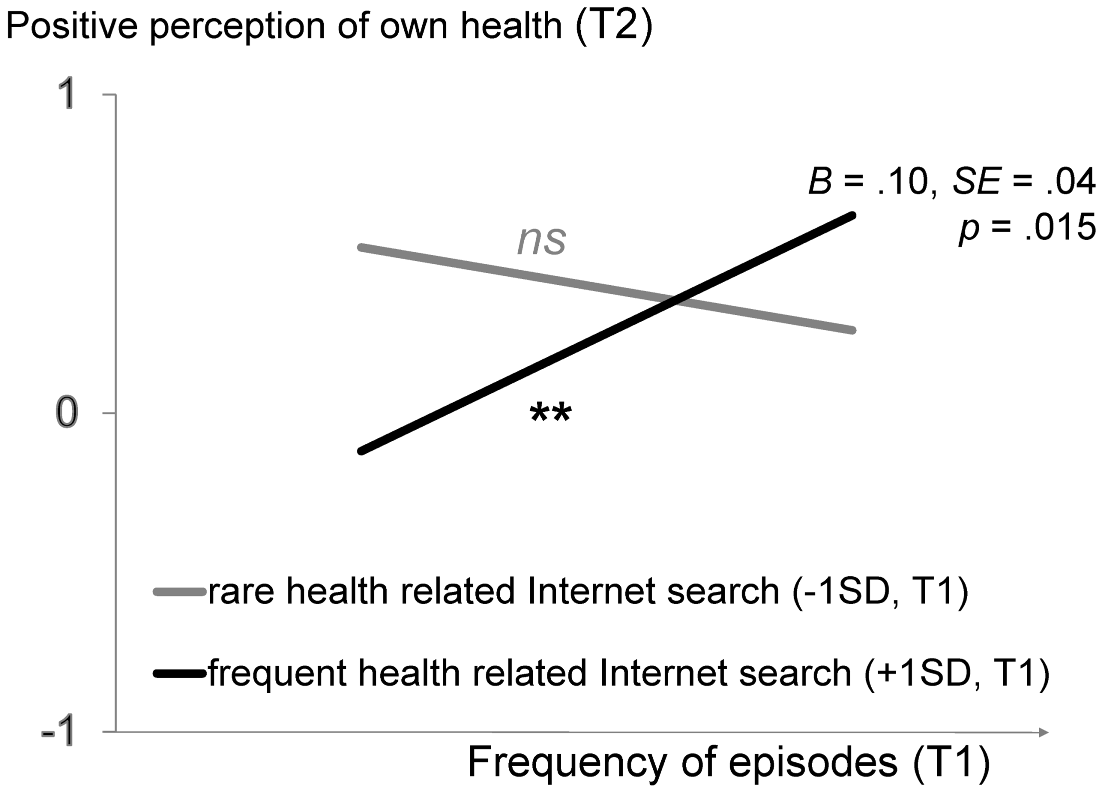
Additional SEMs were computed to gain further insights about this effect. First, a model testing the opposite causal direction did not find evidence for any influence of perception of own health at T1 on the interaction between frequency of episodes and health-related Internet searches at T2 (B=-.03, SE=.10, *P*=.74). This finding provides evidence that the causal direction we assume is underlying the data rather than the opposite causal direction. That is, the perception of own health is affected by the frequency of episodes and the frequency of health-related Internet searches rather than the other way around.

Moreover, another model tested whether the same interaction effect occurred for participation in online social support groups, instead of health-related Internet searches. This analysis served to rule out that any health-related Internet search, which might similarly occur in online social support groups, results in the predicted effects. In this model, no interaction between online social support group participation and frequency of episodes on the perception of own health was found (B=.02, SE=.05, *P*=.63). Hence, in line with our reasoning, the results seem to be driven by Internet searches to acquire health-related information than by Internet use to gain social support.

Finally, two additional models tested whether offline sources of health-related information, namely, social interactive and noninteractive (ie, purely informational) sources, lead to effects similar to those of health-related Internet searches. Again, no interaction occurred between the frequency of episodes and the consultation of health-related offline sources (social interactive sources: B=-.02, SE=.04, *P*=.67; noninteractive sources: B=-.06, SE=.05, *P*=.24). These findings support our expectation that the positively biased perception of own health in case of severe illness refers exclusively to health-related Internet searches.

In sum, the results support the hypothesis that health-related Internet searches for knowledge acquisition and the frequency of episodes associated with the illness have an impact on participants' perception of own health over time; with increasing frequency of episodes, the perception of their own health became more positive when participants used the Internet for health-related information acquisition often, but not when they used it rarely. The additional analyses did not find similar effects for information acquisition from offline media or other individuals, nor from online social support groups. This indicates that the effects described here are unique for self-directed information acquisition on the Internet.

Figure 2. Results from the regression analysis within the structure equation model (SEM) analysis with the latent variable, positive perception of own health, from the second measurement point (T2) as criterion, and frequency of episodes and frequency of health-related information search as predictors controlling for positive perception of own health from the first measurement point (T1). ns: not significant; ***P*<.01.



Discussion

Principal Findings

The current research aimed to test the long-term effects of patients' Internet use on the perception of their own health. We predicted that patients experiencing episodes of illness more frequently have a more positive perception of their health when frequently using the Internet, but not when rarely using the Internet to search for health-related information. This prediction relied on research on counter-regulation [12,13,15,18]. Due to its longitudinal nature and due to the patient sample, the research in this study goes beyond earlier research that had demonstrated among individuals in a negative affective state a positive bias in different stages of the Internet search process (ie, under threat) [25,26].

The interaction between frequency of health-related Internet searches and frequency of episodes of their chronic disease predicted patients' perception of their own health across a 7-month period. Additional analyses did not find evidence for similar effects for other sources (ie, external sources and social support group participation) or for the opposite causal direction. The results clearly indicated that the effects occur, in line with our prediction, only as a consequence of information-related Internet searches and not when social information sources (eg, friends or health professionals) or other offline information sources (eg, books) were resorted to. This suggests that, in line with our assumption, the self-directed nature of information acquisition on the Internet provides the contextual basis for counter-regulation and its impact on information processing and acquisition. In other words, the degrees of freedom the Internet provides during information searches allow for selective information acquisition and the formation of a self-serving (ie, positive) perception of own health when experiencing episodes of illness more frequently. This interpretation of the findings is speculative insofar as this study did not assess any indicators of this assumed process (ie, room for self-regulation leading to selective processing of information in threatened individuals). At the same time, earlier studies have provided ample evidence that self-regulated information searches on the Internet lead to counter-regulation and a preferential processing of positive information in individuals in a negative state [25,26]. Therefore, it seems justified to conclude that the degrees of freedom users have during Internet searches caused the specific outcome of Internet searches, which is different from outcomes involving resorting to other information sources. Nonetheless, it is worthwhile to explore further in future research the processes underlying the long-term effects of information searches on the Internet that were found here for the first time.

Comparison With Earlier Work and Strengths

To the best of our knowledge, this study was the first to study long-term effects of frequency of episodes and Internet searches to acquire health-related information. Earlier research on health within the context of the Internet mostly focused on online prevention programs [31,32] and the effects of online social support [33,34].

Beyond its originality, the strengths of this study are its longitudinal design and the fact that several indicators for the dependent variable have been assessed targeting the perception of own health, as well as the perception of the illnesses patients are suffering from. Separate tests for each of the three indicators show the same results as the analysis across indicators reported above.

Limitations

Only patients with specific chronic diseases were included in the study. In this study, relying on patients with chronic inflammatory bowel diseases allowed for the assessment of a more homogenous and less subjective indicator of the severity of illness, namely, the number of episodes during the last year. In this vein, focusing on one particular group of diseases allowed for the assessment of an appropriate indicator of severity of illness. Nonetheless, further research should definitely aim to replicate the current findings with other chronic diseases and beyond.

One might consider the limited internal consistency of the indicator of health-related risk perception as a weakness of this study. As no scale for risk perception in the context of chronic inflammatory bowel diseases exists in the literature, we developed our own scale that did not work out perfectly. However, given that we use a latent variable for the perception of one’s own health, the error variance included in the risk perception scale does not affect our main statistical test. In addition, risk perception loads relatively low on the latent variable; the model also holds when only the other two indicators of perception of one’s own health are used. For these reasons, we do not consider the unsatisfying internal consistency of the risk perception scale as a threat to the validity of these findings.

A final limitation of this study is that we did not assess what type of information participants studied on the Internet. This would have allowed us to find out whether they select, receive, or remember information in an unbalanced fashion. However, collecting that information and analyzing it across a 7-month period hardly seems feasible. In addition, earlier experimental research has already addressed this aspect and found that all steps of the information search process on the Internet are guided by a preference for positive information in a negative psychological state (ie, threat) [25,26].

Implications

The findings from this study have ambivalent implications for patients. On the one hand, Internet use seems to help patients with severe illnesses to develop a positive perception of their own health because the information-related Internet searches lead to a more positive picture of their own health situation—in particular, if they are severely affected by their disease (ie, frequently suffer from it). Hence, this research has added one more aspect to the list of positive implications of health information searches on the Internet, such as increased empowerment and heightened compliance among patients using the Internet [35,36]. On the other hand, the positive perception of own health can also be seen as evidence for a bias in information processing on the Internet. As has been found in earlier research on counter-regulation, those in a negative state are more likely to preferably process positive information [12,13,15,18]. In the case of patients’ Internet searches, this might imply that when frequently searching the Internet for health-related information, those in a negative state in particular have a distorted picture about their own health—they might perceive their own situation as far too positive (eg, underestimate risks).

This distorted and possibly too-positive perception, in turn, can have implications for the doctor-patient relationship and the medical treatment of those patients. Internet-informed patients might be less willing to accept their doctors' advice and claim more autonomy in health decisions, due to an increased positive perception of their own health as was found in this study. This might in turn lead to less willingness to comply. Therefore, physicians should pay particular attention to this implication in order to prevent their patients, fatally enough, from making decisions against appropriate treatments. At the same time, patients should be aware of the need to carefully conduct Internet searches and examine the integrity of an information source before relying on its information. Further research is needed to gain more insight about these implications as they rely more on speculative conclusions from this study's findings than on the findings themselves.

Conclusions

This study provided evidence for long-term outcomes of Internet searches for health information. The more severe the patients’ illnesses (ie, the more frequently they suffer from them), the more that frequent Internet searches lead to a positive perception of own health. Thus, the accessibility of health-related information on the Internet renders patients more informed than in the past when health-related information was accessible only to health professionals; it also opens an avenue for unbalanced information processing. This unbalanced processing might help patients cope emotionally with their situation; however, it might result in a biased perception of their own health, particularly in those who suffer severely from a disease.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

CFI: comparative fit index
NFI: normed fit index
ns: not significant
RMSEA: root mean square error of approximation
SEM: structure equation model
T1: first measurement point
T2: second measurement point
TLI: Tucker-Lewis index

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Original Paper

Including Online-Recruited Seeds: A Respondent-Driven Sample of Men Who Have Sex With Men

Nathan John Lachowsky[1,2], PhD; Allan Lal[1], BA (Hons); Jamie I Forrest[3], MPH; Kiffer George Card[1,4], BS; Zishan Cui[1], MSc; Paul Sereda[1], BA (Hons); Ashleigh Rich[4], MPH; Henry Fisher Raymond[5,6], PhD; Eric A Roth[7,8], PhD; David M Moore[1,2], MD; Robert S Hogg[1,4], PhD

[1]British Columbia Centre for Excellence in HIV/AIDS, Vancouver, BC, Canada
[2]Division of AIDS, Faculty of Medicine, University of British Columbia, Vancouver, BC, Canada
[3]School of Population and Public Health, Faculty of Medicine, University of British Columbia, Vancouver, BC, Canada
[4]Faculty of Health Science, Simon Fraser University, Burnaby, BC, Canada
[5]Department of Epidemiology and Biostatistics, University of California, San Francisco, San Francisco, CA, United States
[6]San Francisco Department of Public Health, San Francisco, CA, United States
[7]Department of Anthropology, Faculty of Social Science, University of Victoria, Victoria, BC, Canada
[8]Centre for Addictions Research British Columbia, University of Victoria, Victoria, BC, Canada

Corresponding Author:
Robert S Hogg, PhD
Faculty of Health Science
Simon Fraser University
Blusson Hall, Room 11300
8888 University Drive
Burnaby, BC, V5A 1S6
Canada
Phone: 1 778 782 7629
Fax: 1 778 782 5927
Email: robert_hogg@sfu.ca

Abstract

Background: Technology has changed the way men who have sex with men (MSM) seek sex and socialize, which may impact the implementation of respondent-driven sampling (RDS) among this population. Initial participants (also known as seeds) are a critical consideration in RDS because they begin the recruitment chains. However, little information is available on how the online-recruited seeds may effect RDS implementation.

Objective: The objectives of this study were to compare (1) online-recruited versus offline-recruited seeds and (2) subsequent recruitment chains of online-recruited versus offline-recruited seeds.

Methods: Between 2012 and 2014, we recruited MSM using RDS in Vancouver, Canada. RDS weights were used with logistic regression to address each objective.

Results: A total of 119 seeds were used, 85 of whom were online-recruited seeds, to recruit an additional 600 MSM. Compared with offline-recruited seeds, online-recruited seeds were less likely to be HIV-positive (OR 0.34, 95% CI 0.13-0.88), to have attended a gay community group (AOR 0.33, 95% CI 0.12-0.90), and to feel gay community involvement was “very important” (AOR 0.16, 95% CI 0.03-0.93). Online-recruited seeds were more likely to ask a sexual partner’s HIV status always versus <50% of the time (AOR 5.21, 95% CI 1.17-23.23), to have watched the Pride parade (AOR 6.30, 95% CI 1.69-23.45), and to have sought sex online (AOR 4.29, 95% CI 1.53-12-12.05). Further, compared with recruitment chains started by offline-recruited seeds, recruits from chains started by online-recruited seeds (283/600, 47.2%) were less likely to be HIV-positive (AOR 0.25, 95% CI 0.16-0.40), to report “versatile” versus “bottom” sexual position preference (AOR 0.56, 95% CI 0.35-0.88), and to be in a relationship lasting >1 year (AOR 1.65, 95% CI 1.06-2.56). Recruits of online seeds were more likely to be out as gay for longer (eg, 11-21 vs 1-4 years, AOR 2.22, 95% CI 1.27-3.88) and have fewer Facebook friends (eg, 201-500 vs >500, AOR 1.69, 95% CI 1.02-2.80).

Conclusions: Online-recruited seeds were more prevalent, recruited fewer participants, but were different from those recruited offline. This may therefore help create a more diverse overall sample. Our work has shown the value of geosocial networking apps for aiding RDS recruitment efforts, especially when faced with slow participation uptake by other means. Understanding the degree to which networks interact will be an important next step in confirming the efficacy of online RDS recruitment strategies.

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KEYWORDS

men who have sex with men; respondent driven sampling; HIV/AIDS; online recruitment; Internet

Introduction

Respondent driven sampling (RDS), a form of peer referral-based sampling, has become a popular strategy to recruit “hidden” or “marginalized populations” [1,2]. This rise in use has led some researchers to critically assess both theoretical and operational components of the methodology. RDS implementation resembles snowball sampling with several critical caveats [3-6]. Initial participants are purposefully recruited to be “seeds” as long as they fit the study’s eligibility criteria. After completing the study procedures, seeds are offered a limited number of vouchers to recruit their peers to participate. When vouchers are redeemed, eligible participants also complete the same study procedures and are asked to recruit their peers, and this continues until recruitment goals are met. Using specially formulated statistical programs, sampling weights are developed and applied to estimate population parameters. For the purpose of RDS, effective seeds generate large recruitment chains and samples, which has been shown to be associated with motivation and a commitment to the research goals [7].

While many researchers have pointed to the issues around the statistical accuracy and precision of estimates generated from this sampling methodology [2,8,9], few have discussed the practice, innovation, and implementation of RDS. There is growing interest in online-based methods to address the prevalence of Internet use among men who have sex with men (MSM) and acknowledge the growth of online social and sexual networking [10,11]. Innovation around RDS can be helpful in mitigating some of the challenges of implementing the methodology, notably slow recruitment rates [5,12].

The Internet and the rise of online communities of gay and bisexual men remains an underutilized tool for population health researchers. In only a few decades, there has been a rapid uptake of the Internet among gay and bisexual men to facilitate new connections [13,14]. As many as 90% of gay and bisexual men have reported using the Internet for information seeking and socializing [14]. Other reports estimate that between 40% and 97% use the Internet to seek sex [15,16]. With a high prevalence of Internet usage among this population, new connections and networks are formed online now more than ever before [13,17]. As such, the use of traditional venue-based and time-location sampling may reach different segments of the study population at different times [18].

Prior formative research related to implementing RDS identified the importance of having diverse seeds to generate a sample with a greater ability to penetrate harder-to-reach subgroups of the population [1]. Furthermore, previous work has shown that diversity in seed selection methods can produce varying samples but more importantly differing recruitment rates [18,19]. Given increased utilization of specific online virtual spaces among MSM in Vancouver, Canada [20], we supplemented our RDS strategy by recruiting seeds online through a popular geolocation social networking mobile phone app, Grindr, used by MSM to seek sex with other men. The objectives of this analysis were to determine whether there were any meaningful differences in the seeds that we recruited online compared with those recruited through other community venues, and whether participants recruited in network chains that started with an online-recruited seed differed from those participants recruited from other seeds.

Methods

Recruitment

The Momentum Health Study is a longitudinal cohort of gay, bisexual, and other men who have sex with men in Metro Vancouver, British Columbia, Canada, recruited by RDS. The study aims to report on the effect of expanded access to antiretroviral therapy for the treatment of human immunodeficiency virus (HIV) and is the first study to use RDS in the greater Vancouver area to obtain a diverse sample of MSM. Prior to recruitment, we conducted systematic qualitative formative research to map the network structure of MSM in Vancouver and the surrounding area [20].

In February 2012, we began recruitment using 10 initial seeds selected from various community agency partners. Each seed was given three RDS coupons (electronic or laminated card or combination). Initial seeds were instructed to distribute RDS vouchers to other MSM in their social or sexual networks who could then redeem the card to participate in the study. Like many previous studies, we initially distributed three RDS coupons to each participant, but after encountering substantially slow recruitment rates in the first 6 months, we increased the number of RDS coupons from three to six. However, we observed no significant difference in rate of recruitment. Since seeds can be purposively selected [21,22], we decided to utilize a popular networking app for gay and bisexual men (ie, Grindr) to recruit additional seeds. Advertisements in the form of pop-up messages were sent to users within a 25 km radius to downtown Vancouver. The message contained a link to information about the study and an opportunity to leave a message for study staff to contact them by email or phone. In total, study staff sent out nine broadcast messages during the recruitment period.

A CAN $50 honorarium or equivalent entries into a draw for electronics or travel gift cards (CAN $10/entry) was provided to participants who completed the study protocol. A CAN $10 honorarium was provided for each additional recruit who successfully completed the study protocol (to a maximum of 6 recruits/CAN $60).

Independent Variables

In comparing the characteristics and recruitment efficacy of online-recruited seeds with other seeds, we classified each seed as either "online" if they were recruited through the sociosexual networking app advertisement, or as "offline" if they were selected as part of the initial study protocol. Among all study seeds, we compared "online" with "offline" seeds. We also compared the subsequent recruitment chains of "online" with "offline" seeds to compare the sample derived from online versus offline seeds.

Dependent Variables

We investigated a number of sociodemographic, community, and sexual behavioral factors thought to be associated with recruitment RDS dynamics. Sociodemographic variables included age (continuous in years), sexual identity (gay vs all other identity options collapsed: bisexual, queer, questioning, straight, etc), race/ethnicity (white vs all other identity options collapsed: Asian, Aboriginal, Latino, Black, other), birthplace (Canada vs any other country), formal educational attainment (any post-secondary education versus none), current student (or not), currently employed (or not), and annual income (<CAN $30,000 vs ≥$30,000). Living in a house, apartment, or student residence were collapsed together and considered being stably housed versus those who reported being homeless or in temporary housing. HIV status was determined using a point-of-care rapid HIV test administered at the time of the study visit (HIV-positive vs HIV-negative).

Community factors included questions about the gender of those they socialize most with (mostly or only men vs mostly or only women), how many years they consider themselves to have been "out" categorized into quartiles for those who were gay-identified (1-4, 5-10, 11-21, >21, or bisexual-identified, or not out), participation on a gay sports team in the past 6 month (yes vs no), having attended a group or club for gay men in the past 6 months (yes vs no), having attended the Pride parade in the past year (as a volunteer or in the parade vs as a spectator vs not at all), and having used a smartphone/mobile app to seek sex with another man in the past 6 months (yes vs no). Participants were asked to indicate "how important is it to be connected to and involved in the gay community" on a 4-point ordinal scale (not at all, not very or somewhat important, very important). Finally, participants were asked to indicate how many Facebook friends they had on a continuous measure, which was used as a proxy for (online) social network (0-30, 31-200, 201-500, >500).

Sexual behavioral factors included any sex with any females in the past 2 years (yes vs no), male anal sex position preference (bottom, versatile, top, or prefer no anal), marital or common law status as indicated by living together for at least 1 year (not married or common law, married or common law, no regular partner), number of male anal sex partners in the past 6 months measured continuously but categorized into quartiles (0-1, 2-3, 4-7, >7), if they had received any income for sex in the past 6 months (or not), how often they ask their partner's HIV status (less than half the time, more than half the time, or always), whether they had ever been tested for HIV (or not), and whether they have engaged in any "risk sex" defined as any condomless anal intercourse with a partner of opposite or unknown HIV status in the past 6 months.

Statistical Analysis

For all analyses, including the descriptive statistics, RDS-weighted adjustments were generated using RDSAT version 7.1.46, taking into account the network size and homophily. The RDS-derived weights were then imported into SAS (version 9.3) for inclusion in the bivariate and multivariable logistic regression analyses. Two final multivariable logistic regression models were built using backward selection criteria that minimized the Aikaike Information Criterion. The first model compared differences between online-recruited and offline-recruited seeds. The second model compared differences between the samples recruited from online-recruited seeds and offline-recruited seeds. All tests were two-sided and performed with alpha set at the .05 significance level.

Ethical approval for this study was been granted by the research ethics boards of Simon Fraser University, University of British Columbia Providence Healthcare Research Institute, and the University of Victoria.

Results

A total of 119 seeds were used; 85 were recruited online (71.4%). These 119 seeds recruited a subsequent 600 participants for a total sample size of 719 MSM. Most of these seeds cited the following reasons for wanting to participate: help the community (40/119, 33.6%), had an interest in sexual health and HIV (35/119, 29.4%), and interested in gay men's issues (23/119, 19.3%). Online-recruited seeds had significantly smaller networks than other seeds (median 10 vs 15, *P*=.006).

Table 1 provides descriptive statistics and bivariate associations with being an online-recruited seed compared with being an in-person recruited seed. Online recruited seeds were less likely to be HIV-positive (OR 0.34, 95% CI 0.13-0.88), report attending gay-community meetings in the past 6 months (OR 0.27, 95% CI 0.12-0.63), and report that being involved in the gay community was very important vs not important (OR 0.11, 95% CI 0.02-0.54), but were more likely to attend a Pride parade in the past 12 months as a spectator (OR 2.84, 95% CI 1.05-7.69), use apps to seek sex in the past 6 months (OR 3.41, 95% CI 1.49-7.82), and have 31-200 Facebook friends compared to over 500 (OR 3.47, 95% CI 1.07-11.19).

Table 1. Descriptive statistics of and bivariate associations with being an online-recruited seed compared with in-person-recruited seed.

	Offline seeds (n=34)		Online seeds (n=85)		OR	95% CI
	n	% (of row)	n	% (of row)		
Demographic factors						
Age: mean (Q1,Q3)	28.5	(24,38)	31	(25,45)	1.020	0.985-1.056
Gay-identified						
Yes	31	28.2	79	71.8	Ref	
No	3	33.3	6	66.7	0.785	0.185-3.335
White race/ethnicity						
Yes	28	82.4	63	69.2	Ref	
No	6	17.7	22	78.6	1.629	0.595-4.457
Born in Canada						
Yes	28	32.2	59	67.8	Ref	
No	6	18.8	26	81.3	2.056	0.760-5.563
Formal education						
High school or less	4	23.5	13	76.5	Ref	
Any post-secondary training	30	30.0	70	70.0	0.718	0.216-2.383
Current student						
No	25	29.4	60	70.6	Ref	
Yes	9	26.5	25	73.5	1.157	0.474-2.828
Annual income, CAD						
<$30,000	21	30.4	48	69.6	Ref	
≥$30,000	13	26.0	37	74.0	1.245	0.552-2.810
Currently employed						
No	10	33.3	20	66.7	Ref	
Yes	24	27.0	65	73.0	1.354	0.555-3.304
Currently stably housed						
Yes	33	29.5	79	70.5	Ref	
No	1	14.3	6	85.7	2.506	0.290-21.637
HIV test result						
Negative	23	24.0	73	76.0	Ref	
Positive	11	47.8	12	52.2	0.344[a]	0.134-0.882
Community factors						
Only/Mostly socialize with men						
Yes	21	32.3	44	67.7	Ref	
No	13	24.1	41	75.9	1.505	0.668-3.390
Play on gay sports team, past 6 months						
No	25	25.0	75	75.0	Ref	
Yes	9	47.4	10	52.6	0.370	0.135-1.015
Attend gay-specific groups, past 6 months						
No	13	18.1	59	81.9	Ref	
Yes	21	44.7	26	55.3	0.273[a]	0.119-0.627
Pride parade participation, past 12 months						

	Offline seeds (n=34)		Online seeds (n=85)		OR	95% CI
	n	% (of row)	n	% (of row)		
No	12	34.3	23	65.7	Ref	
Yes, spectator	9	15.5	49	84.5	2.841[a]	1.049-7.692
Yes, in or volunteer	13	50.0	13	50.0	0.522	0.185-1.474
Use apps to seek sex, past 6 months						
No	19	45.2	23	54.8	Ref	
Yes	15	19.5	62	80.5	3.414[a]	1.490-7.823
Importance of being connected to and involved in gay community						
Not important	2	8.0	23	92.0	Ref	
Somehow important	14	26.4	39	73.6	0.242	0.050-1.163
Very important	18	43.9	23	56.1	0.111[a]	0.023-0.535
# of Facebook friends						
>500	14	40.0	21	60.0	Ref	
201-500	10	29.4	24	70.6	1.600	0.588-4.353
31-200	5	16.1	26	83.9	3.467[a]	1.074-11.191
0-30	5	26.3	14	73.7	1.867	0.548-6.353
Sex & HIV factors						
Any sex with females						
No	32	28.6	80	71.4	Ref	
Yes	2	28.6	5	71.4	1.000	0.184-5.421
Male anal sex position preference						
Bottom	13	32.5	27	67.5	Ref	
Versatile	8	29.6	19	70.4	1.144	0.397-3.295
Top	12	25.0	36	75.0	1.444	0.570-3.660
No anal	1	25.0	3	75.0	1.444	0.137-15.266
Common law (lived together 1 year)						
No	8	42.1	11	57.9	Ref	
Common Law/Married	6	30.0	14	70.0	1.697	0.453-6.358
No regular partner	20	25.0	60	75.0	2.182	0.770-6.186
# Male anal sex partners, past 6 months						
0-1	11	35.5	20	64.5	Ref	
2-3	9	32.1	19	67.9	1.161	0.394-3.425
4-7	6	20.0	24	80.0	2.200	0.691-7.006
>7	8	26.7	22	73.3	1.513	0.507-4.515
Any income from sex work, past 6 months						
No	32	28.3	81	71.7	Ref	
Yes	2	33.3	4	66.7	0.790	0.138-4.529
Asks partner’s HIV status						
<50% of time	16	34.8	30	65.2	Ref	
>50% of time	14	31.1	31	68.9	1.181	0.492-2.834
100% of time	4	14.3	24	85.7	3.200	0.945-10.839

	Offline seeds (n=34)		Online seeds (n=85)		OR	95% CI
	n	% (of row)	n	% (of row)		
HIV test, ever						
No	2	40.0	3	60.0	Ref	
Yes	32	28.1	82	71.9	1.709	0.273-10.707
Any risky sex [b], past 6 months						
No	22	26.5	61	73.5	Ref	
Yes	12	34.3	23	65.7	0.691	0.295-1.619

[a] Indicates statistical significance at *P*<.05.

[b] Any condomless anal intercourse with a partner of opposite or unknown HIV status.

Table 2 shows the results of the multivariable model identifying factors associated with being an online-recruited seed. In these analyses, online recruited seeds were less likely to feel it was "very important" to be involved in the gay community versus finding it not important (AOR 0.16, 95% CI 0.03-0.93), to have attended gay specific groups in the past 6 months (AOR 0.33, 95% CI 0.12-0.90), and more likely to have been a spectator at the Pride parade in the prior 12 months versus not (AOR 6.30, 95% CI 1.69-23.45), to ask a sexual partners HIV status 100% of the time versus less than 50% of the time (AOR 5.21, 95% CI 1.17-23.23), and to have used an online application to seek sex in the past 6 months than not (AOR 4.29, 95% CI 1.53-12.05).

Although online-recruited seeds comprised 71.4% of all seeds, their subsequent recruitment chains generated only 47.2% of the remaining sample (283/600). Table 3 shows the descriptive statistics and bivariate associates with being recruited from an online-recruited seed chain compared with an in-person-recruited seed's chain.

Table 2. Multivariable analyses of factors associated with being an online-recruited seed compared with in-person-recruited seed.

	AOR	95% CI
Attend gay-specific groups, past 6 months		
No	Ref	
Yes	0.331[a]	0.122-0.900
Pride parade participation, past 12 months		
No	Ref	
Yes, spectator	6.303[a]	1.694-23.454
Yes, in or volunteer	1.192	0.325-4.369
Use apps to seek sex, past 6 months		
No	Ref	
Yes	4.293[a]	1.530-12.048
Importance of being connected to and involved in gay community		
Not important	Ref	
Somehow important	0.380	0.072-2.016
Very important	0.163[a]	0.029-0.929
Asks partner's HIV status		
<50% of time	Ref	
>50% of time	1.032	0.343-3.104
100% of time	5.211[a]	1.169-23.232

[a] Indicates statistical significance at *P*<.05.

Table 3. Descriptive statistics of and bivariate associations with being recruited in a chain started from an online seed compared with a recruitment chain started with an in-person-recruited seed.

	Offline seed's recruitment chain (n=317)		Online seed's recruitment chain (n=283)		OR	95% CI
	n	% (of row)	n	% (of row)		
Demographic factors						
Age: mean (Q1,Q3)	40	(28,49)	31	(25,41)	0.962[a]	0.949-0.976
Gay-identified						
Yes	265	52.8	237	47.2	Ref	
No	52	53.1	46	46.9	0.989	0.641-1.526
White race/ethnicity						
Yes	240	53.6	208	46.4	Ref	
No	77	50.7	75	49.3	1.124	0.778-1.624
Born in Canada						
Yes	258	54.9	212	45.1	Ref	
No	59	45.4	71	54.6	1.465	0.991-2.163
Formal education						
High school or less	88	58.3	63	41.7	Ref	
Any post-secondary training	224	51.3	213	48.7	1.328	0.914-1.930
Current student						
No	268	55.5	215	44.5	Ref	
Yes	49	42.2	67	57.8	1.704[a]	1.131-2.568
Annual income, CAD						
<30,000	216	55.7	172	44.3	Ref	
≥$30,000	101	47.6	111	52.4	1.380	0.986-1.931
Currently employed						
No	144	61.5	90	38.5	Ref	
Yes	173	47.3	193	52.7	1.785[a]	1.278-2.492
Currently stably housed						
Yes	262	51.5	247	48.5	Ref	
No	55	60.4	36	39.6	0.694	0.441-1.094
HIV test result						
Negative	182	42.9	242	57.1	Ref	
Positive	135	76.7	41	23.3	0.228[a]	0.153-0.340
Community factors						
Only/mostly socialize with men						
Yes	187	55.5	150	44.5	Ref	
No	130	49.4	133	50.6	1.275	0.923-1.762
Years out						
1-4	52	52.0	48	48.0	Ref	
5-10	56	45.5	67	54.5	1.296	0.764-2.200
11-21	61	40.7	89	59.3	1.581	0.949-2.632
>21	107	71.8	42	28.2	0.425[a]	0.250-0.723

	Offline seed's recruitment chain (n=317)		Online seed's recruitment chain (n=283)		OR	95% CI
	n	% (of row)	n	% (of row)		
Bisexual	35	55.6	28	44.4	0.867	0.460-1.632
Not out	6	40.0	9	60.0	1.625	0.538-4.906
Play on gay sports team, past 6 months						
No	287	53.4	250	46.6	Ref	
Yes	30	47.6	33	52.4	1.263	0.749-2.131
Attend gay-specific groups, past 6 months						
No	193	52.7	173	47.3	Ref	
Yes	124	53.0	110	47.0	0.990	0.712-1.375
Pride parade participation, past 12 months						
No	125	54.1	106	45.9	Ref	
Yes, spectator	159	54.1	135	45.9	1.001	0.709-1.415
Yes, in or volunteer	33	44.0	42	56.0	1.501	0.888-2.535
Use apps to seek sex, past 6 months						
No	177	59.6	120	40.4	Ref	
Yes	140	46.2	163	53.8	1.717[a]	1.243-2.374
Importance of being connected to and involved in gay community						
Not important	62	45.3	75	54.7	Ref	
Somehow important	168	54.7	139	45.3	0.684	0.456-1.025
Very important	87	55.8	69	44.2	0.656	0.413-1.040
# of Facebook friends						
>500	77	51.3	73	48.7	Ref	
201-500	53	40.2	79	59.8	1.572	0.980-2.523
31-200	73	49.0	76	51.0	1.098	0.698-1.728
0-30	114	67.5	55	32.5	0.509[a]	0.323-0.801
Sex & HIV factors						
Any sex with females						
No	266	52.7	239	47.3	Ref	
Yes	51	53.7	44	46.3	0.960	0.619-1.490
Male anal sex position preference						
Bottom	96	47.8	105	52.2	Ref	
Versatile	98	59.0	68	41.0	0.634[a]	0.419-0.961
Top	107	52.2	98	47.8	0.837	0.567-1.236
No anal	16	57.1	12	42.9	0.686	0.309-1.523
Common law (lived together 1 year)						
No	56	43.4	73	56.6	Ref	
Common law/Married	54	51.4	51	48.6	0.725	0.432-1.215
No regular partner	207	56.6	159	43.4	0.589[a]	0.393-0.883
# Male anal sex partners, past 6 months						
0-1	90	54.5	75	45.5	Ref	
2-3	71	46.1	83	53.9	1.403	0.903-2.180

	Offline seed’s recruitment chain (n=317)		Online seed’s recruitment chain (n=283)		OR	95% CI
	n	% (of row)	n	% (of row)		
4-7	68	50.7	66	49.3	1.165	0.738-1.839
>7	87	59.6	59	40.4	0.814	0.519-1.277
Any income from sex work, past 6 months						
No	296	52.9	264	47.1	Ref	
Yes	21	52.5	19	47.5	1.014	0.534-1.928
Asks partner’s HIV status						
<50% of time	137	51.9	127	48.1	Ref	
>50% of time	98	49.0	102	51.0	1.123	0.777-1.622
100% of time	82	60.3	54	39.7	0.710	0.467-1.081
HIV test, ever						
No	13	38.2	21	61.8	Ref	
Yes	304	53.7	262	46.3	0.534	0.262-1.086
Any risky sex [b], past 6 months						
No	180	50.3	178	49.7	Ref	
Yes	129	56.8	98	43.2	0.768	0.550-1.073

[a] Indicates statistical significance at *P*<.05.

[b] Any condomless anal intercourse with a partner of opposite or unknown HIV status.

These aforementioned associations show that participants recruited from an online-recruited seeds’ chains were less likely to be older (OR 0.96, 95% CI 0.95-0.98), HIV-positive (OR 0.23, 95% CI 0.15-0.34), be versatile than a bottom with regards to sexual position preferences (OR 0.63, 95% CI 0.42-0.96), be in a relationship lasting more than 1 year versus being single (OR 0.59, 95% CI 0.39-0.88), to have between 0 and 30 Facebook friends compared with having more than 500 Facebook friends (OR 0.51, 95% CI 0.32-0.80), been “out” for over 22 years compared with between 1 and 4 years (OR 0.43, 95% CI 0.25-0.72), but were more likely to be currently employed (OR 1.79, 95% CI 1.28-2.49), be a current student (OR 1.70; 95% CI 1.13-2.57), and use apps to seek sex in the past 6 months (OR 1.72, 95% CI 1.24-2.37).

Table 4 reports the results of the multivariable analysis of factors associated with being recruited in a network chain that originated from an online-recruited seed. These results also showed that participants who were recruited from online-recruited seeds’ chains were less likely to be HIV-positive (AOR 0.25, 95% CI 0.16-0.40), be versatile as their sexual position preference (AOR 0.56, 95% CI 0.35-0.88), be in a relationship lasting 1 year versus being single (AOR 1.65, 95% CI 1.06-2.56). However, these participants were more likely to be have been “out” for 11-21 versus 1-4 years (AOR 2.22, 95% CI 1.27-3.88) and to have between 201-500 Facebook friends versus over 500 (AOR 1.69, 95% CI 1.02-2.80).

Table 4. Multivariable analyses of factors associated with being recruited in a chain started from an online seed compared with a recruitment chain started with an in-person-recruited seed.

	AOR	95% CI
HIV test result		
Negative	Ref	
Positive	0.250[a]	0.158-0.396
Years out		
1-4	Ref	
5-10	1.300	0.749-2.256
11-21	2.215[a]	1.266-3.877
22	0.929	0.500-1.724
Bisexual-identified	1.492	0.738-3.015
Not out	2.182	0.662-7.192
# of Facebook friends		
>500	Ref	
201-500	1.689[a]	1.020-2.796
31-200	1.430	0.864-2.367
0-30	0.910	0.536-1.544
Male anal sex position preference		
Bottom	Ref	
Versatile	0.556[a]	0.352-0.877
Top	0.708	0.459-1.091
No anal	0.552	0.226-1.346
Common law (lived together 1 year)		
No	Ref	
Common law/Married	0.711	0.401-1.259
No regular partner	0.605[a]	0.390-0.939

[a] Indicates statistical significance at *P*<.05.

Discussion

Principal Results

In this RDS study of MSM in Vancouver, a total of 119 seeds were used to recruit a subsequent 600 participants. Nearly three-quarters of the seeds used were recruited online, which was meant to address limitations of slow recruitment rates [5,12], but the online seeds recruited less than half of the subsequent sample. As such, these online-recruited seeds were not able to generate as large recruitment chains as those seeds recruited more traditionally through community agencies, which may be a result of different motivations and social networks [7]. Our findings demonstrated that online-recruited seeds who favored using hook-up apps to seek sex were less likely to attend gay-specific groups and felt less importance with respect to participating in the larger gay community. These findings are consistent with previous work indicating that gay men recruited online tend to be different with regard to behavioral and even personal characteristics in comparison with those recruited at other venues [23-25].

Online-recruited seeds and their subsequent recruits were more likely to be HIV-negative, to use apps to seek sex with other men, and to report fewer Facebook friends, a proxy for (online) social network size. We also found that men recruited online were more likely to inquire about a sex partner's HIV status before sex. This suggests that men who participate in online sex seeking may have better communication opportunities to inform and/or interest to adopt more seroadaptive behaviors (ie, sex that uses knowledge of HIV status to inform practices that reduce the risk of HIV transmission) into their sexual practices [26]. This includes serosorting and strategic positioning decisions, which can help reduce HIV transmission. In San Francisco, researchers reported that seroadaptive behaviors are common and have increased in the last decade [27]. This may reflect the changing ways that gay and bisexual men seek and integrate sexual health knowledge that is related to the rise in seeking sex in online spaces.

Comparison With Prior Work

Importantly for the consideration of implementing RDS among urban gay and bisexual men, we found that neither online-recruited seeds nor their recruits were significantly different than the comparator with respect to demographic factors. This is in contrast to previous RDS work that also implemented online or innovative recruitment protocols. Previous studies using RDS recruitment combined with online or self-selected innovations found significant differences with regards to ethnicity, economic status, and education [19,28,29]. This key difference in findings may suggest that online and offline networks are increasingly overlapped as greater numbers of MSM now socialize and seek sex online. It may also reflect regional and national differences in community (both physical and virtual) participation and sex seeking norms.

Limitations

The novel use of a sociosexual mobile app to recruit seeds for RDS allowed us to reach a wider non–location-based audience of the target population interested in participating in a sexual health research study. However, it is important to note that these findings do not compare the characteristics of MSM who self-selected into the study and those who saw our mobile app advertisement but did not respond. Therefore, we cannot be certain whether there are differences among the general online and offline populations and how these differences potentially introduce self-selection biases into our recruitment efforts. RDS employs peer recruitment that requires participants to know someone else’s eligibility status for the study and to disclose their own sexual minority behavior, which also limits generalizability. Our results may also be limited by the fact that online seeds were recruited through an app used for sex seeking, while offline seeds were recruited through community partners whose mission and purpose go far beyond sex seeking. Therefore, it is difficult to assess what differences are attributable to the nature of the recruitment site versus the actual medium of recruitment.

Conclusions

In conclusion, our work has shown the value of geosocial networking apps for aiding RDS recruitment efforts, especially when faced with slow participation uptake by other means. Understanding the degree to which networks interact will be an important next step in confirming the efficacy of online RDS recruitment strategies. Our findings highlighted some differences between online and offline seeds, indicating that, in the current sociosexual milieu, using both online- and traditionally recruited seeds may provide the most diverse sample of MSM in urban areas.

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Conflicts of Interest

None declared.

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Abbreviations

HIV: human immunodeficiency virus
MSM: men who have sex with men
RDS: respondent-driven sampling

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Original Paper

Assessing the Effects of Participant Preference and Demographics in the Usage of Web-based Survey Questionnaires by Women Attending Screening Mammography in British Columbia

Rebecca Mlikotic[1*], BSc; Brent Parker[2*], BSc; Rasika Rajapakshe[1,3,4*], PhD

[1]British Columbia Cancer Agency, Sindi Ahluwalia Hawkins Centre for the Southern Interior, Kelowna, BC, Canada

[2]Interior Health Authority, Department of Surgical Services, Kelowna, BC, Canada

[3]Faculty of Medicine, Department of Surgery, University of British Columbia, Vancouver, BC, Canada

[4]Irving K. Barber School of Arts and Sciences, Department of Computer Science (Unit 5), University of British Columbia, Okanagan Campus, Kelowna, BC, Canada

[*]all authors contributed equally

Corresponding Author:
Rebecca Mlikotic, BSc
British Columbia Cancer Agency
Sindi Ahluwalia Hawkins Centre for the Southern Interior
399 Royal Avenue
Kelowna, BC, V1Y 5L3
Canada
Phone: 1 250 712 3966 ext 686912
Fax: 1 250 712 3911
Email: rebecca.mlikotic@alumni.ubc.ca

Abstract

Background: Increased usage of Internet applications has allowed for the collection of patient reported outcomes (PROs) and other health data through Web-based communication and questionnaires. While these Web platforms allow for increased speed and scope of communication delivery, there are certain limitations associated with this technology, as survey mode preferences vary across demographic groups.

Objective: To investigate the impact of demographic factors and participant preferences on the use of a Web-based questionnaire in comparison with more traditional methods (mail and phone) for women participating in screening mammography in British Columbia, Canada.

Methods: A sample of women attending the Screening Mammography Program of British Columbia (SMPBC) participated in a breast cancer risk assessment project. The study questionnaire was administered through one of three modes (ie, telephone, mail, or website platform). Survey mode preferences and actual methods of response were analyzed for participants recruited from Victoria General Hospital. Both univariate and multivariate analyses were used to investigate the association of demographic factors (ie, age, education level, and ethnicity) with certain survey response types.

Results: A total of 1192 women successfully completed the study questionnaire at Victoria General Hospital. Mail was stated as the most preferred survey mode (509/1192, 42.70%), followed by website platform (422/1192, 35.40%), and telephone (147/1192, 12.33%). Over 80% (955/1192) of participants completed the questionnaire in the mode previously specified as their most preferred; mail was the most common method of response (688/1192, 57.72%). Mail was also the most preferred type of questionnaire response method when participants responded in a mode other than their original preference. The average age of participants who responded via the Web-based platform (age 52.9, 95% confidence interval [CI] 52.1-53.7) was significantly lower than those who used mail and telephone methods (age 55.9, 95% CI 55.2-56.5; *P*<.001); each decade of increased age was associated with a 0.97-fold decrease in the odds of using the website platform (*P*<.001). Web-based participation was more likely for those who completed higher levels of education; each interval increase leading to a 1.83 increase in the odds of website platform usage (*P*<.001). Ethnicity was not shown to play a role in participant preference for the website platform (*P*=.96).

Conclusions: It is beneficial to consider participant survey mode preference when planning to collect PROs and other patient health data. Younger participants and those of higher education level were more likely to use the website platform questionnaire; Web-based participation failed to vary across ethnic group. Because mail questionnaires were still the most preferred survey mode, it will be important to employ strategies, such as user-friendly design and Web-based support, to ensure that the patient feedback being collected is representative of the population being served.

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KEYWORDS

patient preference; patient reported outcomes; patient reported outcome measures; questionnaires; Internet; Web-based system; survey methods; breast cancer screening

Introduction

Survey questionnaires are one of the most prominent data collection methods in cancer health and epidemiological research. Not only do they provide a means for evaluating patient care and treatment efficacy, but they also allow for valuable communication between physicians and patients [1]. However, the collection of patient reported outcomes (PROs) and other clinical data can be both difficult and costly, resulting in the need for more sustainable collection means [2]. Current typical survey methods include in-person, phone, mail, and Internet applications. These methods are used both exclusively (single-mode) and in combination (mix-mode); preference is generally shown for mix-mode questionnaires as they typically lead to higher response rates and reduced costs [3-5].

Increased use of Internet applications within society and health care has led to a shift toward Web-based surveying methods from more traditional methods such as mail or telephone. These methods include Web-based questionnaires, which can be predesigned as a HyperText Markup Language (HTML) form or assembled from a question database, in addition to mobile questionnaires that operate through a tablet or smart phone [6-8]. Web-based methods have also been used in combination with more traditional methods, such as in computer-assisted telephone interviewing (CATI) [9]. Overall, this shift is due to both the speed and ease of Web-based questionnaire delivery [4,10-14]. Web-based platforms also allow for potentially larger sample sizes to be reached [11,12,15], and a more economical dissemination of the questionnaire compared with more traditional methods [4,10-13]. Survey questions can also be dynamically adjusted and their allowable answers varied, based on the answers given to previous questions. These methods also allow for automatic upload of patient responses into databases, reducing human error associated with data entry, and thus increasing data quality [12,13]. Occurrences of missing data are also minimized, as certain applications prevent patients from proceeding until the previous survey question has been completed [1].

However, Web-based questionnaire applications also present certain limitations. Meaningful patient consent is often difficult to ensure, in addition to the successful integration of PRO data into other medical information records [2]. While Web-based questionnaire delivery costs may appear more economical than other methods, they involve the cost of professional programmers and the maintenance of data security [2,5]. Nonresponse bias is also associated with use of Web-based technologies, as patient participation is often due to factors such as Internet access, in addition to a patient's familiarity and comfort level in using Web platforms [2,12,13,16]. Furthermore, demographic groups differ in their personal preferences for and attitudes toward various survey modes. Developing an understanding of which demographic factors influence Web-based application participation will enable both clinicians and researchers to better predict how their platforms will be received in certain settings.

The Screening Mammography Program of BC (SMPBC) is the longest running organized breast screening program in Canada. It was initiated as a single fixed site in Vancouver in July, 1988 [17]. By 2010, geographic coverage of the province was achieved with 42 services employing a variety of delivery modes including four mobile vans. Asymptomatic female residents of BC, age 40 and older, are eligible to attend for regular, bilateral, two-view, screening mammograms in this publically funded program. The SMPBC database contains data on all invasive or in situ breast cancers diagnosed in women who have previously attended the SMPBC and conducts a central pathology review on those cancers. It also uses a paper questionnaire to collect Gail model risk factors from the attending women since its inception in 1988. However, it has been shown that the Tyrer-Cuzic (TC) model is more accurate than the Gail model in predicting breast cancer risk [18,19]. Therefore, a study was conducted during 2009 and 2010 to collect TC model risk factors from a sample of women attending the SMPBC. By doing so, the risk distribution for that population was estimated in order to assess the need for additional magnetic resonance images required to screen high-risk women [20]. The participants were given three options for participating in the study: mail-in paper questionnaire, Web-based questionnaire, or phone interview. Our current study attempts to better characterize the effect of survey mode preference and demographic factors that influenced the usage of a Web-based questionnaire in comparison with more traditional methods (phone and mail) for women participating in the original study. Because the current standard of practice of the SMPBC is to collect breast cancer risk factors using a paper-based questionnaire, it is important to understand these characteristics so that the feasibility of administering Web-based questionnaires in the future can be evaluated. This information may also be helpful to others involved in gathering breast cancer risk factors needed for personalizing breast screening strategies.

Methods

Study Population and Recruitment

Approval of the project was gained through the British Columbia Cancer Agency Research Ethics Board (UBC BCCA REB Certificate #H09-00681). The study data was collected as part of a previous project, where a breast cancer risk assessment was conducted for the women participating in the SMPBC [20]. The focus of this manuscript is a subpopulation of women from the assessment who were attending screening mammography at Victoria General Hospital in Victoria, British Columbia (BC) from August 2009 to January 2010. All participants gave voluntary informed consent prior to study involvement, and were 40 to 79 years of age at the time of the study. The study involved the development and administration of a questionnaire to collect personal information related to common risk factors for breast cancer of women attending the SMPBC [20]. Within the consent form, participants were also asked to state their preferred method of response as either mail, telephone, or the study website platform, should they agree to participate [21]. The questionnaire was distributed by both clerks and on-site volunteers, with each participant invited to complete it at her own convenience using her preferred method of response. All participant information and responses were stored in a study database. Once the questionnaire was completed, an unique study identification was assigned to each participant to ensure confidentiality and anonymity.

Statistical Analysis

In order to better understand patient preferences and factors influencing questionnaire response type, both univariate and multivariate analyses were used to explore demographic factors associated with certain response types. All analyses were performed using STATA 13.1.

Univariate Analysis

Survey mode preferences were compared with actual response type. Age was grouped into four cohorts: 40 to 49, 50 to 59, 60 to 69, and 70 to 79. The distribution of questionnaire response types was determined for three demographic factors: age, education level, and ethnicity. Mean participation rates for each demographic variable were analyzed using the Mann-Whitney U test, Wilcoxon Rank-Sum test, or Fisher's exact test.

Multivariate Analysis

Of specific interest was improved characterization of the association between the available demographic factors and Internet participation, and differences between proportions were assessed using chi-square and Fisher's exact tests. Multivariate logistic regression was used to evaluate the association between Web-based survey usage versus other modes, adjusting for age, education level, and ethnicity. Each of these three variables was forced into the logistic model. Of the demographic variables, interaction was found only between education and age. Statistical significance was defined as *P*<.05.

Results

Participant Survey Mode Preference

A total of 1192 women successfully completed the study questionnaire at Victoria General Hospital. Of the three survey modes, distribution by mail was the most preferred (509/1192, 42.70%), followed by website platform (422/1192, 35.40%), and telephone (147/1192, 12.33%; Table 1). Approximately 10% of participants (114/1192, 9.56%) did not specify a preferred method of response in their consent form.

Survey mode preference differed between younger (<60 years) and older (>60 years) patients, as preference for mail and telephone questionnaires strengthened with age (Figure 1). In contrast, the Web-based option became less preferred with each subsequent age grouping. Higher levels of post-secondary education led to a stronger preference for Web-based questionnaires, while the opposite trend was observed for mail. With regards to ethnicity, nearly all groups expressed a preference for the mail mode.

Variation Between Preferred and Actual Participant Survey Response

In all, 80.12% (955/1192) of patients completed the questionnaire in the mode that was previously specified as their most preferred method (Tables 2, 3, Figure 2). For those who responded in a method other than their original preference, mail was the most common response type. In addition, for those who did not specify a preferred response method, mail was also the most common response type (Table 3).

Table 1. Preferred method of questionnaire response stratified by participant demographics.

	Telephone	Mail	Website	Unspecified	Total
	n=147	n=509	n=422	n=114	n=1192
Age					
40-49	44	174	171	30	419
50-59	41	149	139	37	366
60-69	49	144	97	41	331
70-79	13	42	15	6	76
Education					
Grade 9 or Less	2	9	0	1	12
Some high school	10	30	15	7	62
High school diploma	37	119	50	20	226
Some college	42	192	123	52	409
University degree	56	159	234	34	483
Ethnicity					
White[a]	133	478	386	111	1108
Other	6	10	20	3	39
East/Southeast Asian	4	10	8	0	22
First Nation/Métis	2	5	5	0	12
South Asian	1	4	2	0	7
African/African American	1	2	1	0	4

[a] White = British/French/Irish/Scottish/Welsh/(Northern, Southern, Eastern, or Western) European.

Figure 1. Percent distribution of participant demographics for each preferred method of questionnaire response (n = 1192).

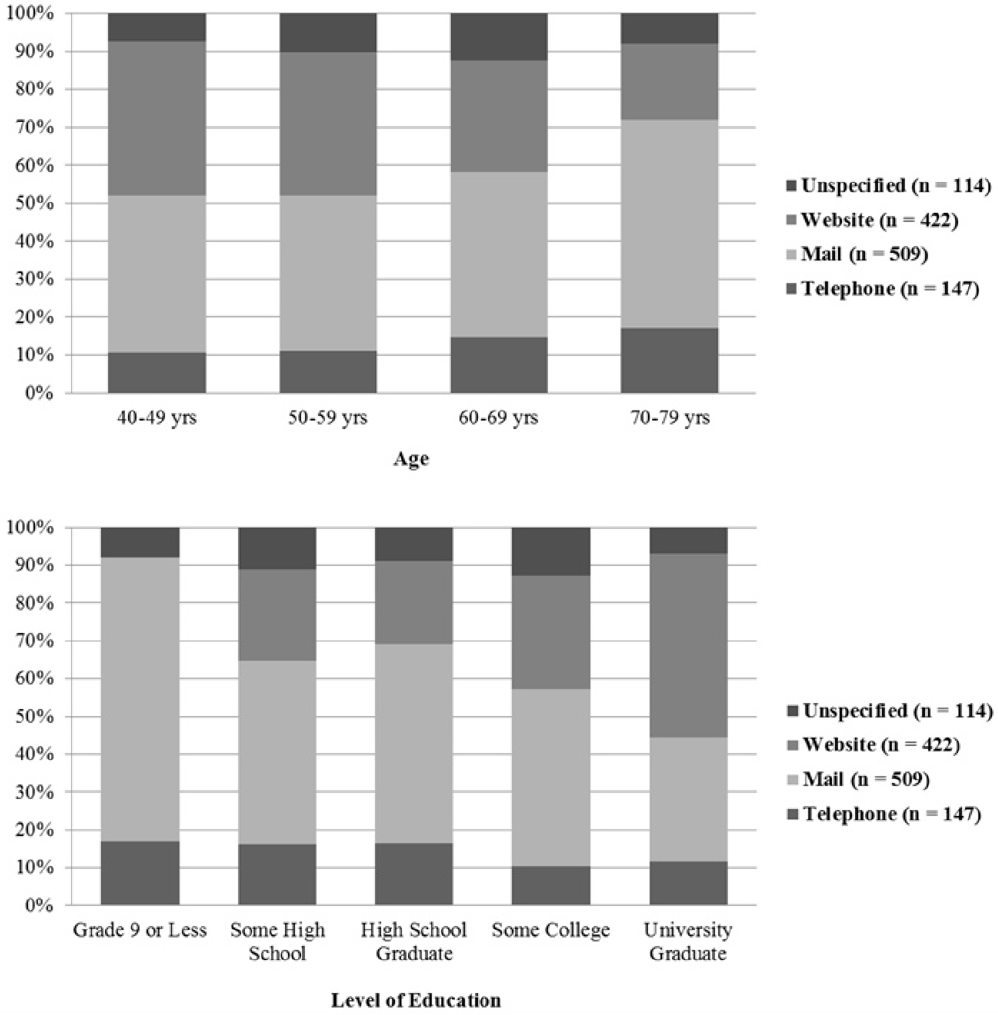


Table 2. Actual method of questionnaire response stratified by participant demographics.

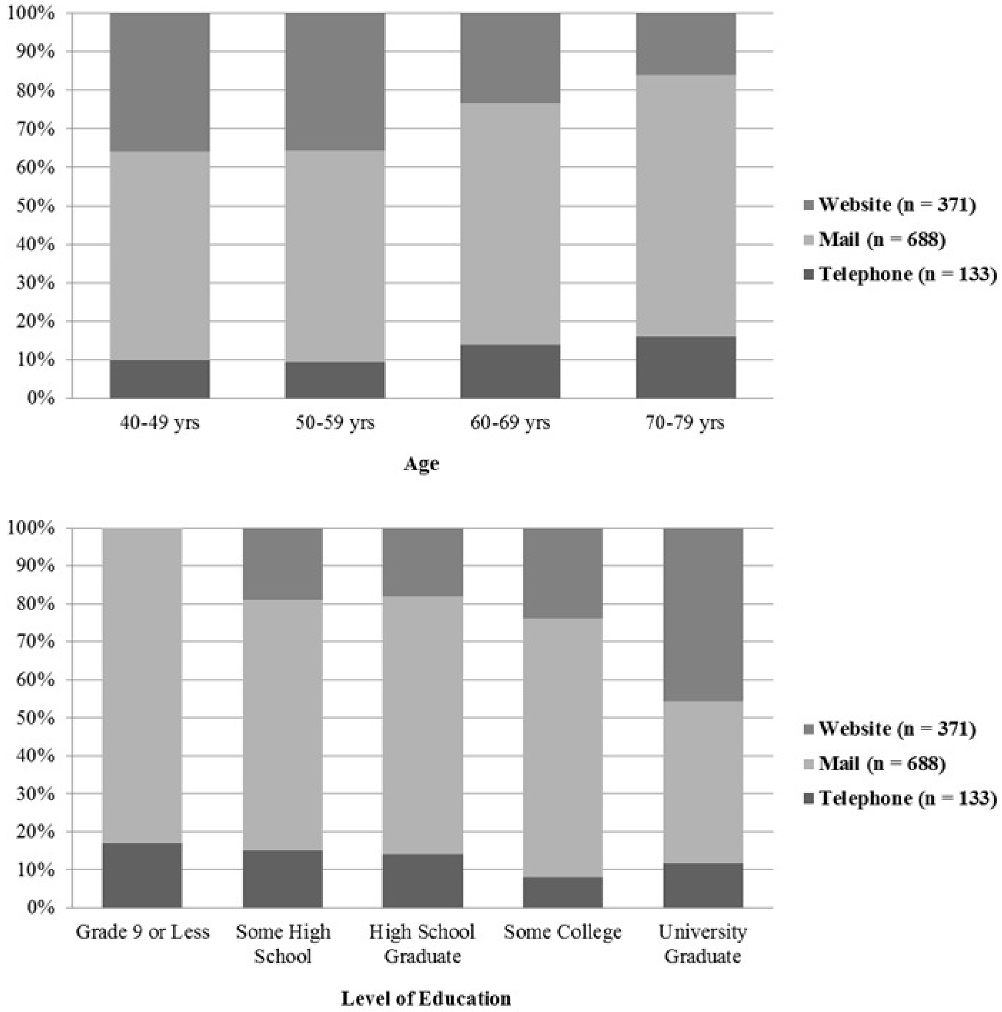
	Telephone	Mail	Website	Total
	n=133	n=688	n=371	n=1192
Age				
40-49	41	227	151	419
50-59	34	201	131	366
60-69	46	208	77	331
70-79	12	52	12	76
Education				
Grade 9 or Less	2	10	0	12
Some high school	9	41	12	62
High school diploma	32	153	41	226
Some college	33	279	97	409
University degree	57	205	221	483
Ethnicity				
White[a]	116	649	343	1108
Other	7	13	19	39
East/Southeast Asian	4	13	5	22
First Nation/Métis	4	6	2	12
South Asian	1	5	1	7
African/African American	1	2	1	4

[a] White = British/French/Irish/Scottish/ Welsh/(Northern, Southern, Eastern, or Western) European.

Table 3. Comparison of participant-stated preferences and actual survey response types.

	Actual Response Type			
	Telephone	Mail	Website	Total
	n=133	n=688	n=371	n=1192
Preferred response type				
Telephone	120	23	4	147
Mail	5	492	12	509
Website	8	71	343	422
Unspecified	0	102	12	114

Figure 2. Percent distribution of participant demographics for each actual questionnaire response type (n = 1192).



Actual Patient Survey Response

The study uptake at the Victoria General Hospital for which this analysis is performed was found to be 47% [20]. This is comparable with the on-site study uptake of 31% to 50% in a similar risk assessment study conducted by Evans and colleagues [22]. Of the questionnaires that were completed, 57.72% (688/1192) were submitted via mail, followed by the 31.12% (371/1192) completed using the website platform, and the 11.16% (133/1192) by telephone (Tables 2, 3). The overall average age for participation was 55 years (95% confidence interval [CI] 54.4-55.5). The average age of participants was significantly lower for those who responded via the website platform (52.9, 95% CI 52.1-53.7) compared with those who used telephone or mail (55.9, 95% CI 55.2-56.5; *P*<.001).

Each additional level of education showed an increased number of respondents, with university graduates being the largest group to complete the questionnaire (483/1192, 40.52%). Web-based participation was also more likely in higher education groups (*P*<.001). With regards to ethnicity, the study population was dominated by White participants (1108/1192, 92.95%); additional ethnic groups were then consolidated into a “Nonwhite” group for subsequent analysis.

Logistic regression demonstrated that, after adjusting for age and education level, ethnicity (White vs nonwhite) was not predictive of survey mode usage (*P*=.96) (Table 4). Both age and education were significantly associated with Web-based participation versus other modes (*P*<.001 for both variables).

Each decade of increased age was associated with a 0.97-fold decrease in the odds of a patient participating on the website platform when compared to other available methods (odds ratio [OR] 0.97, *P*<.001). Each interval increase in education level saw a 1.83-fold increase in the odds of website platform usage (OR 1.83, *P*<.001). However a low R^2 value (0.06) denotes that age and education alone are poor predictors of response type, even when considering them together. Therefore, these results suggest that there are factors other than age and level of education that are likely to influence which mode people use to participate.

Table 4. Odds ratios from multivariate logistic regression predicting survey mode usage within each demographic variable (age, education level, and ethnicity).

Demographic Variable	Odds Ratio	Standard Error	*P*
Education[a]	1.83	0.08	< .001
Age[a]	0.97	0.01	< .001
Ethnicity,[b] Nonwhite	1.01	0.25	.96
Constant	0.00	1.62	< .001

[a] Education and age treated as continuous/ordinal variables.

[b] White (British/French/Irish/Scottish/Welsh/[Northern, Southern, Eastern, or Western] European).

Discussion

Principal Results

Consistent with other single-mode survey studies, response rates were higher in the mode that was originally stated as the participant's preferred mode [16,23]. Mail was the most preferred type of questionnaire response, and was also the most commonly used method when participants responded in a mode other than their original preference. Previous studies conducted on men and women have found that both participant attitudes toward, and familiarity with, a certain type of survey technology play an important role in their usage of that particular mode [16,24]. Therefore, it is not surprising that the mail method was commonly reverted to, especially due to the massive use of paper (mail) in our current culture. However, as Internet usage among adults continues to grow in our society, from a rate of 14% in 1995 to 87% in 2014, for example [25], we may begin to see a shift away from more traditional methods, such as mail toward Internet technologies such as Web-based questionnaires (as offered through this study), mobile applications, email, and text message. Moreover, familiarity with specific survey modes may vary across many demographic groups. For example, studies have shown that both younger participants and those with higher education are more likely to use the Internet and Web-based technologies [26-31]. This is consistent with our findings. In turn, our results did not show ethnicity to be a predictor for (or against) Web-based questionnaire usage in this study. This is consistent with a recent systematic literature review that reported research based in five multiethnic developed countries (Canada, United States, United Kingdom, New Zealand, and Australia); results found that Nonwhite populations (eg, African American, Asian, and Hispanic) who participate in surveys are as likely to participate in research as Whites [32].

For all respondents included in the Weisstock et al. study [20], a mean age of 56.6 years (SD 9.6 years) was observed, which was comparable to our subpopulation mean of 55 years (95% CI 54.4-55.5). These respondents displayed an age distribution comparable to that of women in the SMPBC and British Columbian residents at the time of the study. Our subpopulation was dominated by White participants (1108/1192, 92.95%), which included those of British / French / Irish / Scottish / Welsh / (Northern / Southern / Eastern / Western) European descent (Tables 1, 2). This is consistent with the overall study population for Weisstock et al. [20], where the most prevalent ethnicity was British/Irish/Scottish/Welsh (54% of respondents); furthermore, 49% of British Columbians self-reported ethnic backgrounds of British Isles / European / English / Scottish / Canadian / Irish / Welsh descent during the 2006 census. As with our results, age was found to influence questionnaire response mode, as younger women responded more frequently using the Web-based questionnaire, while older participants tended to respond via mail (Table 2).

As Internet technology continues to be integrated into society at various social, educational, and institutional levels, these demographic groups may not be so predictive of Web-based survey usage. While we expect the Internet to continue to become more accepted as a common means of communication, there are still many individuals, particularly those from older generations and lower education levels, who prefer mail and may be intimidated by their lack of familiarity with mobile platforms or anticipated difficulties in navigating Web-based systems [24,27]. This is especially significant in Canada, where approximately 1 in 6 Canadians are at least 65 years of age [33]. In turn, the current estimated growth rate of this population is 3.5%, approximately four times that of the total population growth rate. While many individuals within this age group may become more comfortable with technology use as they age, we must still prepare for a large proportion of this population to still prefer mail for the duration of their lifetime. Therefore, studies similar to this one will be important in future work, in order to assess how people over the age of 40, the typical age demographic for cancer diagnoses, respond to various forms of survey methods.

With regards to breast cancer, the use of alternative approaches to screening has been proposed [34]. These alternative approaches would involve making more individualized decisions based on a woman's breast cancer risk factors and beliefs about the risks and benefits of screening mammography. This will require the collection of detailed breast cancer risk information from the eligible women, in order to estimate their risk of developing breast cancer. Web-based collection of the breast cancer risk factors may be an effective way to collect this information and, therefore, the results of this study will be of importance as personalized breast screening regimens become more main stream.

Moving forward, there is a need to protect already declining response rates [5,15,16]. The inclusion of a paper option to a Web-based survey (or vice versa) may be needed so as to prevent a premature dependency on mobile survey methods.

Furthermore, it will be beneficial to develop platforms that are user-friendly and intuitive for various age groups, especially those of older generations. This is especially important for research and health service work that aims to obtain a representative sample of the population of interest. It will also be helpful to provide support through study personnel or educational materials, in order to instruct patients on how to properly use a Web-based survey system and increase their confidence with its usage [24]. Integration of such strategies will help minimize the sample bias that may typically occur should survey participation factors not be considered.

Limitations

The predominant limitation of this study is that all participants involved were registered with the SMPBC, and were consequently adult females in the age range eligible for screening mammography (40-79 years). With the median age of Canadians being 39.9 years, we acknowledge that women within our study are generally older than the general population in Canada [35]. In turn, our population does not allow for any determination of the effect of gender on response rate and mode. Therefore, our results regarding the effects of participant preference and demographic effect on survey mode response may not be generalizable to populations that include males and females of other ages.

Conclusions

Our findings suggest that it is important to consider participant's survey mode preference when designing and implementing PRO surveys. In turn, younger participants and those with higher levels of education were more likely to use the mobile platform; Web-based participation failed to vary across ethnic groups. Overall, this information will be very valuable during the planning stages of future studies. PROs are becoming increasingly used in breast cancer screening regimens and health care systems of the developed world, making it imperative that approaches to obtaining patient feedback are representative of the population being served. For this reason, clinicians and researchers must be diligent in implementing survey modes that capture data of their desired patient cohorts.

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Conflicts of Interest

None declared.

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Abbreviations

CATI: computer-assisted telephone interviewing
CI: confidence interval
HTML: HyperText Markup Language
OR: odds ratio
PRO(s): patient reported outcome(s)
SMPBC: Screening Mammography Program of British Columbia
TC: Tyrer-Cuzic

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Original Paper

Entertainment or Health? Exploring the Internet Usage Patterns of the Urban Poor: A Secondary Analysis of a Randomized Controlled Trial

Rachel F McCloud[1], MPH, ScD; Cassandra A Okechukwu[2], MPH, MSN, ScD; Glorian Sorensen[1,2], MPH, PhD; Kasisomayajula Viswanath[1,2], MA, PhD

[1]Dana-Farber Cancer Institute, Center for Community-Based Research, Boston, MA, United States

[2]Harvard TH Chan School of Public Health, Department of Social and Behavioral Sciences, Boston, MA, United States

Corresponding Author:
Rachel F McCloud, MPH, ScD
Dana-Farber Cancer Institute
Center for Community-Based Research
450 Brookline Avenue
LW 601
Boston, MA, 02215
United States
Phone: 1 617 232 6586
Fax: 1 617 582 7425
Email: rachel_faulkenberry@dfci.harvard.edu

Abstract

Background: Important gaps remain in our knowledge of how individuals from low socioeconomic position (SEP) use the Internet for resources and in understanding the full range of activities they perform online. Although self-report data indicate that low SEP individuals use the Internet less than high SEP people for health information and for other beneficial capital-enhancing activities, these results may not provide an accurate overall view of online use.

Objective: The aim of this study was to determine the ways in which low SEP individuals use the Internet, including for entertainment, social networking, and capital-enhancing functions, and how they are associated with health information seeking.

Methods: Detailed Web tracking data were collected from 118 low SEP individuals who participated in the intervention group of a randomized controlled trial that provided Internet access. Websites were grouped by topic, including categories of capital-enhancing websites that provided access to resources and information. Different types of online activities were summed into an Internet use index. Single and multiple negative binomial regression models were fitted with the Internet use index as the predictor and health information seeking as the outcome. Next, models were fitted with low, medium, and high Web usage in capital-enhancing, entertainment, and social network categories to determine their associations with health information seeking.

Results: Participants used the Web for diverse purposes, with 63.6% (75/118) accessing the Internet for all defined types of Internet use. Each additional category of Internet use was associated with 2.12 times the rate of health information seeking (95% CI 1.84-2.44, $P<.001$). Higher use of each type of capital-enhancing information was associated with higher rates of health information seeking, with high uses of government (incident rate ratio [IRR] 8.90, 95% CI 4.82-16.42, $P<.001$) and news (IRR 11.36, 95% CI 6.21-20.79, $P<.001$) websites associated with the highest rates of health information seeking compared to their lowest use categories. High entertainment website use (IRR 3.91, 95% CI 2.07-7.37, $P<.001$) and high social network use (IRR 2.06, 95% CI 1.08-3.92, $P=.03$) were also associated with higher health information seeking.

Conclusions: These data clearly show that familiarity and skills in using the Internet enhance the capacity to use it for diverse purposes, including health and to increase capital, and that Internet usage for specific activities is not a zero sum game. Using it for one type of topic, such as entertainment, does not detract from using it for other purposes. Findings may inform ways to engage low SEP groups with Internet resources.

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KEYWORDS

health communication; socioeconomic factors; information-seeking behavior; Internet

Introduction

The vast quantities of online information have transcended some barriers to information, such as time and geography, to provide people with relevant, timely information that may increase their health and well-being [1]. The extent to which individuals are able to take advantage of available information and use the Internet to acquire benefits and opportunities [2-3] depends on their ability to navigate the online environment and requires diverse forms of online engagement [4-5]. Those who are unable to fully engage with these technologies are at a disadvantage to reap benefits that the online world may offer [1]. Digital inequalities describe the differing levels of ability to engage with the Internet among those with access [6], with research often emphasizing the differences in how individuals from lower socioeconomic position (SEP) incorporate the Internet into their lives compared to those with higher SEP [7-10]. However, focusing on a deficits approach in which low SEP individuals are compared to those with greater means may overshadow the myriad ways low SEP individuals benefit from the Internet. This study, from a randomized controlled trial involving low SEP individuals, used innovative, real-time Web tracking data to contextualize more fully the Internet information seeking of low SEP individuals.

Health information seeking may occur most often when need for a specific disease or medical decision making arises [1,11-14], but may not be indicative of everyday Internet use. Indeed, health information seeking serves as an important marker of disparities, with widespread evidence indicating that individuals from low SEP seek online health information less than their high SEP counterparts [11,15-17]. However, this seeking behavior must be placed in context of the entire spectrum of Internet engagement to fully understand the impact of digital inequalities.

Explorations of the ways low SEP individuals use the Internet, including the range and breadth of activities performed on the Internet for a variety of functions [3], may more fully contextualize the online environment for underserved groups. Beyond accessing health information, there is a need to participate in Internet-mediated economic, political, and social networks to take full advantage of what the online world has to offer and to meaningfully participate in an increasingly digital society [2,5,18]. “Capital-enhancing” (p. 606 [19]) information seeking represents exploring websites and topics that may enhance one’s life chances and offer upward mobility, such as helping with career advancement or consulting financial services, and serve to improve one’s life circumstances by increasing access to material and informational resources [20]. The inclusion of a range of topics that may impact health and well-being reflects a social determinants perspective, in which access to resources such as wealth, education, and adequate housing may impact health outcomes [21-22]. Specifically, capital-enhancing Internet use may be defined in this context as using the Internet to increase access to tangible and information-based resources that can address structural-level factors such as housing, education, employment, finances, and access to government resources.

Despite the potential benefits of such capital-enhancing information, research indicates that individuals with lower SEP take fewer opportunities to use the Internet comprehensively beyond amusement and communication, suggesting that the underserved may not fully take part in the new media environment [3]. Studies have found that, compared to individuals with higher income, low SEP individuals are less likely to use the Internet for capital-enhancing activities [19,23,24], instead using the Internet predominantly for entertainment purposes [20,23,25,26]. Such a “usage gap” between information and entertainment uses of the Internet may serve as an indicator of disparities, identifying who is not able to fully participate in and reap the benefits of the online world [18,19,23,26].

However, many studies reporting such a usage gap rely on self-report Internet use information [3,18,20,23,24], which is subject to the limitations of self-report data, such as bias and inaccuracy, particularly over longer periods of recall [27]. Relying on dichotomies of use (eg, never/ever use) of selected website categories from self-reported data may overgeneralize findings and may not accurately reflect or contextualize Internet usage in low SEP groups [3].

Additionally, providing a broad comparison between the Internet usage patterns of different income strata do not account for the differences in how low SEP individuals may engage with and learn from the Web in unique ways from their high SEP counterparts. Beyond the scope of entertainment versus information, scholars have suggested that a broader and more sophisticated use of the Internet, particularly engaging with the Web for diverse purposes, allows an individual a greater opportunity to acquire benefits and opportunities to meet individual and social goals [3]. The range and breadth of activities performed on the Internet, such as visiting a number of different types of sites that perform a variety of functions [3], may indicate that an individual is better situated to participate in a society that has transitioned many services online [4]. Use of the Internet for functions such as shopping, social network use, blogs, email, and reference sites are rarely captured in Internet studies and are even rarer if not nonexistent for low SEP individuals. Including an assessment of these activities from observed (tracked) Internet activity may provide useful context to Internet activities of interest, such as health information seeking, and if other types of Internet use serve to complement or substitute health seeking. Furthermore, they may indicate that the individual is more adept at using the Internet for a number of diverse functions.

Determining the detailed usage patterns of low SEP individuals may highlight the best ways to engage them in online activities that provide them with resources to improve their health or socioeconomic position.

The purpose of this paper is to build on our prior work [28] using a unique dataset containing directly tracked Internet use from Click to Connect (C2C), a randomized controlled trial that provided first-time at-home Internet access to the urban poor to explore their Internet behaviors. We were able to directly capture the Internet sites that participants visited to provide a detailed look at the Internet seeking behaviors of low SEP individuals. The nature of this study allowed us to capture all instances of information seeking in a natural setting. Previously, we examined the Internet browsing patterns of low SEP individuals and discovered that although Internet portals and social networking sites were the most used, the heterogeneity of the websites visited suggested the participants were using the Internet for a diverse range of functions [28]. In this study, we sought to provide a detailed description of the diverse ways that low SEP individuals use the Internet, including the range of functions individuals perform online, information seeking for specific beneficial functions, and entertainment use. Then, we explored how this use was associated with health information seeking within the context of everyday, home-based computer use in this low SEP sample.

Methods

Data for this study were drawn from "Click to Connect: Improving Health Literacy Through Computer Literacy" (C2C), a randomized controlled trial funded through the National Cancer Institute to understand computer- and Internet-related challenges, barriers, and facilitators among a low SEP population. Intervention details may be found elsewhere (see [28,29]). Recruitment efforts were designed to recruit low-income, urban poor who are seldom represented in national surveys [29]. For the purposes of this study, we included data from the intervention group participants of all three waves of implementation who were given computers and Internet access during the course of the trial. Human participant approval for this study was granted by the Institutional Review Board (IRB) for the Dana-Farber Cancer Institute.

Data Sources

Two sources of data were merged for this study: (1) a baseline 45-minute telephone survey that contained detailed measures of demographic information and (2) Internet use throughout the intervention period (9-18 months) tracked directly through participants' computers using Spector 360, software that logs each URL visited into a secure server on the study premises through a virtual private network (VPN). The use of the Spector 360 process allowed us to capture real-time data of websites visited and number of times visited. Once all tracking data were collected, we submitted deidentified domain information to an online application program interface (API) through the Webroot BrightCloud Content Classification Service [30], which categorized each domain into one of 82 predetermined topic categories using a proprietary algorithm. These categories served as the basis for our Internet-based measures. Categorized websites then underwent additional crosschecks for accuracy for inclusion to the final list of topics used in our analysis. For example, we first reviewed the URLs for each categorized website to determine appropriateness for inclusion because websites encode useful words into the URL [31]. URLs that could not be immediately classified were entered into the search bar of Google for a brief website description. When needed, BrightCloud categories were combined to create larger groups of websites that better fit our definition of the topic. All survey and browsing data were merged for each study participant and analyzed in STATA version 13 (StataCorp LP, College Station, TX, USA). For reasons of confidentiality per the IRB mandate, we tracked household browsing activity rather than individual browsing information. Self-reported Internet use data from the survey were crosschecked with the browsing data to determine that there were no discrepancies in observed and self-reported Internet activity and that the participant was an active user of the Internet during the study.

Measures

Internet health information seeking was conceptualized as the purposeful seeking of health information through visiting health websites. Our definition of "health" was broad to include all topics that participants may perceive as health information, including websites for health information of unknown quality, in order to capture health seeking from the participant's perspective. Due to the broadened definition of health operationalized in this study, websites categorized by BrightCloud underwent a second, detailed coding process by study staff. We first created a list of health-related topics, derived from several sources, including the Healthy People 2020 topic list and Centers for Disease Control and Prevention and World Health Organization website indexes of health topics. We then used these keywords to search for additional URLs visited by the participants to add to the list of BrightCloud categorized health websites. Once a list of all potential health websites was created, two trained independent coders reviewed each URL and related website description and designated them as a health website (yes/no). A test coding block was first conducted with 10% of the sample to answer questions and clarify coding terms. Then, the two coders coded the full list independently and concurrently. The interrater reliability of the coding was strong, with a Cohen kappa of .94. The final list of health websites included sites such as the Cancer Society, , and HealthyPlace.com, among others. For the purposes of this study, each "hit," or separate visit to a particular health-related website, was considered an instance of information seeking.

Internet Use Index

We constructed an Internet use index corresponding to a number of different types of activities one may perform on the Web [3,18]. To construct this index, we analyzed Internet behavior for a diverse range of Internet functions, including social networks, streaming media, blogs, news, email, search engines, reference, Internet portals, and types of capital-enhancing seeking (described subsequently) as defined through our modified BrightCloud categories. The exact components of this index and related definitions of each can be found in Multimedia Appendix 1. To construct this index, each Web function was dichotomized as one (having visited at least one website in a particular category) or zero (meaning that the participant had not used the Web for this purpose). Dichotomized variables were then summed with higher scores equaling use of the

Internet for a higher number of diverse purposes. The index included 16 potential categories for Internet use.

Capital-Enhancing Information Seeking

Each category of capital-enhancing information seeking was coded as a separate variable and each hit was considered an instance of information seeking. Websites for each type of capital-enhancing seeking were derived from our modified BrightCloud categories. The category descriptions are described subsequently.

Education Information Seeking

Hits for information pertaining to higher education, including college websites, college-finding services, collegiate test preparation, GED courses or materials, and online degree program information.

Job Information Seeking

Hits for sites for information on employment, including human resources departments, job finders, or resume help.

Residence Information Seeking

Hits for information on renting, buying, or selling properties or real estate, including apartment listing services, roommate finders, and real estate websites.

Finance Information Seeking

Hits for money-related information, including banking services, loans, credit, accounting, stock trading, asset management, and investment accounts.

Government Information Seeking

Hits to websites for government agencies (local to national level), services, and explanation of laws, including political advocacy websites that promote politicians, political discussions, or other social advocacy issues.

News Information Seeking

Hits to websites for current events, including radio, newspaper and headline news sites, newswire services, personalized news, and weather sites.

Entertainment Site Usage

Entertainment usage was derived from the modified BrightCloud categories and was also conceptualized as the number of hits to websites for sites discussing television, movies, music, celebrity news/gossip, entertainment reviews, or the performing arts. Sites for music, online gaming, nudity, and pornography were included. Examples of such websites included FreeGamesOnline.com, Access Hollywood, and IMDb.

Social Network Site Usage

Social network usage was defined as the number of hits to sites that have user communities where users interact, post messages, pictures, and communicate, such as Myspace and Facebook.

Covariates

We measured sex, race/ethnicity (white, African American, Latino), employment status (working yes/no), and age (categorized as younger than 35 years, 35-49 years, and 50 years or older) from our baseline telephone survey. Income and education were not included as covariates due to our recruitment of low SEP participants with a restricted income and education range. We also controlled for study wave to adjust for any differences by administration year.

Analysis

We first analyzed descriptive statistics and frequencies for all variables. We next fitted an unadjusted and adjusted negative binomial regression model with our Internet use index and our outcome, Internet health information seeking. Negative binomial regression was used for these analyses due to the nature of the outcome as a count-based variable that had a strong right skew [32]. Potential confounders that were significant at the $P \leq .25$ level with the predictor and outcome were entered into the adjusted analysis. We set this conservative alpha threshold to capture potential confounders that may not emerge as significant due to our small sample size. All capital-enhancing variables were first assessed as continuous variables to gain descriptive statistics on the range, median, and mean number of hits to each category. Then, each capital-enhancing category was divided by thirds into levels of low, medium, and high use based on number of hits, with low users as the referent group. They were then entered into unadjusted and adjusted negative binomial regression models with the outcome. We then combined all the hits from the capital-enhancing categories into one measure and divided it into three categories and followed the same process as described previously. We then repeated this process with entertainment and social network site usage as the predictor of interest.

Results

The demographic characteristics of the sample can be found in Table 1, which illustrates the focus of C2C on low SEP groups compared to national communication surveys. The majority of the sample was black (55.1%, 65/118), with 80 of 118 (67.8%) older than 35 years, and 73 of 118 (61.8%) female. The sample was low income, with 33.1% (39/118) reporting a household income of less than US $10,000 per year and 90 of 118 (76.2%) reporting less than a high school degree.

Table 1. Demographic comparisons between Click to Connect (C2C) and selected national surveys.

Demographic characteristic	C2C, n (%) N=118	US Census 2010 N=308,745, 538[a] [33]	HINTS 2014 Cycle 3, n (%) N=3185 [34]	Pew Internet Tracking Survey 2013, n (%) N=4178 [35]
Sex				
Male	45 (38.2)	49%	1197 (37.58)	2059 (49.28)
Female	73 (61.8)	51%	1906 (59.84)	2119 (50.72)
Age (years)				
18-34	38 (32.2)	21% (20-34 years)	426 (13.38) (18-34 years)	926 (22.16) (<30 years)
35-49	54 (45.8)	33% (35-59 years)	712 (22.35)	1329 (31.81) (30-49 years)
50-64	26 (22.0)	12% (55-64 years)	1070 (33.59) (50-64 years)	1155 (27.64)
Race/Ethnicity				
African American	65 (55.1)	13%	421 (13.22)	527 (12.61)
White	8 (6.87)	78%	1584 (49.73)	3113 (74.51)
Hispanic	23 (19.1)	16%	511 (16.04)	545 (13.04)
Income (US$)				
<10,000	39 (33.1)	8%	680 (21.35) (<20K)	370 (8.86)
10,000-19,999	37 (31.4)	6% (10K-<15K)		479 (11.46)
20,000-29,999	19 (17.9)	11% (15K-<25K)	418 (13.12) (20K-<35K)	438 (10.48)
30,000-39,999	9 (8.4)	10% (25K-<35K)		440 (10.53)
40,000-49,999	3 (2.5)	14% (35K-<50K)	394 (12.37) (35K-<50K)	286 (6.85)
50,000-74,999	2 (1.7)	18%	446 (14.00)	622 (14.89)
≥75,000	0 (0)	32%	801 (25.15)	816 (19.53)
Education				
≤Grade school	16 (13.6)	6%	297 (9.32) (≤high school)	312 (7.47) (<high school)
Some high school	74 (62.7)	8%		
High school graduate/ GED	3 (2.5)	50%	699 (21.94)	1401 (33.53)
Some college	0 (0)	21%	691 (21.70)	1311 (31.38)
≥Bachelor's degree[b]	9 (7.6)	28%	1167 (36.64)	1143 (27.36)

[a] Population estimate (exact numbers not available).

[b] For C2C: college completed in another country.

Description of Internet Information-Seeking Behaviors

The outcome, Internet health information seeking, received a median of 85.5 hits (range 0-3537; mean 214.59, SD 411.65 hits) over the study period (Table 2). The highest median number of hits for capital information–seeking variables was news information seeking, which had a median of 219 hits (range 0-8043) over the study period. Residence information seeking (median 9.5, range 0-2442 hits) was the lowest of all the categories. In comparison to the total universe of hits to all websites (Table 3), health information seeking represented 0.49% (24,972/5,084,901) of all hits over the study period. Social network sites received the highest number of hits of all categories.

Table 2. Descriptive statistics for online seeking for health, capital-enhancing variables, entertainment, and social networks by number of hits.

Type of seeking	Mean (SD)	Median (range)
Health	214.59 (411.65)	89 (0-3537)
Capital-enhancing		
Job	234.53 (379.68)	61 (0-1832)
Residence	119.03 (333.37)	10 (0-2442)
Government	132.88 (204.65)	62 (0-1583)
Education	175.81 (287.48)	70 (0-1470)
Finances	505.20 (1052.30)	110 (0-7833)
News	509.09 (993.48)	219 (0-8043)
Entertainment	4164.70 (6286.96)	1497 (0-31,023)
Social networks	15,740 (27,989.97)	4276 (0-169,875)

Table 3. Percentage of total hits contributed by each Web category.

Category	% of total hits n=5,084,901
Health information hits	0.49%
Capital-enhancing hits	5.97%
Residence	0.29%
Government	0.34%
Education	0.41%
Job	0.48%
Financial	1.22%
News	3.23%
Entertainment hits	9.74%
Social networks	36.54%
Hits for other forms of Internet use	
Internet portals	12.63%
Shopping	6.11%
Search engine	5.64%
Streaming media	5.01%
Personal sites and blogs, peer-to-peer, shareware and freeware, personal storage	2.04%
Society	1.81%
Web-based email	1.74%
Training and tools, reference and research, other education, translation	1.10%
Other websites visited (computer sites,[a] malware, hacking, phishing, frauds, spyware, spam, dead sites)	10.62%

[a] Web ads, Web hosting, parked domains, pay to surf, proxy, content and file delivery systems.

Internet Use and Internet Health Information Seeking

All participants participated in at least 6 of 16 Web activities over the course of the study (Table 4). The majority (63.6%, 75/118) visited websites from all categories of use, and 18.6% (22/118) visited all but one category. Participants who engaged in greater Internet use had a significantly higher rate of health information seeking (Table 5); every additional Web category a participant visited was associated with an increase in the rate of health information seeking by a factor of 2.1 in the adjusted model (incident rate ratio [IRR] 2.12, 95% CI 1.84-2.44, *P*<.001).

Table 4. Percentage of participants using the Web for diverse purposes (N=118).

Number of website types visited	Participants, n (%)
7	3 (2.5)
8	2 (1.7)
11	1 (0.8)
12	3 (2.5)
13	6 (5.1)
14	6 (5.1)
15	22 (18.6)
16	75 (63.5)

Capital-Enhancing Information Seeking and Health Information Seeking

As shown in Table 5, each type of capital-enhancing information seeking was significantly positively associated with Internet health information seeking and this relationship increased as usage increased. For example, participants who were medium users of education sites had 3.0 times the rate of Internet health information seeking compared to those who were low users of education sites when other factors were held constant (IRR 3.04, 95% CI 1.64-5.54, *P*<.001), whereas high users of education had 7.0 times the rate of health information seeking compared to low users (IRR 6.94, 95% CI 3.73-12.92, *P*<.001). Notably, high users of government sites had 9.0 times the rate of health information seeking compared to low users (IRR 8.90, 95% CI 4.82-16.42, *P*<.001) and high news site users had 11 times the rate of health information seeking compared to low users (IRR 11.36, 95% CI 6.21-20.79, *P*<.001) in adjusted models. When combined into a measure of total capital-enhancing Internet use, medium capital-enhancing site users had 4.2 times the rate of health information seeking compared to low capital-enhancing users (IRR 4.24, 95% CI 2.43-7.40, *P*<.001) when other factors were held constant and high capital-enhancing users had 13.1 times the rate of health information seeking of low users (IRR 13.01, 95% CI 7.29-23.20, *P*<.001).

Entertainment Site Use and Health Information Seeking

Compared to low entertainment site users (Table 5), medium users sought health information at 3.3 times the rate when other factors were held constant (IRR 3.34, 95% CI 1.82-6.14, *P*<.001), whereas high entertainment site users sought information at 3.9 times the rate of low users (IRR 3.91, 95% CI 2.07-7.37, *P*<.001).

Social Network Site Use and Health Information Seeking

High social network site users sought health information at 2.1 times the rate of low users in the adjusted model (IRR 2.06, 95% CI 1.08-3.92, *P*=.03).

Table 5. Bivariate and adjusted associations between each type of capital-enhancing seeking, entertainment site usage, social network site usage, and health information seeking (N=118).

Predictor variable	Bivariate associations		Adjusted models[a]	
	IRR (95% CI)	*P*	IRR (95% CI)	*P*
Multimodal use	2.16 (1.87-2.50)	<.001	2.12 (1.84-2.44)	<.001
Capital-enhancing use				
Financial site users (ref: low users)				
Medium	2.64 (1.42-4.90)	.002	1.93 (1.01-3.68)	.047
High	5.19 (2.81-9.59)	<.001	5.13 (2.81-9.34)	<.001
Education site users (ref: low users)				
Medium	2.570 (1.41-4.68)	.002	3.04 (1.64-5.54)	<.001
High	6.75 (3.72-12.23)	<.001	6.94 (3.73-12.92)	<.001
Residence site users (ref: low users)				
Medium	2.89 (1.51-5.41)	.001	2.16 (1.11-4.19)	.02
High	3.96 (2.10-7.46)	<.001	3.91 (2.03-7.53)	<.001
Job search site users (ref: low users)				
Medium	3.23 (1.75-5.97)	<.001	3.05 (1.65-5.64)	<.001
High	5.79 (3.13-10.69)	<.001	6.17 (3.28-11.62)	<.001
Government site users (ref: low users)				
Medium	4.14 (2.31-7.43)	<.001	4.82 (2.64-8.80)	<.001
High	8.90 (4.98-15.91)	<.001	8.90 (4.82-16.42)	<.001
News site users (ref: low users)				
Medium	4.91 (2.77-8.71)	<.001	5.87 (3.32-10.38)	<.001
High	11.29 (6.38-19.96)	<.001	11.36 (6.21-20.79)	<.001
Total capital site users (ref: low users)				
Medium	4.69 (2.72-8.09)	<.001	4.24 (2.43-7.40)	<.001
High	14.77 (8.59-25.39)	<.001	13.01 (7.29-23.20)	<.001
Entertainment site users (ref: low users)				
Medium	3.65 (1.97-6.76)	<.001	3.34 (1.82-6.14)	<.001
High	4.66 (2.49-8.73)	<.001	3.91 (2.07-7.37)	<.001
Social network site users (ref: low users)				
Medium	0.93 (0.47-1.85)	.85	1.04 (0.52-2.08)	.92
High	2.15 (1.14-4.08)	.02	2.06 (1.08-3.92)	.03

[a] Adjusted for race, age, native language, employment status, and wave.

Discussion

This study represents in-depth research of natural online behaviors of low SEP individuals over a period of several months that draws from directly tracked Internet data. Through this method, we were able to place health information seeking, capital-enhancing information seeking, entertainment use, social network use, and other diverse forms of Internet use within the context of the total Web use experience of low SEP individuals, data that are not often captured in such detail for this group. Participants sought information on a number of domains; 64% visited all the categories of the Internet use index over the study period and each additional category of computer use was associated with double the rate of health information seeking. Higher use of all individual types of capital-enhancing seeking was associated with increased rates of Internet health information seeking, with the highest increases seen in education and governmental website use. When all capital-enhancing categories were combined, the highest users of capital information sought health information at 13 times the rate of low users. Furthermore, both medium and high entertainment users were significantly associated with higher health information seeking compared to those who used entertainment sources to a low extent, and high social network site use was associated with higher health information seeking compared to low use.

Broader use of the Internet may provide individuals with skills to become more active online consumers [3]. Indeed, once online, low SEP individuals in the current study used the Internet for a diverse range of functions, from information gathering to sharing data to using search engines to springboard to other types of information. Importantly, this increased use was associated with increases in health information seeking. Although this behavior may present differently from that of a high SEP seeker, it points to the diverse ways in which low SEP individuals use the Web to find numerous types of content, including health information. This also indicates that even those who have not had much prior Internet use experience are able to quickly acclimate to the Web and use it for diverse functions beyond just entertainment once they are provided with access.

Evidence shows that health outcomes are patterned by access to material resources, education, and occupation [22]. By engaging in capital-enhancing information seeking, participants may gain an increase in resources that improves their SEP and subsequently improves their health. Thus, capital-enhancing functions may be important to consider when understanding how low SEP groups are using the Internet. Although all capital categories were significantly associated with higher Internet health information seeking, the notable rates of seeking associated with news, government, and education uses of the Internet may highlight the importance of these functions working to complement one another for the goal of greater well-being. For example, the literature has documented how online governmental information seeking and using the Internet as a civic resource and forum strongly influences civic engagement [36]. It may be that those who are more likely to research current events, governmental and political information, and engage with their communities may be more prone to research information pertaining to other avenues to well-being; participants may also visit government sites to access services such as food stamps or housing assistance.

In all, these associations suggest that higher levels of Internet use for functions such as searching for a job, financial resources, or educational programs correspond with higher levels of searching for health information. Past literature has found that in certain contexts, financial information served as a competing concern to health information for low SEP individuals [37]. In contrast, this study supports a conceptualization of complementation of seeking for types of beneficial sites instead of substitution. In other words, instead of the search for money or adequate housing replacing health information seeking due to competing needs, different types of capital-enhancing information may work together to provide a more comprehensive set of resources to increase well-being.

Although participants visited entertainment websites more frequently than health or capital websites reflecting past literature, we also observed entertainment use of the Internet was positively associated with greater health information seeking. This is an important distinction; instead of entertainment use taking precedence over higher-order activities, individuals who spend more time online may do so in varied topic areas as they gain more confidence in using the Web [18] and as complex skills required for Web 2.0 uses develop [38]. This may also indicate that once individuals gain more exposure to the Internet, their perceived utility of the Web for different functions increases. Such findings are an important distinction, particularly in a media environment that often portrays low SEP individuals as using entertainment content to the extent that it overshadows other forms of Internet use. For example, a recent *New York Times* article claimed that increased access to technology creates a “time-wasting gap” in which the entertainment uses of the Internet by low SEP individuals eclipse its use for positive, educational uses, particularly for youth [39]. In contrast, our study illustrates that Internet behaviors must be placed in context of the larger seeking environment; although entertainment content was highly accessed, high entertainment users were also more likely to use the Internet to gather health information.

Although both health and capital information seeking represented only a small total of all websites visited compared to categories such as social networking, Internet portals, and entertainment, it may be indicative of the nature of the sites’ structure. For example, sites with constantly changing content, such as celebrity gossip, and particularly user-generated content, such as social network sites, may require more frequent interaction to remain up-to-date with activity. However, static sites may only require one visit to gather needed information, such as referencing a health diagnosis. Other sites, such as job sites, may be visited only as a certain need arises. The frequency with which these dynamic sites, such as social network sites, are accessed provide a promising platform for future eHealth content delivery [28]. This may point to more diverse use of social network sites for patient support and delivery of important health information, particularly because they are already a familiar platform for many Internet users. Social network sites also represent an important source of information exchange and a growing number of Internet users are turning to these sites to post about their own health activities, follow friends’ health experiences, or find health information [40].

Limitations

Although these data may give us valuable insight into the information-seeking behaviors of lower income adults, this sample may not be generalizable to other low SEP Internet users in the Boston area or in the United States. Although the restricted range of our sample precluded us from gauging differences by income or education, the nature of the sample made it ideal for studying the communication behaviors of a low SEP group. For this study, we recruited participants through presentations at adult education centers, which may have led to selection bias. Our focus on adults aged 25 to 60 years precludes us from understanding Internet usage patterns in younger adults, who are often more frequent Internet users; however, this allowed us to focus on a sample of novice Internet users who may not have as much exposure to the Internet through school or other sources. Due to our IRB mandate, our data were restricted to the household level, so we were unable to determine use from particular individuals in the household. It is possible that there were several users in each household and that different household members used the Internet for different purposes. To address this discrepancy, self-report Internet use data from each participant was crosschecked with website tracking data to determine if the participant’s level of reported usage matched the observed level of Internet use in the tracking data. Furthermore, additional models accounting for other potential household members did not change our regression estimates. Our use of BrightCloud coding to determine our topic categories may have limited us from including certain relevant websites in our analyses; although we conducted a second-level crosscheck to include or exclude inappropriately categorized sites, we may have overlooked certain URLs or we may be unable to determine if health information seeking occurred on a site such as a social network platform or multipurpose webpage. Despite these limitations, the ability to capture real-time, Web-recorded data provides valuable insight into the information-seeking behaviors of the urban poor.

Conclusion

Results indicate that once online, low SEP individuals use the Internet for a broad range of purposes. The growth of health information technologies provides opportunities to incorporate features of interactivity and multimedia to revolutionize health communication. As evidenced by the diverse Web behaviors in this group, they may be familiar with these concepts and well positioned to participate in upcoming Web interventions. This finding may have important implications for interventions and design of policy-based websites because low SEP individuals may take advantage of a number of different well-being and health-related website formats. Given the popularity of social network sites, this platform may be particularly suited for trusted, reliable health information. However, certain safeguards to information structure, accessibility, and content must be considered when designing Web resources for low SEP groups.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Definitions of website categories.

[PDF File (Adobe PDF File), 30KB - jmir_v18i3e46_app1.pdf]

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Abbreviations

C2C: Click to Connect
IRB: Institutional Review Board
IRR: incident rate ratio
SEP: socioeconomic position

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Original Paper

Health-Related Internet Use by Informal Caregivers of Children and Adolescents: An Integrative Literature Review

Eunhee Park[1*], RN, PhD, APHN-BC; Heejung Kim[2*], RN, GNP-BC, PhD; Andreanna Steinhoff[3], RN, MLS

[1]University of North Carolina at Greensboro, School of Nursing, Greensboro, NC, United States

[2]Yonsei University, College of Nursing, Seoul, Republic Of Korea

[3]University of Kansas Medical Center, School of Nursing, University of Kansas, Kansas City, KS, United States

[*]these authors contributed equally

Corresponding Author:
Heejung Kim, RN, GNP-BC, PhD
Yonsei University
College of Nursing Room 614
50-1 Yonsei-ro, seodaemun-gu
Seoul,
Republic Of Korea
Phone: 82 2 2228 3273 ext 8
Fax: 82 2 392 5440
Email: hkim80@yuhs.ac

Abstract

Background: Internet-based health resources can support informal caregivers who are caring for children or adolescents with health care needs. However, few studies discriminate informal caregivers’ needs from those of their care recipients or those of people caring for adults.

Objective: This study reviews the literature of health-related Internet use among informal caregivers of children and adolescents.

Methods: A total of 17 studies were selected from literature searches conducted in 6 electronic databases: PubMed, Cochrane, CINAHL, PsycINFO, ERIC, and EMBASE. All databases searches were limited to articles published in the years 2004 to 2014 in peer-reviewed publications. Search terms consisted of “health-related Internet use,” “eHealth,” “Internet use for health-related purpose(s),” “Web-based resource(s),” and “online resources,” combined with informal caregiver (or “parents”) of “child,” “adolescent,” “student,” “youth,” and “teen.” The age range of the children receiving care was limited to younger than 22 years. Their informal caregivers were defined as persons (parents) who provided unpaid care or assistance to a child or an adolescent with health problems.

Results: Among 17 empirical studies, the majority of informal caregivers of children with medical issues were the parents. Quantitative studies (14/17, 77%) reported prevalence and predictors of health-related Internet use, while mixed-methods and qualitative studies (3/17, 24%) investigated informal caregiver perceptions of helpful health-related Internet use and barriers of use. The prevalence of health-related Internet use varied (11%-90%) dependent upon how health-related Internet use was operationalized and measured. Disease-specific information was used for decision making about treatment, while social support via virtual communities and email were used for informal caregiver emotional needs. A digital divide of Internet access was identified in lower educated minorities. Most studies had methodological challenges resulting from convenience sampling, cross-sectional surveys, lack of theoretical frameworks, or no clear definitions of health-related Internet use.

Conclusions: This study provides an important understanding of how family members use Internet-based information and support systems during child caregiving. Healthcare providers and policy makers should integrate family needs into their current practices and policies. Further rigorous research is required to design efficient and effective nursing interventions.

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KEYWORDS

Internet; caregivers; children; adolescent; eHealth; consumer health information

Introduction

The Internet continues to play an increasingly important role in our everyday lives, particularly regarding the delivery of health care services and interventions. Health-related Internet use is defined as any activity involving Internet-based information and resources for improving health and well-being [1-3]. Characteristics of the Internet that are important in delivering health care services and resources include: (1) medical information and health care resources can be accessed from diverse locations; (2) interactive features allow people to be more proactive health care consumers; and (3) Internet-based health resources can support patients and their informal caregivers of different ages in a cost-effective manner [4,5].

Childhood and adolescence are critical periods with unique developmental and health care needs [6]. Children and adolescents undergo dramatic changes in growth and development in physical, cognitive, and social domains. With brain development, maturation of their cognitive abilities allows higher levels of thinking, influencing their understanding of self and social surroundings [7]. The etiology of diseases varies depending on this developmental trajectory. Responses to disease differ based on social function such as language acquisition, which allows more mature self-functioning with different levels of autonomy depending on the developmental stage. In this process, family and peer influence are important [8].

Considering these critical changes, informal caregivers also have unique needs while caring for ill children and adolescents. Informal caregivers have a responsibility to optimize the healthy development of their children as part of the parenting process [9]. Knowledge of the physical and mental development of children with health care needs allows informal caregivers to evaluate disease processes along with normal developmental responses [10]. Optimal care can be provided by enhancing child self-care to maximize patient autonomy; this ultimately allows for better patient outcomes. Thus, parental understanding of the developmental stages and physical and psychosocial functioning of their children is vital [11]. Moreover, the responsibility of providing continuous intensive care can add extra burden and stress to informal caregivers [8]. Relationships with emotional attachments can also produce higher levels of stress and feelings of guilt [12].

Unique needs in the disease and caregiving trajectories may be met using the benefits of Internet-based health care service and resources. It is important to know how Internet-based health care services and resources have been used and what their perceived benefits and barriers are. To our knowledge, there have been no systematic reviews conducted to discriminate informal caregiver needs from those of their care recipients or from those caring for adults. Our integrative review on this topic proposed to synthesize the current understanding and state of the art regarding health-related Internet use by informal caregivers of children and adolescents with health care needs in order to identify better ways to help them. The aims of this integrative review were to (1) explore how Internet-based health care services and resources have been used by informal caregivers of children with health care needs; (2) identify the perceived benefits and barriers in health-related Internet use; and (3) examine the conceptual and methodological issues of the previous studies on this topic.

Methods

This integrative review was based on a comprehensive approach of a literature search [13] and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines [14].

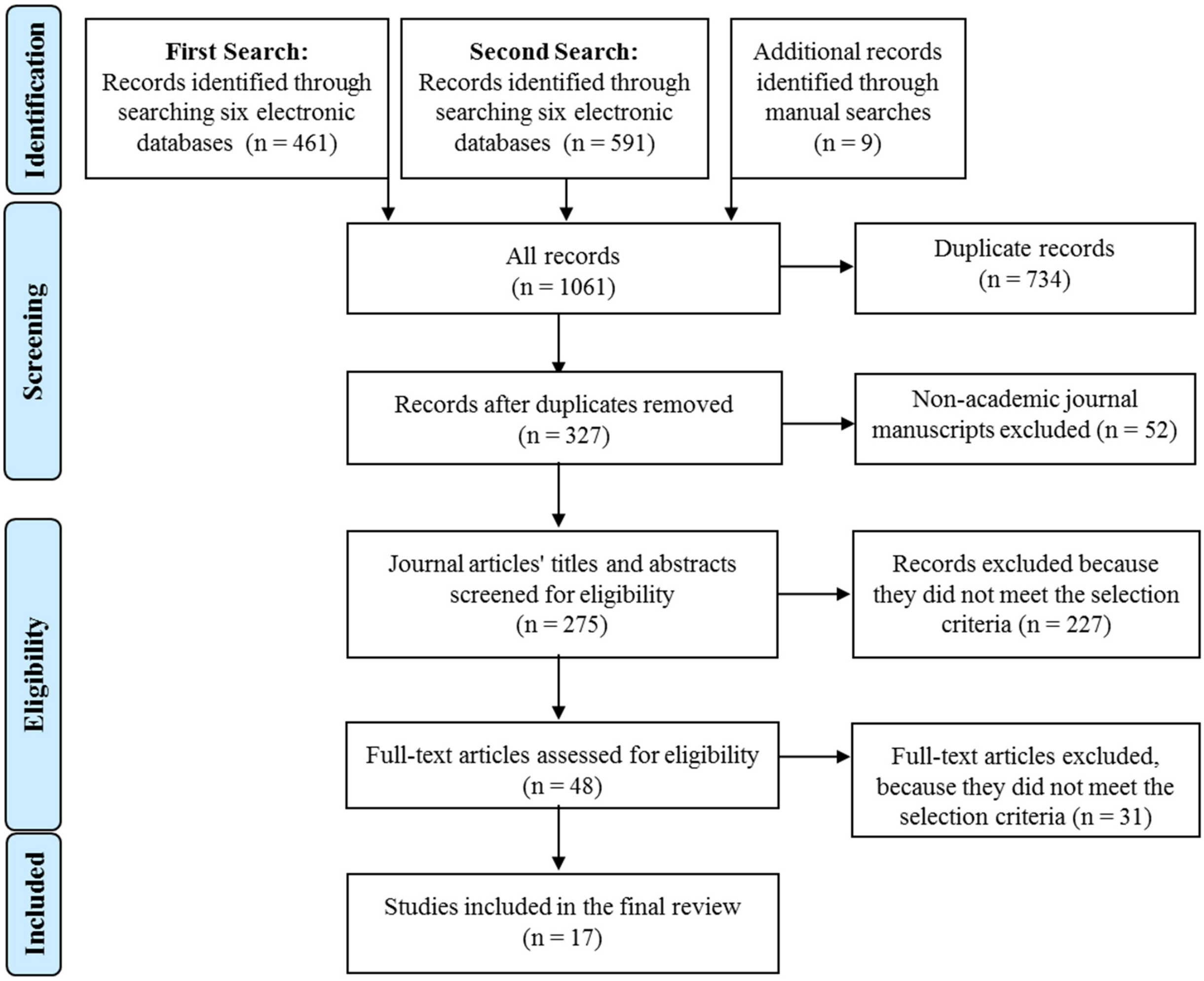
Search Strategy

For this integrative literature review, an initial literature search was conducted from July 2014 to September 2014 and an additional search was conducted in July 2015. The first search in 2014 did not specify the types of informal caregivers who took care of sick children. After we analyzed the first 14 studies chosen, it was found that most of informal caregivers related to this age group of care recipients were parents. The authors chose to conduct additional searches specifying parent(s) who are primarily responsible for child care.

Initially, we searched for studies published from 2009 to 2014, very few studies met this strict time period. Thus, we decided to expand the publication period to the years 2004 to 2014. A total of 6 computerized databases were searched: PubMed, the **Cochrane Library,** the Cumulative Index of Nursing and Allied Health Literature (CINAHL), PsycINFO, the Education Resources Information Center (ERIC), and EMBASE. Additional manual searching was performed on Google Scholar based on an ancestry search of citation and reference lists obtained from retrieved articles. Additional searching was also performed within the journals Pediatrics and the Journal of Medical Internet Research [15].

The initial set of search terms consisted of “health-related Internet use,” “eHealth,” “Internet use for health-related purpose(s),” “Web-based resource(s),” and “online resources,” combined with “caregiver” of “child,” “adolescent,” “student,” “youth,” and “teen.” For the second search, “caregiver” was replaced with “parent(s).” Titles, abstracts, and full texts were selected by applying the following inclusion and exclusion criteria. If the article was a systematic review, Cochrane review, literature review, or expert opinion, we used it as background information and examined its references but did not include it in the analysis. The first search results consisted of 470 records of which 14 studies were selected for the review. The second set of search results consisted of 591 records of which 3 studies were added for the review (see Figure 1).

Figure 1. PRISMA flow diagram outlining the search and review process.



Eligibility Criteria

Inclusion criteria were as follows:

- Children with health care needs receiving informal care were limited to ages younger than 22 years because of discrepancies in legal age among different countries
- Primary study participants recognized themselves as informal caregivers (or parents) of children with health care needs
- Informal caregivers (or parents) were limited to ages 21 years or older
- Studies could include no interventional Internet use in order to examine phenomenological usage in a natural setting without investigator manipulation
- Studies were observational studies to examine user-initiated Internet use
- Studies were written in English or Korean

Exclusion criteria were as follows:

- Study participants were mixed with other populations aged 20 years or younger
- Care recipients were mixed with other age groups aged 22 years or older
- Ages of recipients or informal caregivers (or parents) were not specified or reported
- Study participants were trained or professional health care providers (eg, physicians, nurses, or medical or nursing students)
- Intervention modality was combined with other non–Web-based technologies (eg, telephone)
- Studies using the Internet as a modality for survey, recruitment, or searching for relevant literature only focused on quality assurance of specific websites
- Studies were grey literature including dissertations, conference proceedings, papers or abstracts, or editorials

Data Extraction, Analysis, and Synthesis

One author (HK) initially evaluated titles and abstracts by applying potential eligibility criteria to exclude articles that did not investigate Internet use in informal caregivers (or parents) of children with health care needs. Two authors (HK and EP) fully reviewed the selected articles after developing definite eligible criterion and had a satisfying level of agreement over 95% regarding final selection of the articles. Two authors (HK and EP) entered data from selected articles into an analysis table, and an outside validator (AS) with a Master of Library and Information Management degree examined the articles and edited the table entries for accuracy (99% verification). To answer research questions 1 and 2, the coding scheme was developed based on our study purposes and Eysenbach's framework [1]. To evaluate the quality of study methodologies responding to research question 3, we modified the guidelines of the Agency for Healthcare Research and Quality on rating the strength of scientific evidence considering our context [16].

Results

Characteristics of Study-Participating Care Recipients and Informal Caregivers

Of 17 studies, 7 were conducted in the United States. In the selected studies, children experienced a wide range of medical needs including (1) hearing loss [17]; congenital disease or developmental problems [18]; asthma [19,20]; hydrocephalus [21]; rare genetic diseases [22]; ear, nose, and throat surgeries [23]; and type 1 diabetes [24]. Study topics also included nonspecific diseases requiring primary health care [25-30], emergency care [30-32], and disability [33]. The majority of the 17 studies (12/17, 71%) used a wide range of age criteria even within a single study. Only 5 studies focused on specific age groups such as those aged 2-6 years [19,23,25,29] or preschoolers to 8th grade [19,23,24,29].

The selected studies had limitations in representing diverse populations including relationships to children, gender, race and ethnicity, insurance status, employment, education level, and the regions where informal caregivers live. The majority of studies were limited to parents or legal guardians (14/17, 82%); the remaining studies were of relatives as caregivers (3/17, 18%). The majority of participants were female, usually mothers [17,23,24,27-29,33]. A high proportion of racial and ethnic minorities were found in only 4 studies; African Americans were the largest group in these studies, with proportions ranging from 32% [21] to 83% [32]. Although the selected studies did not aim to recruit low-income families, 6 studies (35%) included low-income study participants (determined based on insurance and employment status). A high percentage of participants receiving Medicaid or government-provided insurance were included in 4 studies (56%-92%). More than 50% of study participants in the DeMartini and colleagues study [26] lived in a high-poverty area. In addition, 3 studies [17,29,33] reported a moderate to high proportion of those who were unemployed or with unsecured jobs. A summary of the study setting, study participants, and their characteristics is shown in Multimedia Appendix 1.

Health-Related Internet Use

The definition, prevalence, purpose, and detailed types of general and health-related Internet use are summarized in Multimedia Appendix 2.

Prevalence of General Versus Health-Related Internet Use

General Internet use was defined based on access to the Internet via computer, cell phone, or other mobile handheld device [34]. The prevalence of general Internet use among informal caregivers was reported with a wide range, 62% to 99%. Half or more were daily users (49%-70%). In 2009, the generic search engines most frequently used were Google (79%), Yahoo (3%), and others (18%) [23]. Among general users, the most common places to access the Internet were at home (45%-87%) followed by anywhere using a smartphone (28%-71%), worksite (33%) and other places (3%-15%) including the library, community agencies, schools, and Internet cafés.

The prevalence of health-related Internet use varied (11%-90%) depending upon how it was operationalized and measured. Only one study used a comprehensive definition of health-related Internet use based strictly on Eysenbach's framework [1]—using the Internet for health-related information, support, and health care education [17]. The most common definition of health-related Internet users included people using the Internet for seeking health-related information for child caregiving [18,19,23,25,28,29,32]. Using a narrow definition was likely to be associated with a lower prevalence of health-related Internet use: 11% used the definition of those with access to care over the Internet focusing on email use [27], 58% used the definition of those with health-specific uses of digital technology [26], and 82% used a general definition of informal caregivers who used the Internet related to their children's health [21,22,31,33].

Types of Health-Related Internet Use

Information (Content)

The most prevalent purpose for health-related Internet use was seeking information regarding child health care needs; 15% to 90% of caregivers knew how to find health-related information on behalf of care recipients [17-26,28-33]. In one study, many Internet users (87%) chose a generic search engine; almost half (44%) also visited specialized websites for specific health needs [17]. Only 35% used the Internet at the time of the care recipients' diagnosis [18]; a small group of informal caregivers (9%) sought Web-based information immediately prior to their onsite clinic visit [31].

Informal caregivers were not confident in their ability to appraise health-related information found on the Internet or distinguish the quality of information and support from health care providers. According to Knapp and colleagues [28], only half of the users felt confident enough to evaluate the quality of Web-based information, although the Internet was the most commonly used source for health information according to Bouche [25]. From 10% to 50% of informal caregivers discussed the information found through Internet searches with their health care providers during onsite clinic visits [17,23]. Half of them stated that their health care providers were interested in the Web-based information [17].

Communication

Informal caregivers used the Internet for communicating with their health care providers or peers [21,27,30,32]. The informal caregivers expressed a strong interest in using the Internet and emails to communicate with primary health care providers (80%-86%) [31,33] and health care providers in the emergency department (93%), including receiving lab results [32]. In addition, informal caregivers thought that electronic communication between primary and emergency department care providers would be helpful (34%) [32]. The informal caregivers also expressed a strong interest in using the Internet and emails to contact organizations related to health concerns and promotion (36%) [31,33].

As a communication method with their health care providers, the informal caregivers wanted to receive information via an electronic newsletter about current disease trends (77%), discharge instructions (66.0%), and educational content about common illnesses (73%) [32]. These findings are similar to the study showing the information that respondents want to receive from their health care providers online includes common infections (77%), age-appropriate activities (73%), healthy eating (71%), required well-child visits and screening tests (65%), and resources in community (62%) [26,30].

Support (Community)

The Internet was also commonly used by informal caregivers for obtaining emotional and social support [17,21,22,24]. Almost 30% used emotional support groups and 35% used the Internet for communication with parents in similar situations [20]. As many care recipients had life-long chronic illnesses, the Internet played an important role in helping informal caregivers cope with their emotions by having more information [22,24]. Internet support groups helped informal caregivers adjust to their children’s condition [22]. Peer communication using email was beneficial for expanding their interaction beyond the membership of a certain online group [21].

Education

The Internet was also commonly used by informal caregivers to educate themselves about obtaining care for themselves and their care recipients simultaneously [17]. To educate themselves regarding their personal health care, 86% of informal caregivers found the Internet helpful in learning about diseases [21], and 78% of participants used YouTube for educational videos related to health. Most informal caregivers wanted guidance and recommendations from their health care providers about which online resources to use [21]. Only 58% of those who sought information regarding their personal health care questions trusted the information received, and then only sometimes or somewhat [21].

eCommerce

None of the studies investigated any purchases of medical products or medications via online shopping.

Associated Factors of Health-Related Internet Use

There was evidence that a higher education level in informal caregivers was associated with more frequent use of the Internet related to health [17,21,28], which is consistent with findings from previous studies [2,35]. Higher education levels seemed to be correlated with adequate health literacy [19,20]. A digital divide existed for racial and ethnic minorities such as African Americans and Hispanics and among non-English-speaking groups [21,27,28,32].

Caregiving-specific factors of health-related Internet use included (1) a strong intention to understand children's health information [29], (2) unmanageable situations beyond the capacity of parental adjustment [22,24], and (3) specific treatment requirements of the children [18,24]. However, no relationship with health-related Internet use was found regarding geographic location, age of parents, status of disease, or number of consultations with primary care providers [17,21,25].

Perceived Benefits

Informal caregivers stated that it was easy to find helpful information regardless of the time and their location. Information helped informal caregivers understand a child’s medical condition [18,31], understand specific treatment [19,23], and make decisions about treatment [23,26]. In terms of Internet use as a support system, they were highly satisfied with Internet-based parental support groups, citing obtaining usable ideas, improved informal caregiver relationships with their children, finding people to trust, and seeking stress-coping strategies as specific benefits [22].

Perceived Barriers

There were several barriers that informal caregivers encountered using the Internet for health-related purposes. The quality of websites was a main barrier [17]. Only half felt confident assessing the quality of Web-based information [28]. This may explain why 94% of participants responded that they were not able to find the information they wanted on the Internet [20,31]. Most participants did not remember the specific health-related websites they used [31]. In addition, they hesitated to discuss the Web-based information they found with their health care providers [17,20,23]. This may be based on warnings from their health care providers not to trust Internet-based health information. Additional reasons caregivers do not use Internet health-related information may include personal logistical barriers, fear, and mistrust of information on websites [26]. Other barriers included cost, limited access, lack of knowledge, lack of time, medical disabilities, vision problems, concern about the negative effects of computer use, lack of transportation, and a lack of child care [31,33].

Conceptual and Methodological Evaluations

Issues of Conceptualization

Most studies did not clearly define health-related Internet use. Using or accessing the Internet to find health-related information was the common operational definition. However, researchers did not provide the rationales for why they defined health-related Internet use based on the access to use Internet [34]. Only 2 studies (2/17, 12%) used theoretical frameworks to explain why health-related Internet use was important during the caregiving trajectory. The frameworks used were the theory of planned behavior [29,36] and Antonovsky’s concepts of sense of coping and coherence [22,37]. Other frameworks were used to understand the parental factors and their decisions to use online health information regarding diagnosis and treatment [29,36]. These frameworks considered the Internet a resource for helping informal caregivers reestablish a sense of coherence after they experienced stressful events due to their child's illness [22,37].

Study Design

All 17 studies were cross-sectional. The most frequently used study designs were quantitative (13/17, 77%) and prospective (16/17, 94%). Descriptive (8/17, 47%), correlational (9/17, 53%), qualitative (2/17, 12%) [22,24] and mixed-methods design (1/17, 6%) were also used [17]. Quantitative studies tended to report prevalence and predictors of health-related Internet use, and qualitative or mixed-method studies investigated informal caregiver perceptions of helpful and harmful health-related Internet use. There was no longitudinal study found to imply causality. Walsh and colleagues used multiple observation time points [29]. All of them were 1-group studies without any comparison group. Almost half of the 17 studies used a single recruitment site. Others used multiple sites including caregiver databases [25,33], online recruitment [29], multiple clinical sites [17,21,26], and large-scale clinical trials [19].

Study Sample

Convenience sampling was the most common. Only 4 studies used more rigorous systematic sampling methods based on probability such as random selection [20,28,33] and stratified sampling [25]. Sample sizes ranged widely from 10 to 2371. Based on the selected study design, data analyses, and justification of sample sizes, 8 studies (8/14, 57%) measured quantitative data and had adequate sample sizes, while 6 studies (5/13, 43%) had excessively large sample sizes. Only 2 studies [22,24] used a qualitative study design, but they had very small sample sizes (n=10 and n=27), although saturation was achieved. Most of the study participants spoke English, limiting generalizability to non-English-speaking populations. Nonresponder bias due to low response rates was identified in 5 studies; 4 of them collected data once [18,25,27,28] with response rates between 49% and 76%. Walsh and colleagues [29] collected data at 2 observation times and reported a 48% response rate at follow-up after 2 months from baseline.

Data Collection and Analysis

Almost all studies used surveys; one conducted unstructured interviews individually or as part of a focus group [22,24]. Onsite surveys seemed to be preferred (10/17, 59%) followed by postal (3/17, 18%), telephone (2/17, 12%), and online modality (1/17, 6%) surveys. Porter and Edirippulige conducted an online survey [17], and Walsh and colleagues used online recruitment [29], which decreased generalizability of this study to non-Internet users [38].

The gold standard instruments regarding health-related Internet use were the Health Information National Trends Survey questionnaire [39] and the Pew Internet and American Life study of consumers’ use of the Internet for health care information questionnaire [34]. However, only 2 studies used or modified these questionnaires [19,32]; most studies used their own. These survey questionnaires were developed with a lack of or poorly described psychometrics. Thus, the validity and reliability of these investigator-developed instruments were not well established.

Most of the types of data analyses were descriptive: univariate analyses (chi-square, student *t*, Pearson *r*, or other nonparametric tests), descriptive frequency statistics (numbers, percentages, means, and standardized deviations), or multivariate analyses (multivariate analyses of variance, linear regressions, or logistic regressions). The types of analysis statistics were appropriately chosen based on levels of data and measurement types. However, there was very limited information about reporting statistical assumptions checked, handling missing data, reporting pre-analysis, or including significant covariates in the analysis. The summary of methodological evaluation is shown in Multimedia Appendix 3, and the evaluation criteria are explained in Multimedia Appendix 4.

Discussion

Principal Findings

This integrative literature review provides an important understanding of how informal caregivers of children with health care needs used Internet-based information and support systems. In spite of variability, health-related Internet use among informal caregivers of children is similar to that of caregivers of adults [2,40,41]. The most prevalent use of the Internet is for disease-specific information about disorders and treatments, affecting decision making about treatment. Social support for emotional needs via a virtual community was also commonly used by informal caregivers.

Comparison With Prior Work

A digital divide exists for racial and ethnic minorities and those with low education and limited Internet access. Consistent with previous study findings, the predictive values of education levels were well represented [41]. A secondary data analysis using National Alliance for Caregiving data found that those with a college-level education were 3.4 times more likely to be health-related Internet users than those who were educated to the level of high school or less [2]. A higher education level may be associated with either a higher level of knowledge of health-related resources, better computer skills, or more eHealth literacy [35].

Information is the key driving force behind increasing health-related Internet use. This is consistent with Internet use among informal caregivers of adult populations [5,40-42]. Informal caregivers of children with health care needs require comprehensive and timely information for monitoring their child's condition (85%), performing therapeutic support (65%), managing medications or treatment regimens (64%), giving physical therapies (44%), preparing a special diet (40%), or arranging available services in the community (39%) [43]. Most of the study participants were parents who needed information to make a decision on behalf of their child. Informal caregivers managed uncertainty through information exchanging behavior [44]. Thus, health-related Internet use provided supplemental resources to ensure that informal caregivers knew how to deal with their children (84%), how to advocate for themselves (72%) or on behalf of the child (85%), and how to manage financial issues (63%) [43].

Support through online communication and community is the second driving force of health-related Internet use among informal caregivers of children with health care needs. Informal caregivers' emotional stress has been shown as a need variable that facilitates their use of resources [45]. The secondary analysis using National Alliance for Caregiving data found that the higher the emotional stress being experienced by dementia caregivers, the more health-related Internet use they reported [2]. Based on the stress-appraisal theory [46] and the stress process model [45], there is a positive relationship between recognized stress levels and efforts to alleviate stress. Thus, health-related Internet use may be considered a coping strategy for reducing informal caregiver subjective stress or burden [46] and a way to modulate between caregiving stress and negative outcomes [45].

Implications for Current Practice and Research

Our study found that health-related Internet use is highly prevalent and that caregivers need better guidance identifying quality information sources. Our study assists clinicians and researchers who want to provide information and communication technology (ICT)-based interventions for improving the quality of care for informal caregivers and their care recipients. First, information should be evidence-based and written at a sixth grade level or lower to include informal caregivers with low levels of education [47]. Second, informal caregivers and their care recipients should be provided with educational opportunities to learn about computers, the Internet, and multimedia devices and technologies based on the consumer health informatics guidelines [48]. Third, Internet-based interventions should be consumer-centered reflecting their needs for health care, preferences, and capacity to use. Recent work by Davies and colleagues has provided a great example of this approach. This research project consisted of four steps: (1) a literature review to assess what is known about the selected topic, (2) the development of a health information website based on a standardized approach, (3) a usability study to reflect users' lived experiences and opinions for further revision of ICT-based interventions, and (4) a feasibility study to examine the effect of the ICT-based intervention. Thus, we believe that this integrative literature review is a foundation for moving forward to develop consumer-centered Internet-based interventions for informal caregivers of children requiring special health care.

Study Limitations

This study has several limitations. Although it adhered to the systematic review process, there might be potential errors and biases. Although clear inclusion and exclusion criteria were set up and a systematic review process was conducted, there is a possibility that reviewers might have missed appropriate studies in the search process. Multiple authors conducted the coding process independently and the results were compared, but potential biases of the authors might have influenced the review process. In addition, while two authors evaluated the quality of studies based on the guidelines of the US Department of Human Services Agency for Healthcare Research and Quality, there was still subjectivity in evaluating the studies.

Further research should overcome critical methodological limitations. First, the definition of health-related Internet use should be more clearly operationalized and stated. Consistent use of definitions and measures will allow us to compare prevalence across studies. Second, further studies should use probability sampling to increase generalizability of findings. Low response rates should be addressed to reduce self-selection bias. Third, there is an ongoing need to develop and use reliable and valid instruments to capture more comprehensive behaviors of health-related Internet use. Self-report bias is inevitable in survey studies, thus objective measures used for a long-term follow up would be helpful to conclude causality. Fourth, theory-based studies are required to explain the complexity of health-related Internet use. Last, more rigorous statistical analyses are required. For example, for studies recruiting participants from multiple sites, the heterogeneous characteristics of sites should be controlled as confounding variables. Further studies should consider institutional-level variables affecting characteristics of study participants from different sites.

Conclusions

In spite of its limitations, this study provides important information for health care providers and policy makers to integrate the need of informal caregiver who take care of their children and adolescents when developing Internet-based interventions and services. There is sufficient evidence that health-related Internet use is highly prevalent, and there are increasing needs for better use of the Internet among informal caregivers. The findings of this review also reveal gaps in the literature, which could direct further research. In addition, the information provided in this study provides important implications in designing intervention programs for the target population.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of characteristics of informal caregivers and care recipients from 17 studies.

[PDF File (Adobe PDF File), 39KB - jmir_v18i3e57_app1.pdf]

Multimedia Appendix 2

Summary of prevalence and characteristics of health-related Internet use.

[PDF File (Adobe PDF File), 51KB - jmir_v18i3e57_app2.pdf]

Multimedia Appendix 3

Methodological evaluation of study quality.

[PDF File (Adobe PDF File), 48KB - jmir_v18i3e57_app3.pdf]

Multimedia Appendix 4

Modified guideline of Agency for Healthcare Research and Quality criteria.

[PDF File (Adobe PDF File), 18KB - jmir_v18i3e57_app4.pdf]

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Abbreviations

CINAHL: Cumulative Index of Nursing and Allied Health Literature
ERIC: Education Resources Information Center
ICT: information and communication technology

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Original Paper

Differences in Access to and Preferences for Using Patient Portals and Other eHealth Technologies Based on Race, Ethnicity, and Age: A Database and Survey Study of Seniors in a Large Health Plan

Nancy P Gordon[1], ScD; Mark C Hornbrook[2], PhD

[1]Kaiser Permanente Northern California, Division of Research, Oakland, CA, United States
[2]Kaiser Permanente Northwest Region, The Center for Health Research, Portland, OR, United States

Corresponding Author:
Nancy P Gordon, ScD
Kaiser Permanente Northern California
Division of Research
2000 Broadway
Oakland, CA, 94612
United States
Phone: 1 510 891 3587
Fax: 1 510 891 3606
Email: nancy.gordon@kp.org

Abstract

Background: Patients are being encouraged to go online to obtain health information and interact with their health care systems. However, a 2014 survey found that less than 60% of American adults aged 65 and older use the Internet, with much lower usage among black and Latino seniors compared with non-Hispanic white seniors, and among older versus younger seniors.

Objective: Our aims were to (1) identify race/ethnic and age cohort disparities among seniors in use of the health plan's patient portal, (2) determine whether race/ethnic and age cohort disparities exist in access to digital devices and preferences for using email- and Web-based modalities to interact with the health care system, (3) assess whether observed disparities in preferences and patient portal use are due simply to barriers to access and inability to use the Internet, and (4) learn whether older adults not currently using the health plan's patient portal or website have a potential interest in doing so in the future and what kind of support might be best suited to help them.

Methods: We conducted two studies of seniors aged 65-79 years. First, we used administrative data about patient portal account status and utilization in 2013 for a large cohort of English-speaking non-Hispanic white (n=183,565), black (n=16,898), Latino (n=12,409), Filipino (n=11,896), and Chinese (n=6314) members of the Kaiser Permanente Northern California health plan. Second, we used data from a mailed survey conducted in 2013-2014 with a stratified random sample of this population (final sample: 849 non-Hispanic white, 567 black, 653 Latino, 219 Filipino, and 314 Chinese). These data were used to examine race/ethnic and age disparities in patient portal use and readiness and preferences for using digital communication for health-related purposes.

Results: Adults aged 70-74 and 75-79 were significantly less likely than 65-69 year olds to be registered to use the patient portal, and among those registered, to have used the portal to send messages, view lab test results, or order prescription refills. Across all age groups, non-Hispanic whites and Chinese seniors were significantly more likely than black, Latino, and Filipino seniors to be registered and to have performed these actions. The survey found that black, Latino, and Filipino seniors and those 75 years old and older were significantly less likely to own digital devices (eg, computers, smartphones), use the Internet and email, and be able and willing to use digital technology to perform health care-related tasks, including obtaining health information, than non-Hispanic whites, Chinese, and younger seniors (aged 65-69), respectively. The preference for using non-digital modalities persisted even among Internet users.

Conclusions: Health plans, government agencies, and other organizations that serve diverse groups of seniors should include social determinants such as race/ethnicity and age when monitoring trends in eHealth to ensure that eHealth disparities do not induce greater health status and health care disparities between more privileged and less privileged groups.

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KEYWORDS

eHealth disparities; patient portals; race-ethnic disparities; seniors; Internet use; health information technology disparities

Introduction

The adoption of digital technology has been accelerating rapidly, and the Internet has become an important tool for health care-related communications and transactions. Increasingly, health care organizations and government agencies are using their websites as key modes of informing patients and the public about health, health care, and health care coverage. In addition, email and secure website portals are used for informational, health care delivery, and business transactions [1]. This rapid shift to Web-based transactions among health care providers is in part being driven by Centers for Medicare and Medicaid Services (CMS) "Meaningful Use" requirements that mandate the deployment of digital technology to increase patient engagement with their health and health care outside the clinic setting [2,3], and in part by growing consumer demand for online access to health and health care information [4-8]. As health care organizations continue to embrace expanded uses of their websites and other health information (eHealth) technologies as primary channels for delivery of health and health care information, patient education, provider-patient communication, and health care-related business transactions, a worrisome health policy issue is exacerbation, rather than elimination, of health and health care disparities among already vulnerable populations if universal adoption of eHealth technologies does not occur [3,9,10].

It is well documented that digital divides exist in the general US population by race/ethnicity, income, educational attainment, and health literacy [11-31]. Recent studies have found similar disparities in use of patient portals [13,23-29,32,33] and the Internet as a source of health information [11-14,23,24,29]. Although older adults are among the fastest growing group of Internet users in the United States, surveys show that their use still significantly lags behind even that of middle-aged adults. In 2014, an estimated 87% of US adults used the Internet to access websites and/or to exchange emails [31]. In 2013, 59% of adults (72% of Internet users) had looked on the Internet for health information of some kind in the past year [6]. However, adults aged ≥65 years were significantly less likely than those aged 50-64 to be Internet users (57% vs 88%, respectively) [31] and significantly less likely to have gone online for health information in the past year (33% of all seniors and 58% of senior Internet users vs 62% of 50-64 year olds and 71% of Internet users in that age group) [6]. Within the senior age group, computer access and ability to use the Internet has been shown to be lower among blacks and Hispanic/Latinos than among non-Hispanic whites [12,17,18,27,32,34-36], those aged ≥75 [12,16,17,31,34-39], those with a high school diploma or less [12,17,18,26,34-36], those with a low household income [12,18,35], and those with low levels of literacy and health literacy [32,38].

To date, limited information has been available about the extent to which race/ethnic and age-related eHealth digital divides exist within the senior age group, and beyond access issues, are a function of eHealth literacy and preferences for using digital technology for health-related purposes. Additionally, of the relatively few studies that have focused on race/ethnic differences among seniors, most have been restricted to non-Hispanic whites, African-American/blacks, and Hispanic/Latinos, leaving a gap in information regarding use of digital technology for health-related purposes among the growing Asian segment of the senior population.

Seniors are being expected to make the shift from print and telephonic health communications to interacting via websites, email, text messages, and interactive voice response systems along with other adult age groups. As such, an emerging research and policy priority is to identify the extent to which age and race/ethnic differences in seniors' access to and comfort with using eHealth have the potential to create or exacerbate disparities in access to timely health care–related information, patient education, and lower-cost health care options such as video visits and online ordering and purchasing of prescription medications and medical equipment. Recognizing this potential, *Healthy People 2020* included an expanded set of goals for use of "health communication strategies and health information technology to improve population health outcomes and health care quality and to achieve health equity" [40].

As part of "Stage 3 Meaningful Use" requirements for electronic medical record systems, health plans, hospitals, and medical offices may be asked to identify and act on patient communication preferences for clinical summaries, reminders, and patient educational materials [41]. From a health care provider perspective, this generates an imperative to understand how the characteristics of Medicare-age members may affect meeting meaningful use targets. Member engagement with a health plan's portal and/or website may be more limited for plans with a high percentage of older members who cannot or prefer not to go online for health care transactions. Similarly, government and non-governmental agencies and organizations that serve seniors should take into account the health care-related digital divide when developing information technology (IT) programs, planning for dissemination of important information, and requiring information and communications to be transmitted online.

In this study, we assessed the extent to which race/ethnic and age-related eHealth digital divides exist among the racially and ethnically diverse seniors of Kaiser Permanente Northern California (KPNC) and what might be driving the divides that are observed. We used a two-pronged approach. We first examined race/ethnic and age-group differences in overall registration to use and patterns of use of four features of the health plan's secure patient portal in 2013 in a large study population of non-Hispanic white, black, Hispanic/Latino, Filipino, and Chinese adults aged 65-79. Concurrently, we surveyed a sample of this population to obtain information about the types of digital devices (eg, computer, mobile phone, tablet) and digital technologies (Internet, email, text messaging, Skype) they were using, as well as their readiness and preferences for using digital modalities for health-related purposes. The study had four main aims: (1) to identify race/ethnic and age cohort disparities among seniors in use of the health plan's patient portal, (2) to determine whether race/ethnic and age cohort disparities exist in access to digital devices and preferences for using email- and Web-based modalities to interact with the health care system, (3) to assess whether observed disparities in preferences and patient portal use are due simply to barriers to access and inability to use the Internet, and (4) to learn whether older adults who are not currently using the health plan's patient portal or website have a potential interest in doing so in the future and, if so, what kind of support might be best suited to help them.

Methods

Setting

KPNC is a vertically integrated health care delivery system that serves over 2.4 million adult members and their family members who mostly reside or work in the San Francisco Bay Area, Silicon Valley, Sacramento area, or the Central Valley in Northern California. The KPNC adult membership is highly similar to the insured population of Northern California with regard to demographic and health characteristics [42]. KPNC has a comprehensive website that provides health plan and health information (eg, about health conditions, medications, healthy behaviors/lifestyle) accessible to both members and the general public, and a secure patient portal that is available only to health plan members who register for and activate a patient portal account. Once members activate their account, they can use a variety of secure features on the website. These features include communicating with their health care providers and Member Services specialists using secure messaging, viewing laboratory test results, ordering and paying for prescription refills, viewing and scheduling appointments for primary care and vision care, checking their preventive care status (eg, use of recommended immunizations and cancer screening services) and their prescribed medication list, completing online health questionnaires, using patient/health education programs not available to the public, and downloading a variety of forms for use within Kaiser Permanente.

Study Population

Our primary aim was to determine whether race/ethnic and age-related differences exist in preferences for using the health plan's patient portal features and health education resources, which are primarily available in English. The health plan also has Spanish language websites, but at the time of this study, these did not have full functionality in Spanish and were not as comprehensive with regard to health information. Because previous research has shown a sharp drop in Internet use after age 75, we restricted the study population to members aged 65-79 who had no indication in health plan records of having a preference for oral or written communication in a language other than English (non–limited English proficient [non-LEP]). Within this age group, we restricted our study to a cohort of adults who had been assigned to one of the health plan's five largest race/ethnic groups: non-Hispanic white, African-American/black (black), Hispanic/Latino (Latino), Filipino-American (Filipino), or Chinese-American (Chinese) using data from administrative and research sources. In 2013, these five race/ethnic groups accounted for approximately 95% of all non-LEP health plan members aged ≥65. Furthermore, members aged 65-79 in these race/ethnic groups accounted for approximately 75% of all non-LEP members aged ≥65. Because we wanted everyone to have had at least 2 years of opportunity and encouragement to create a kp.org account and to use the website's secure features, we further restricted the study population to people who in November 2013 had been continuous KPNC members for at least 2.5 years.

Patient Portal Use Study

The full study population for the patient portal use study included 183,565 non-Hispanic white members, 16,898 black members, 12,409 Latino members, 11,896 Filipino members, and 6314 Chinese members aged 65-79. Of these, 114,752 non-Hispanic white, 13,006 black, 8755 Latino, 9329 Filipino, and 4087 Chinese members were in the health plan's diabetes, hypertension, and/or coronary artery disease registry. We used the full study sample to calculate percentages of members who were registered to use the kp.org patient portal and from whom at least one secure email had been received by December 31, 2013. We used the subgroup of members who had at least one laboratory test in the 2013 calendar year to calculate percentages who viewed lab test results online at least once in 2013, and the subgroup who had at least one prescription refill in 2013 to calculate percentages who used the online prescription refill ordering feature at least once. We also calculated use of these secure features, plus signing into the secure portal at least once during the calendar year, among the same subgroups of members, first restricting analyses to those who had a kp.org account by the end of 2013 and then restricting to those in a chronic disease registry. It should be noted that these members may not have had a kp.org account or activated a kp.org account at the time they might have wanted to communicate with a doctor, obtain a lab test result, or order a prescription refill. However, in 2013, it was possible for nearly all adult members to create, activate, and immediately start to use a kp.org account within a few minutes.

All analyses for the patient portal study were conducted using SAS version 9.3 [43]. Proc Means was used to generate percentages, and multivariable models run using Proc Logistic assessed whether registration and use significantly (*P*<.001) differed across age groups (70-74 and 75-79 vs 65-69), race/ethnic groups (black, Latino, Filipino, and Chinese vs non-Hispanic white) for ages 65-79 and individual age groups, and age groups within each race or ethnicity. Denominators for Tables 1 and 2 cell percentages are provided in Multimedia Appendix 1.

Survey Study

Sampling Design

From the study population, we selected stratified random samples of approximately equal numbers of women and men from three age groups (65-69, 70-74, 75-79) within each race/ethnic group: 1320 non-Hispanic whites, 1320 blacks, 1320 Latinos, 510 Filipinos, and 510 Chinese. The Filipino and Chinese samples were smaller than the others because their data were originally intended to be used for pilot study purposes.

Data Collection

The survey was conducted using a mailed print questionnaire available only in English, with interviewer administration upon request. An online option was not made available due to our prior experience that a very small percentage of seniors choose to participate using an online questionnaire when both modalities are offered. Participants were offered a US $5 gift card as recognition for returning a completed survey. The first survey was mailed in mid-November 2013, and a second mailing was conducted in mid-December 2013 to those who had not responded. People who did not respond to either of the first two survey mailings were sent a third, slightly shorter, questionnaire in early February 2014. Participants were told that the survey was being done to help Kaiser Permanente and other organizations learn about seniors' use of digital tools (like computers, mobile devices, and the Internet) and how they prefer to give and get information about their health and health care. The survey materials stated that participation was important even if they did not use a computer, the Internet, email, or a mobile phone, or did not use the Kaiser Permanente website and did not want to use it. A copy of the survey questionnaire can be found in Multimedia Appendix 2.

Data Analysis

Survey respondents were assigned analytic weighting factors to adjust for sampling design and nonresponse. The weighting factors were created by dividing the number of people in the full study population who were in the age–sex–race/ethnicity–kp.org account status stratum that the respondent was representing by the number of survey respondents in that stratum. Patient portal account status was included as a component of the weighting after we discovered that in several race/ethnicity × age group strata, members who had signed up for a kp.org account by the time of the survey were significantly more likely to have responded than those who had not. Because approximately 6.84% (178/2602) of the sample completed the slightly shorter form of the survey, separate sets of weighting factors were created for those items included in both longer and shorter forms of the survey and for those items that were included only in the longer form. The raw (ie, unweighted) and weighted age-sex composition of the race/ethnic groups and the full sample are available on request.

All analyses were conducted using SAS version 9.3 procedures for complex datasets [43]. Proc Surveymeans was used to produce weighted percentages with 95% confidence intervals. Proc Surveylogistic was used to test whether statistically significant differences between age cohorts were observed (ie, 70-74 and 75-79 vs 65-69) for the full respondent sample, within race/ethnic groups, between race/ethnic groups (ie, black, Latino, Filipino, Chinese vs non-Hispanic white) for ages 65-79, and to test for significant differences by race/ethnicity, age, and other independent variables (eg, being an Internet user, being in fair or poor health, no formal education beyond high school) after controlling for multiple factors. All comparisons cited as statistically significant in the text had a Wald chi-square value of $P<.05$. No adjustment was made for multiple comparisons, but results of all comparisons are reported.

Kaiser Foundation Research Institute's Institutional Review Board approved both the patient portal and survey studies.

Results

Patient Portal Use

In the full study population and across all racial and ethnic groups, older seniors (ie, adults aged 70-74 and 75-79) were significantly less likely than those aged 65-69 to have registered to use the patient portal, to have signed into the patient portal at least once, and to have used the patient portal to send a secure message, view lab test results online, or order prescription refills at least once by the end of the year (see Table 1). Across all age groups, black, Latino, and Filipino health plan members were significantly less likely than non-Hispanic white and Chinese members to have created a kp.org account by December 31, 2013, and to have used its secure patient portal features. Only 26.35% (1472/5587) of black members aged 75-79 years used the patient portal at least once in 2013 to send a message to their doctor, view a lab test result, refill a prescription, or make a doctor's appointment, as compared to 56.31% (33,930/60,255) of non-Hispanic white members in the same age group. These race/ethnic and age group differences in the use of the patient portal were present even among members who had a kp.org account during at least part of 2013. Even among members included in one or more of the health plan's chronic disease registries, significant age group and race/ethnic differences were observed in use of secure messaging and any of the four patient portal features (see Table 2).

Characteristics of Survey Respondents

The overall survey response rate was 53.45% (2602/4868) after excluding ineligibles (14 not reachable by mail, 65 non-members, 32 deceased, 1 with dementia). Response rates were similar across age groups: 52.01% (841/1617) for ages 65-69, 53.87% (878/1630) for ages 70-74, and 54.47% (883/1621) for ages 75-79, with no significant sex difference within age group. However, response rates differed significantly by race/ethnic group: 65.26% (849/1301) for non-Hispanic whites, 44.44% (567/1276) for blacks, 50.50% (653/1293) for Latinos, 44.42% (219/493) for Filipinos, and 62.18% (314/505) for Chinese, with no significant differences in response by age and sex within each race/ethnic group.

Table 1. Registration for and use of the patient portal by age group and race/ethnicity[a].

Use of the patient portal in 2013	Age	All	Non-Hispanic white	Black	Latino	Filipino	Chinese
Was registered to use the patient portal by end of 2013, %							
	65-79	77.1	81.1	54.1[b]	62.5[b]	60.5[b]	81.4
	65-69	82.2	86.3	61.3[b]	67.0[b]	65.4[b]	86.1
	70-74	78.6[c]	82.6[c]	55.4[b,c]	63.7[b,d]	61.1[b,c]	83.7
	75-79	71.5[c]	75.5[c]	47.3[b,c]	57.9[b,c]	55.2[b,c]	75.6[b,c]
Signed onto the patient portal ≥1 time in 2013 (if registered to use patient portal at least part of 2013), %							
	65-79	80.5	82.2	65.9[b]	70.8[b]	68.9[b]	85.5[b]
	65-69	83.3	85.0	69.4[b]	75.6[b]	74.1[b]	87.5
	70-74	81.6[c]	83.5[c]	66.9[b]	71.8[b,d]	69.1[b,c]	86.2[b]
	75-79	76.4[c]	78.2[c]	61.3[b,c]	65.7[b,c]	63.3[b,c]	83.1[b,c]
Used the patient portal to send a message to a doctor, view lab test results, order a prescription refill, or make an appointment ≥1 time in 2013, %							
All members							
	65-79	59.5	64.2	32.9[b]	41.4[b]	38.8[b]	67.3[b]
	65-69	65.9	70.8	39.6[b]	47.7[b]	45.3[b]	72.7
	70-74	61.7[c]	66.6[c]	34.3[b,c]	42.8[b,c]	39.3[b,c]	70.1[b]
	75-79	51.9[c]	56.3[c]	26.3[b,c]	35.1[b,c]	32.3[b,c]	60.3[c,e]
Members registered to use the patient portal for at least part of 2013							
	65-79	77.1	79.1	60.9[b]	66.2[b]	64.1[b]	82.6[b]
	65-69	80.1	82.0	64.7[b]	71.2[b]	69.3[b]	84.4
	70-74	78.5[c]	80.6 [c]	62.0[b]	67.2[b,d]	64.3[b]	83.8[b]
	75-79	72.6[c]	74.6 [c]	55.7[b,c]	60.7[b,c]	58.5[b,c]	79.8[b,c]
Sent a secure message through the patient portal ≥1 time in 2013, %							
All members							
	65-79	46.3	50.8	23.3[b]	30.1[b]	26.1[b]	49.1
	65-69	52.3	56.9	29.4[b]	35.2[b]	31.9[b]	54.2
	70-74	48.1[c]	52.8[c]	24.1[b,c]	31.1[b,c]	26.5[b,c]	52.0
	75-79	39.7[c]	43.7[c]	17.9[b,c]	25.4[b,c]	20.4[b,c]	42.2[c]
Members registered to use the patient portal for at least part of 2013							
	65-79	60.1	62.6	43.1[b]	48.2[b]	43.1[b]	60.3[b]
	65-69	63.5	66.0	47.9[b]	52.5[b]	48.8[b]	63.0
	70-74	61.3[b]	63.9[b]	43.6[b,c]	48.8[c]	43.3[b,c]	62.1
	75-79	55.5[b]	57.9[b]	37.9[b,c]	44.0[b,c]	36.9[b,c]	55.8[c]
Viewed lab test results using the patient portal ≥1 time in 2013, %							
All members who had ≥1 lab test in 2013							

Use of the patient portal in 2013	Age	All	Non-Hispanic white	Black	Latino	Filipino	Chinese
	65-79	62.8	68.0	33.9[b]	42.7[b]	40.0[b]	69.1
	65-69	69.2	74.5	40.5[b]	49.6[b]	47.8[b]	74.6
	70-74	64.6[c]	69.9[c]	35.0[b,c]	44.1[b,c]	40.3[b,c]	71.7
	75-79	55.6[c]	60.6[c]	27.6[b,c]	36.0[b,c]	32.7[b,c]	62.2[c]
Members who had ≥1 lab test in 2013 and were registered to use the patient portal during at least part of 2013							
	65-79	79.6	82.1	60.6[b]	66.5[b]	64.1[b]	83.6
	65-69	82.4	84.8	63.7[b]	71.4[b]	70.2[b]	85.7
	70-74	80.6[c]	83.0 [c]	61.3[c]	67.6[b,d]	64.3[b,c]	84.9
	75-79	75.7[c]	78.3 [c]	56.4[b,c]	60.9[b,c]	57.3[b,c]	80.3[c]
Ordered a prescription refill using the patient portal ≥1 time in 2013, %							
All members who refilled ≥1 prescription in 2013							
	65-79	35.0	38.6	16.5[b]	21.2[b]	18.5[b]	37.0
	65-69	42.1	46.5	21.2[b]	26.6[b]	22.9[b]	44.4
	70-74	36.5[c]	40.4[c]	17.5[b,c]	21.8[b,c]	18.1[b,c]	38.4
	75-79	28.1[c]	31.0[c]	11.9[b,c]	16.9[b,c]	15.5[b,c]	31.1[c]
Members who refilled ≥1 prescription in 2013 and were registered to use the patient portal at least part of 2013							
	65-79	44.3	46.6	29.3[b]	33.0[b]	29.7[b]	44.8
	65-69	49.9	52.6	32.9[b]	38.0[b]	33.8[b]	50.8
	70-74	45.4[c]	47.8[c]	30.5[b]	33.3[b,d]	28.7[b,c]	45.2[d]
	75-79	38.3[c]	40.0[c]	24.3[b,c]	28.8[b,c]	27.1[b,c]	40.3[c]

[a] Cell percentages represent use among adults in that age, race/ethnic, or age-race/ethnic subgroup. The denominator for cell percentages in the “All” column includes all non-Hispanic white, black, Latino, Filipino, and Chinese members in that age group. See Multimedia Appendix 1 for cell denominators. Due to the very large denominators for all cells, comparisons with *P* values ≥.055 are not reported. See Multimedia Appendix 3 for detailed *P* values.

[b] Significantly differs (*P*<.001) from non-Hispanic whites within same age group after controlling for sex.

[c] Significantly differs (*P*<.01) from 65-69 age group within All or within same race/ethnic group after controlling for sex.

[d] Significantly differs (*P*<.01) from non-Hispanic whites within same age group after controlling for sex.

[e] Significantly differs (*P*<.05) from non-Hispanic whites in same age group after controlling for sex.

Table 2. Differences by age cohort and race/ethnic group in use of the health plan's patient portal in 2013 among patients ages 65-79 who have diabetes, hypertension, and/or coronary artery disease[a].

Use of the patient portal in 2013	Age	All	Non-Hispanic white	Black	Latino	Filipino	Chinese
Was registered to use the patient portal by end of 2013, %							
	65-79	76.9	81.5	55.2[b]	63.0[b]	61.9[b]	82.0
	65-69	82.2	86.8	63.5[b]	68.3[b]	67.3[b]	87.9
	70-74	78.5[b]	83.3[c]	56.2[b,c]	64.6[b,d]	62.7[b,c]	83.7[d]
	75-79	71.9[b]	76.5[c]	48.4[b,c]	57.9[b,c]	56.3[b,c]	77.0[c]
Used the patient portal to send a secure message to a doctor, view lab test results, order a prescription refill, or make an appointment ≥1 time in 2013, %							
	65-79	63.3	69.2	36.2[b]	44.5[b]	42.8[b]	71.7[e]
	65-69	70.3	76.7	44.1[b]	51.4[b]	50.5[b]	78.6
	70-74	65.4[b]	71.6[c]	37.2[b,c]	46.4[b,c]	43.2[b,c]	74.6[e,f]
	75-79	56.6[b]	61.9[c]	29.9[b,c]	38.2[b,c]	35.8[b,c]	64.9[b]
Sent a secure message through the patient portal ≥1 time in 2013, %							
	65-79	49.3	54.8	25.8[b]	32.6[b]	28.7[b]	52.8[e]
	65-69	56.0	62.2	32.5[b]	38.2[b]	35.5[b]	59.6
	70-74	51.2[b]	57.0[c]	26.6[b,c]	34.1[b,g]	29.2[b,c]	56.6
	75-79	43.0[b]	47.9[c]	20.4[b,c]	27.6[b,c]	22.4b[b,c]	45.1[c,g]

[a] Study population for this table is members who were in a health plan diabetes, hypertension, or coronary artery disease registry in 2013. Cell percentages represent use among adults in that age, race/ethnic, or age-race/ethnic subgroup. The denominator for cell percentages in the "All" column includes all non-Hispanic white, black, Latino, Filipino, and Chinese members in that age group. See Multimedia Appendix 1 for cell denominators. Due to the large denominators for all cells, comparisons with *P* values ≥.055 are not reported. See Multimedia Appendix 3 for detailed *P* values.

[b] Significantly differs (*P*<.001) from non-Hispanic white within same age group after controlling for sex.

[c] Significantly differs (*P*<.001) from 65-69 age group within All or within same race/ethnic group after controlling for sex.

[d] Significantly differs (*P*<.01) from 65-69 age group within All or within same race/ethnic group after controlling for sex.

[e] Significantly differs (*P*<.05) from non-Hispanic white within same age group after controlling for sex.

[f] Significantly differs (*P*<.05) from 65-69 age group within All or within same race/ethnic group after controlling for sex.

[g] Significantly differs (*P*<.01) from non-Hispanic white within same age group after controlling for sex.

The full respondent sample, after weighting, was predominantly non-Hispanic white (79.4%) and aged 70-74 (43.7%) (see Table 3). The age group composition of all five race/ethnic groups and the race/ethnic composition of all three age groups were nearly identical to those of the full sample. About 40% of the full sample was college educated, with an additional 33.7% having attended at least some college. Based on 2011 survey data for the same health plan population, 30.3% would be expected to be low income by community standards (household income ≤US $35,000/year), and 27.7% to have a household income >US $80,000/year. Most considered their health to be "good" or better, with only 18.1% rating their health "fair" or "poor." Slightly over 70% had been diagnosed with a chronic cardiovascular condition (ie, in a diabetes, hypertension, or coronary artery disease registry), and 90% reported taking at least one prescription medication for a chronic condition.

Significant differences across age and race/ethnic groups were observed for educational attainment, income, and health status. Compared with 65-69 year olds, those aged 70-74 and 75-79 were significantly less likely to be college graduates and significantly more likely to be low income. Compared with non-Hispanic white seniors, black and Latino seniors were significantly less likely to be college graduates, whereas Filipino and Chinese seniors were significantly more likely to have college degrees. Nearly one-fourth (22.0%) of Latinos did not graduate from high school, compared with around 4% of the other race/ethnic groups. Black, Latino, and Filipino seniors were significantly more likely than non-Hispanic white seniors to be in the low-income group and significantly less likely to be in the higher income group, whereas the income distribution of Chinese seniors did not significantly differ from that of non-Hispanic white. Seniors aged 75-79 were significantly more likely to consider their health to be fair or poor than those in the younger groups, and black, Latino, and Filipino seniors were significantly more likely than non-Hispanic white seniors to consider themselves to have fair or poor health and to have cardiovascular conditions.

Table 3. Characteristics of survey respondents, after weighting, by age group and race/ethnicity[a] .

	All, %	By age group, %			By race/ethnicity,%				
	65-79 (N=2602)	65-69 (n=841)	70-74 (n=878)	75-79 (n=883)	Non-Hispanic white (n=849)	Black (n=567)	Latino (n=653)	Filipino (n=219)	Chinese (n=314)
Age group									
65-69	23.5	n/a	n/a	n/a	23.4	23.6	23.6	25.6	23.1
70-74	43.7	n/a	n/a	n/a	43.8	43.3	42.3	45.0	42.0
75-79	32.8	n/a	n/a	n/a	32.8	33.1	34.1	29.4	34.9
Sex									
Women	54.1	53.8	53.9	54.5	53.8	56.9	54.8	57.1	48.2
Men	45.9	46.2	46.1	45.5	46.2	43.1	45.2	42.9	51.8
Race/ethnicity									
Non-Hispanic white	79.4	79.0	79.6	79.5	n/a	n/a	n/a	n/a	n/a
Black	7.3	7.3	7.3	7.4	n/a	n/a	n/a	n/a	n/a
Hispanic/Latino	5.4	5.4	5.2	5.6	n/a	n/a	n/a	n/a	n/a
Filipino	5.2	5.6	5.3	4.6	n/a	n/a	n/a	n/a	n/a
Chinese	2.7	2.7	2.6	2.9	n/a	n/a	n/a	n/a	n/a
Educational attainment									
Non-high school graduate	5.0	3.2	3.1	8.9[b]	3.9	4.7	22.0[c]	4.7	4.1
High school graduate/GED[d]	21.3	14.5	19.9	28.1	21.0	25.2	31.0	14.1	14.3
Some college	23.8	33.4	36.1	30.8	34.2	45.0	27.8	22.7	24.6
College graduate	39.9	48.9	40.9[e]	32.2[b]	40.9	25.0[c]	19.2[c]	58.4[c]	57.0[c]
Household income in US $ in 2010 [d]									
≤25,000	17.7	11.9	18.7[b]	26.7[b]	15.8	26.1[c]	22.3[c]	29.3[c]	16.8
25,001-35,000	12.6	10.0	13.2	16.5	11.9	16.3	17.5	17.5	8.7
35,001-80,000	42.0	42.9	42.6	39.6	42.1	39.7	43.9	43.9	41.3
>80,000	27.7	35.2	25.5[b]	17.2[b]	30.2	17.8[c]	16.3[c]	16.3[c]	33.3
Self-rated health									
Very good or excellent	43.8	49.7	46.8	35.6[b]	48.3	21.2[c]	28.0[c]	25.9 [c]	38.9[g]
Good	38.1	34.8	38.2	40.2	35.9	48.8	39.9	49.7	44.8
Fair or poor	18.1	15.5	15.0	24.2[b]	15.8	30.0[c]	32.1[c]	24.4[g]	16.3
History of diabetes, hypertension, coronary artery disease, heart failure, or stroke[h]	71.7	62.1	70.3[e]	80.6[b]	69.0	87.4[c]	77.8[c]	86.5[c]	70.5
Takes medication for ≥1 chronic condition	90.5	87.2	90.3	93.3[i]	89.9	95.4[c]	90.7	94.9[j]	86.8

[a] Cell percentages are based on weighted data for everyone in that age or race/ethnic group. Ns at the top of columns are the unweighted number of respondents in that group. *P* values ≥.055 are not reported. See Multimedia Appendix 3 for detailed *P* values.

[b] Significantly differs ($P<.001$) from 65-69 age group after controlling for race/ethnicity and sex.

[c] Significantly differs ($P<.001$) from non-Hispanic white after controlling for age group and sex.

[d] GED=General Educational Development (credential indicating that an individual has met high school level academic skills).

[e] Significantly differs ($P<.05$) from 65-69 age group after controlling for race/ethnicity and sex.

[f] Based on estimates from a 2011 health survey of the same health plan membership. A household income ≤$35,000 qualifies an individual for income-subsidized, low income housing.

[g] Significantly differs ($P<.01$) from non-Hispanic white after controlling for age group and sex.

[h] In ≥1 of the health plan’s chronic disease registries for these conditions.

[i] Significantly differs (P<.01) from 65-69 age group after controlling for race/ethnicity and sex.

[j] Significantly differs (P<.05) from non-Hispanic white after controlling for age group and sex.

Seniors’ Access to Digital Technology

Although 81% of seniors aged 65-79 had a mobile phone, less than one-third (31.2%) had a smartphone, and less than half (47.2%) were able to send and receive text messages (see Table 4). Seniors ages 75-79 were less likely to have smartphones and text messaging capabilities than younger seniors. Among those seniors who had smartphones, over three-fourths were using apps. Over 80% (81.5%) of seniors had access to a desktop, laptop, or netbook computer. Fewer of the seniors had a tablet, and most tablet and smartphone owners (>90%) also had a desktop or laptop computer. Access to these devices declined with increasing age, and across all age groups, black, Latino, and Filipino seniors were significantly less likely than non-Hispanic white seniors to have these digital devices. Access to Internet at home also varied among the race/ethnic groups and declined with age across all of the race/ethnic groups. Of those who did not have home Internet, approximately 34.9% said that this was due to the cost.

Ability to Use the Internet

Ability to use the Internet to get health information from websites or to communicate with others significantly differed by race/ethnicity and age (see Table 4). Approximately 80% of non-Hispanic white (83.9%) and Chinese (79.2%) seniors reported being able to use the Internet alone or with some help, as compared with 64.4% of black, 58.2% of Latino, and 53.2% of Filipino seniors. A similar spread of approximately 20 percentage points was observed between 65-69 year olds and 75-79 year olds. Slightly over 10% of these Internet users required help or someone else to go online for them. Overall, 7.9% of seniors said they had a physical problem that made it difficult for them to use a computer or the Internet, but this was more of an issue for the 75-79 age group (12.4% vs 5.6% of 65-74 year olds) and for non-Hispanic whites (11.4% of blacks, 11.8% of Latinos, and 16.3% Filipinos versus 6.7% of non-Hispanic whites). Nearly all (>95%) of seniors who use the Internet do so at home using a computer, although significantly higher percentages of Latino and Filipino seniors than non-Hispanic whites (but still under 10%) only do so using a mobile device (tablet, smartphone, or cellular phone). Black, Latino, and Filipino seniors who went online did so less frequently than non-Hispanic whites. Chinese seniors did not significantly differ from non-Hispanic whites in frequency of Internet use.

Ability to Use Email

Whereas 80% of non-Hispanic white and Chinese seniors were able to send and receive email, only approximately 60% of black, Filipino, and Latino seniors were able to do so, even with help (see Table 4). Among those who used email, approximately 83.8% had their own email address and 16.2% used a shared email address or someone else’s email address. Over 90% (93.6%) of email users checked their email using a computer, laptop, or netbook, and 36.8% of email users at least sometimes used a mobile device (tablet, smartphone, or cellular phone) to access email. Only 6.2% of seniors solely used a mobile device, with no significant differences by age group or race/ethnicity. Seniors aged 65-74 were significantly more likely than 75-79 year olds to access email at least sometimes using a smartphone (27.5% vs 12.3%; P<.001), and blacks, Latinos, and Filipinos were significantly more likely than non-Hispanic whites (10.3%, 5.0%, 15.1% vs 1.8%, respectively; P<.01) to access email using a cellular phone at least some of the time. Approximately two-thirds (67.9%) of all email users checked their email at least once a day. Nearly one-fourth (23.5%) of black, Latino, and Filipino email users checked their email once a week or less.

Ability to Perform Health Care–Related Tasks Using Digital Technology

Nearly two-thirds (64.2%) of seniors thought that they could use the patient portal on their own to send a secure message to their doctor or to look up a lab test result, 60.6% thought they could print out information or forms from a website, and 50.9% thought they could get to a website to get information or forms if given a URL verbally or in print (see Table 5). Whereas 65.4% thought they could complete a questionnaire on a computer by themselves, only 52.1% thought they could complete a questionnaire by interactive voice response (IVR) administration and 35.2% by using a touchscreen tablet at the clinic. These percentages increased by only 10-14 percentage points when we also included those who said they could do these tasks with some help. Across all of these tasks, seniors in the two older age groups were significantly less likely than 65-69 year olds to indicate being able to perform these tasks alone or with help. Similarly, black, Latino, and Filipino seniors were significantly less likely than non-Hispanic white seniors to say they could perform these tasks alone or with help, with many differences greater than 15 percentage points. Chinese seniors did not differ from non-Hispanic white seniors.

Seniors’ Use of and Preference for Using the Patient Portal and Digital Technologies for Health Care–Related Tasks

Seniors were presented with five health care–related tasks that could be carried out using the patient portal and asked to indicate which of the methods listed they currently used or were willing to use and which method they most preferred to use. They were also asked how they preferred to receive information about health care benefits and health newsletters. Finally, they were asked how they would like to get health information and advice, in addition to getting this information directly from their doctor and other clinicians.

Table 4. Seniors' access to digital devices, Internet, and email, by age group and race/ethnicity[a].

	All	By age group			By race/ethnicity				
	65-79 (N=2602)	65-69 (n=841)	70-74 (n=878)	75-79 (n=883)	Non-Hispanic white (n=849)	Black (n=567)	Latino (n=653)	Filipino (n=219)	Chinese (n=314)
Has access to a mobile phone (cellular phone or smartphone), %	81.0	88.4	84.3	71.2[b]	82.2	82.8	72.6[c]	70.2[c]	77.0
Has a smartphone	31.2	43.4	33.9[d]	18.7[b]	32.8	30.5	22.0[c]	19.6[c]	26.6[e]
Able to receive text messages	47.2	61.5	51.4[d]	31.4[b]	47.4	53.6[f]	41.0[f]	45.1	54.9
If has a mobile phone	60.5	71.2	63.1[g]	46.5[b]	60.5	59.6	68.4[h]	59.9	67.0
Owns or has easy access to a computer, laptop, netbook, or tablet, %	81.5	91.5	82.5[b]	73.1[b]	85.3	70.7[c]	63.0[c]	57.5[c]	82.8
Desktop, laptop, or netbook	79.5	90.4	80.0[b]	71.2[b]	83.5	69.1[c]	61.1[c]	53.1[c]	79.8
Tablet	25.1	34.3	27.4[g]	15.6[b]	27.1	16.0[c]	12.6[c]	20.1[f]	28.3
Has home Internet	83.8	91.3	85.5[d]	76.2[b]	87.4	71.9[g]	68.4[h]	61.0[c]	84.8
Able to use the Internet, %									
Able to use on own or with help	79.4	88.9	81.5[b]	68.7[b]	83.9	64.4[c]	58.2[c]	53.3[c]	79.2
Uses on own	69.4	80.7	70.8[b]	59.4[b]	74.4	51.8[c]	48.0[c]	39.3[c]	69.4
Uses with help or proxy uses	10.0	8.2	10.7	10.3	9.5	12.6	10.2	14.0	9.8
If uses the Internet, how frequently goes online	(n=1886)	(n=707)	(n=637)	(n=542)	(n=714)	(n=390)	(n=410)	(n=125)	(n=247)
Daily	64.2	70.0	64.3	58.8[d]	66.2	51.1[c]	53.7[c]	47.2[c]	66.0
≤1x/wk	16.6	16.7	16.7	18.8	15.1	28.3[c]	25.8[c]	26.2[f]	14.4
Able to use email, %	(n=2594)	(n=839)	(n=876)	(n=879)	(n=848)	(n=565)	(n=650)	(n=217)	(n=314)
Able to use by self or with help	79.3	86.1	81.2[g]	72.1[b]	83.4	63.2[c]	59.6[c]	58.5[c]	80.8
Uses on own	70.0	80.2	71.9[g]	60.3[b]	74.7	52.6[c]	49.1[c]	43.0[c]	72.6
Uses with help or proxy uses	9.3	5.9	9.3	11.8[d]	8.8	10.6	10.6	15.6[h]	8.2
Has an email address	76.2	82.4	78.4	68.6[b]	80.5	60.0[c]	57.9[c]	51.3[c]	76.3
Has own email address	63.8	68.5	66.3	57.2[b]	67.3	51.2[c]	48.2[c]	42.6[c]	65.7
Shares an email address (may also have own)	11.3	13.5	11.4	9.5	13.0	6.2[c]	6.9[c]	4.9[h]	8.2[f]
Uses someone else's email address	1.8	1.4	1.7	2.2	1.4	3.1[f]	3.6[f]	3.7[f]	2.4
If receives email, how frequently checks for email	(n=1866)	(n=682)	(n=630)	(n=554)	(n=699)	(n=377)	(n=420)	(n=124)	(n=246)
Daily	67.9	70.4	68.6	64.8	70.0	49.5[c]	59.5[c]	56.4[h]	70.5
≤1x/wk	13.8	12.4	12.2	17.4	12.3	24.6[c]	22.9[c]	22.2[f]	13.7

[a] Cell percentages based on weighted data for everyone in that age or race/ethnic group. Ns at top of columns are the unweighted number of respondents in that group except when analyses are restricted to a subset of that group. *P* values ≥.055 are not reported. See Multimedia Appendix 3 for detailed *P* values.

[b] Significantly differs (*P*<.001) from 65-69 age group after controlling for race/ethnicity and sex.

[c] Significantly differs (*P*<.001) from non-Hispanic white after controlling for age group and sex.

[d] Significantly differs (*P*<.01) from 65-69 age group after controlling for race/ethnicity and sex.

[e] Significantly differs (*P*=.053) from non-Hispanic white after controlling for age group and sex.

[f] Significantly differs (*P*<.05) from non-Hispanic white after controlling for age group and sex.

[g] Significantly differs (*P*<.05) from 65-69 age group after controlling for race/ethnicity and sex.

[h] Significantly differs (*P*<.01) from non-Hispanic white after controlling for age group and sex.

Table 5. Seniors' perceptions of their ability to perform health care–related tasks involving digital technology[a].

Task	All	By age group			By race/ethnicity				
	65–79 (N=2586)	65-69 (n=837)	70-74 (n=875)	75-79 (n=874)	Non-Hispanic white (n=847)	Black (n=562)	Latino (n=648)	Filipino (n=218)	Chinese (n=311)
Send a message to doctor through the patient portal if had a question, %									
Could do by self	64.2	76.1	66.3[b]	52.9[c]	68.6	47.2[d]	44.3[d]	40.9[d]	63.3
Could do by self or with help	79.7	88.2	81.7[b]	71.1[c]	82.9	67.2[d]	63.6[d]	66.1[d]	79.6
Look up test result on the patient portal, %									
Could do by self	64.5	76.4	66.8[b]	52.8[c]	69.0	45.7[d]	43.6[d]	40.2[d]	68.2
Could do by self or with help	78.4	87.3	80.5[b]	69.2[c]	81.9	63.8[d]	60.6[d]	61.2[d]	82.6
Complete a short form or questionnaire on a computer, %									
Could do by self	65.4	76.0	68.9[b]	53.2[c]	69.4	51.2[d]	45.3[d]	45.0[d]	67.2
Could do by self or with help	76.4	86.1	78.9[b]	66.3[c]	79.8	63.3[d]	59.3[d]	58.4[d]	79.7
Complete a questionnaire using a touch screen tablet (such as an iPad) while sitting in a clinic waiting room, %									
Could do by self	35.2	51.4	38.1[c]	20.0[c]	37.6	28.1[d]	23.0[d]	21.6[d]	34.3
Could do by self or with help	45.9	63.5	49.3[c]	28.7[c]	47.7	40.6[e]	34.6[d]	36.1[f]	47.4
Answer questions about your health using your phone's keypad (eg, Enter 1 if Always, 2 if Sometimes, 3 if Never), %									
Could do by self	52.1	62.5	55.0[g]	41.0[c]	54.6	49.4	37.8[d]	34.5[d]	50.3
Could do by self or with help	59.3	70.9	61.3[b]	48.5[c]	61.0	57.3	46.2[d]	50.9[e]	59.5
Go to a website to get information or forms using a URL (website address) given orally or in a letter, %									
Could do by self	50.9	66.9	52.1[c]	38.0[c]	55.2	37.9[d]	30.4[d]	24.3[d]	51.3
Could do by self or with help	60.2	75.3	61.8[c]	47.4[c]	63.3	49.6[d]	42.6[d]	42.9[d]	65.2
Print information or forms from a website, %									
Could do by self	60.6	72.0	63.2[b]	48.8[c]	65.3	46.2[d]	39.2[d]	30.8[d]	60.7
Could do by self or with help	70.4	81.7	72.3[c]	59.9[c]	74.0	58.1[d]	50.8[d]	50.8[d]	74.3

[a] Cell percentages are based on weighted data for everyone in the age or race/ethnic group. *P* values ≥.055 are not reported. See Multimedia Appendix 3 for detailed *P* values. Ns at top of columns are the unweighted number of respondents in that group.

[b] Significantly differs (*P*<.01) from 65-69 age group after controlling for race/ethnicity and sex.

[c] Significantly differs (*P*<.001) from 65-69 age group after controlling for race/ethnicity and sex.

[d] Significantly differs (*P*<.001) from non-Hispanic white after controlling for age group and sex.

[e] Significantly differs (*P*<.05) from non-Hispanic white after controlling for age group and sex.

[f] Significantly differs (*P*<.01) from non-Hispanic white after controlling for age group and sex.

[g] Significantly differs (*P*<.05) from 65-69 age group after controlling for race/ethnicity and sex.

Overall, over half (58.2%) of seniors said they send secure messages to their doctors in non-urgent situations, approximately the same percentage as communicates by phone (see Table 6). Over half (54.4%) used the patient portal to view their lab test results online, which rose to 66.7% when getting results in a secure message was included in that calculation. Significantly lower percentages of seniors used or said they would be willing to use the patient portal to order prescription refills (35.7%), to get appointment reminders via secure message (24.3%), or to complete health assessment questionnaires (49.1%). One-third of seniors said they would definitely (18.0%) or possibly (15.8%) be interested in having video visits with their doctors when the doctor did not feel it was necessary for them to be seen in person (see Figure 1).

Table 6. Methods used and preferred for performing tasks that could be done through the patient portal[a].

	All	By age group			By race/ethnicity				
	65-79	65-69	70-74	75-79	Non-Hispanic white	Black	Latino	Filipino	Chinese
Initiate non-urgent communications with doctors	(N=2534)	(n=822)	(n=858)	(n=854)	(n=826)	(n=555)	(n=628)	(n=215)	(n=310)
Send a secure message using the patient portal, %									
Uses this method	58.2	70.0	58.7[b]	48.8[b]	63.6	33.8[c]	36.6[c]	32.2[c]	55.6[d]
Most prefers this method	51.8	63.9	53.8[e]	40.5[b]	57.7	25.2[c]	29.0[c]	25.0[c]	46.7[f]
Send a message using regular email (discouraged), %									
Uses this method	8.2	8.5	9.8	6.0	8.1	7.0	7.3	10.1	14.5[f]
Most prefers this method	4.8	3.5	6.4	3.5	4.9	3.3	4.4	3.3	7.5
Leave phone message and get return call, %									
Uses this method	53.7	48.0	50.0	62.6[b]	48.8	76.9[c]	71.3[c]	75.9[c]	58.0[d]
Most prefers this method	43.5	32.9	39.9[g]	56.0[b]	37.5	71.6[c]	67.0[c]	72.7[c]	45.8[d]
Obtain results of lab tests	(N=2594)	(n=838)	(n=874)	(n=882)	(n=847)	(n=566)	(n=649)	(n=219)	(n=313)
Look up results online using the patient portal, %									
Uses this method	54.4	64.9	55.4[e]	45.5[b]	58.8	31.1[c]	36.3	33.5[c]	63.6
Most prefers this method	38.9	47.3	41.2	30.1[c]	42.9	21.4[c]	21.4[c]	15.6[c]	45.7
Result sent in a secure message using the patient portal, %									
Uses this method	32.9	35.7	35.1	27.8[g]	34.2	25.0[c]	26.1[f]	32.7	28.2
Most prefers this method	19.1	19.6	20.4	17.2	20.4	11.1[c]	15.1[d]	19.6	10.7[c]
Look up results online or get in secure message using the patient portal, %									
Uses this method	66.6	74.4	69.3	57.5[b]	70.8	43.6[c]	48.4[c]	51.6[c]	71.4
Most prefers this method	57.9	66.8	61.2	47.3[c]	63.1	32.3[c]	36.3[c]	35.2[c]	56.5
Get a letter in the mail with the result, %									
Uses this method	51.8	48.6	50.3	56.0[g]	47.9	71.2[c]	66.3[c]	68.3[c]	53.6
Most prefers this method	35.6	28.7	33.1	44.0[c]	30.5	57.6[c]	54.0[c]	63.2[c]	40.4[f]
Have someone from call with the result, %									
Uses this method	18.4	16.7	17.1	21.4	17.7	27.9[c]	22.1	15.1	13.5
Most prefers this method	7.3	5.1	6.5	9.9[g]	7.1	10.5	11.0[g]	3.9	3.8
Order prescription refills [h]	(N=2258)	(n=715)	(n=764)	(n=779)	(n=731)	(n=521)	(n=561)	(n=187)	(n=258)
Place order online using the patient portal, %									
Uses this method	35.7	45.0	39.1	24.8[b]	39.7	20.0[c]	22.1[c]	12.8[c]	36.1
Most prefers this method	33.5	42.3	37.4	21.7[b]	37.2	16.3[c]	19.8[c]	12.2[c]	34.3
Place order by phone, %									
Uses this method	63.3	58.5	59.5	71.6[b]	61.4	70.8[f]	72.3[c]	72.7[f]	59.0
Most prefers this method	57.2	51.2	53.3	66.9[b]	55.9	61.8	64.5[f]	67.5[d]	52.8
Place order in person at the pharmacy, %									
Uses this method	20.6	18.9	19.8	23.0	17.3	37.0[c]	31.3[c]	32.6[c]	26.0[f]

	All	By age group			By race/ethnicity				
	65-79	65-69	70-74	75-79	Non-Hispanic white	Black	Latino	Filipino	Chinese
Most prefers this method	9.5	6.5	9.7	11.4[g]	7.1	22.4[c]	16.1[c]	20.9[c]	12.9[d]
Get reminders about appointments, immunizations, etc.	(N=2586)	(n=835)	(n=871)	(n=880)	(n=843)	(n=565)	(n=646)	(n=218)	(n=314)
Get a secure message using the patient portal, %									
Uses this method	24.3	29.2	24.4	20.6[e]	26.6	16.0[c]	16.7[c]	9.5[c]	20.6
Most prefers this method	9.4	11.5	9.0	8.5	10.4	6.4[d]	6.0[d]	2.5[d]	8.9
Get a regular email, %									
Uses this method	44.8	54.1	48.9	32.8[b]	48.9	28.4[c]	26.2[c]	24.7[c]	44.7
Most prefers this method	29.2	33.6	35.1	18.3[b]	33.0	12.3[c]	13.3[c]	9.3[c]	25.4[d]
Get an automated phone message from a computer system, %									
Uses this method	39.2	41.8	41.3	34.5	39.7	45.0	40.3	25.6[c]	34.0
Most prefers this method	13.4	14.8	14.3	11.3	13.2	18.2[c]	18.7[d]	6.5[d]	11.7
Get a letter/postcard sent by regular mail, %									
Uses this method	67.8	61.9	65.4	75.1[g]	65.1	78.6[d]	75.2[c]	85.1[c]	68.6
Most prefers this method	47.8	39.5	41.1	62.4[b]	43.2	63.5[c]	62.8[c]	80.5[c]	54.9[f]
Use the Kaiser Permanente preventive care app, %									
Uses this method	5.2	6.4	6.7	2.4[e]	5.3	5.7	4.1	5.3	3.6
Most prefers this method	0.8	0.6	1.5	0.1	0.8	1.2	0.3	1.2	0.5
Complete health questionnaires	(N=2570)	(n=832)	(n=862)	(n=876)	(n=839)	(n=560)	(n=643)	(n=216)	(n=312)
Online questionnaire accessed via the patient portal, %									
Uses this method	49.1	59.1	52.0[g]	38.2[b]	54.5	28.3[c]	27.4[c]	21.1[c]	41.6[c]
Most prefers this method	35.1	42.3	39.3	24.2[b]	39.3	19.1[c]	18.6[c]	12.8[c]	27.8[c]
Touchscreen tablet or computer at medical facility, %									
Uses this method	7.4	11.5	7.9	3.6[b]	7.8	6.7	5.1[d]	3.9[d]	6.3
Most prefers this method	1.3	1.8	2.0	<0.1	1.5	<0.1	0.8	0.3	0.9
IVR questionnaire [i], %									
Uses this method	12.5	11.5	13.3	12.1	12.6	17.1[d]	10.3	7.8	10.0
Most prefers this method	2.0	2.5	1.6	2.2	1.9	3.5	2.4	2.2	1.3
Paper (print) questionnaire, %									
Uses this method	77.2	70.4	76.1	83.5[b]	75.3	85.0[c]	83.1[c]	87.4[c]	79.3
Most prefers this method	56.6	50.1	52.4	67.0[b]	52.2	71.4[c]	71.1[c]	82.4[c]	66.6[c]
Interviewer administered, %									
Uses this method	18.5	13.2	18.8[g]	21.7[e]	18.3	24.0[d]	21.4	12.4	12.9

	All	By age group			By race/ethnicity				
	65-79	65-69	70-74	75-79	Non-Hispanic white	Black	Latino	Filipino	Chinese
Most prefers this method	5.5	3.9	5.3	7.0	5.4	6.6	8.7[d]	3.2	3.4

[a] Most preferred method restricted to people who indicated only one method or a most preferred method if >1 method was indicated. Cell percentages are based on weighted data for everyone in the age or race/ethnic group. Ns at top of columns are the unweighted number of respondents in that group. *P* values ≥.055 are not reported. See Multimedia Appendix 3 for detailed *P* values.

[b] Significantly differs (*P*<.001) from 65-69 age group after controlling for race/ethnicity and sex.

[c] Significantly differs (*P*<.001) from non-Hispanic white after controlling for age group and sex.

[d] Significantly differs (*P*<.05) from non-Hispanic white after controlling for age group and sex.

[e] Significantly differs (*P*<.01) from 65-69 age group after controlling for race/ethnicity and sex.

[f] Significantly differs (*P*<.01) from non-Hispanic white after controlling for age group and sex.

[g] Significantly differs (*P*<.05) from 65-69 age group after controlling for race/ethnicity and sex.

[h] Restricted to seniors who take medications for a chronic condition and do not rely totally on others to order their prescription refills.

[i] "By phone using the phone keypad to enter answers to questions read by a nice taped voice."

Half of seniors were willing to get information about health care benefits (50.9%) or health newsletters (54.5%) by email (see Table 7). We found significant age and race/ethnic group differences in use of or willingness to use the patient portal or other digital technologies to conduct the five health care–related tasks (see Table 6) that paralleled some subgroup differences in perceived ability to perform these tasks (see Table 5). Older seniors were less likely to use or be willing to use the patient portal to perform some or all of these tasks than those 65-69 years old and were also significantly less willing to use video visits. For all five patient portal tasks, black, Latino, and Filipino seniors were significantly less likely than non-Hispanic whites to use or be willing to use the patient portal features instead of more traditional methods of communicating information and were also significantly less likely to be interested in video visits (see Table 6 and Figure 1). Chinese seniors were significantly less likely than non-Hispanic whites to use secure messaging and online questionnaire completion, but these differences were smaller than those of the other race/ethnic groups, and they did not differ from non-Hispanic whites on willingness to use video visits. Overall, seniors were significantly less willing to receive information about health care benefits via email or by automated calls than regular mail (50.9% and 9.4% vs 76.7%) or to get health newsletters by email versus regular mail (54.5% vs 65.9%) (see Table 7).

Of those who indicated use of any method for these health care tasks and communications, approximately 90% of seniors indicated a preferred method for communicating with doctors, ordering prescription refills, and completing health questionnaires. Around 80% had a preferred method for obtaining lab test results or receiving reminders. All indicated a health communications preference. Although seniors aged 65-69 and 70-74 were significantly more likely to prefer secure messaging with their doctor than leaving a phone message, the reverse was true for 75-79 year olds. Similarly, non-Hispanic white seniors were significantly more likely to prefer secure messaging over use of the phone, but black, Latino, and Filipino seniors were significantly more likely to prefer phone calls over secure messaging, with Chinese seniors equally split between these two options. A similar demographic pattern was observed for viewing lab test results online versus receiving them in a mailed letter. Seniors aged 65-69 were significantly more likely to order prescription refills online than by phone, but the opposite was true for the two older groups and for all race/ethnic groups. All age and race/ethnic groups significantly preferred getting reminders by regular email rather than in a secure message that required them to sign into the patient portal. With respect to completion of health questionnaires, seniors in the two older age groups and in all race/ethnic groups significantly preferred to use a print versus an online questionnaire accessed by the patient portal. Combining online and facility-based touchscreen tablet data entry (both of which enable real-time direct flow of member data into the electronic medical record) resulted in very little increase in the percentages that preferred digital questionnaires. Across all age and race/ethnic groups, seniors preferred getting health care benefit information and newsletters by regular mail than by email. Seniors in the oldest age group were significantly (*P*<.001) more likely than those in the younger groups to say they wanted to get health benefits information only by regular mail, not email (60.6% vs 40.1% and 44.9%, respectively), as were blacks (63.6%), Latinos 64.6%, and Filipinos (68.9%) compared to non-Hispanic whites (45.1%). The same differences were seen for newsletters (data not shown).

Table 7. Methods seniors are willing to use and would prefer for receiving newsletters and benefits information[a].

	All	By age group			By race/ethnicity				
	65-79	65-69	70-74	75-79	Non-Hispanic white	Black	Latino	Filipino	Chinese
Get information about benefits or other topics related to your health	(N=2581)	(n=838)	(n=865)	(n=878)	(n=839)	(n=564)	(n=647)	(n=219)	(n=312)
Get an email containing all information in the body of the email, %									
Willing to use this method	38.6	41.9	42.5	31.1[b]	41.4	27.8[c]	27.7[c]	22.9[c]	37.5
Most prefers this method	17.8	17.6	22.1	12.2[d]	19.8	8.6[c]	10.7[c]	8.5[c]	14.5
Get an email with pdf attachment, %									
Willing to use this method	23.3	31.9	25.9	13.7[b]	25.6	15.9[c]	12.2[c]	12.5[c]	18.1[e]
Most prefers this method	8.9	10.6	10.5	5.6[f]	10.0	5.7[e]	3.5[c]	2.9[c]	6.7
Get an email with a link to a website, %									
Willing to use this method	22.8	34.6	22.7[b]	14.6[b]	25.1	13.8[c]	13.1[c]	13.3[c]	18.1[g]
Most prefers this method	7.7	12.9	6.9	5.1	8.8	2.9[c]	4.1[g]	1.2[c]	5.7
Get the information by one or more of the above types of emails, %									
Willing to use this method	50.9	59.5	55.0	39.3[b]	54.8	36.0[c]	34.0[c]	30.7[c]	47.9[h]
Most prefers this method	34.3	41.1	39.5	22.8[b]	38.6	17.3[c]	18.4[c]	12.7[c]	26.9[g]
Get print information by regular mail, %									
Willing to use this method	76.6	74.0	73.3	82.7[f]	74.4	87.1[c]	84.0[c]	87.2[c]	76.9
Most prefers this method	60.7	52.6	56.4	72.1[b]	57.3	73.3[c]	75.3[c]	78.8[c]	64.1[e]
Get an automated phone message [i], %									
Willing to use this method	9.4	9.6	8.8	9.9	9.1	13.8[g]	13.0[g]	4.4[g]	6.4
Most prefers this method	0.6	0.9	0.3	0.7	0.4	1.8[g]	2.5[e]	0.4	<0.1
Get health newsletters [i]	(N=2377)	(n=769)	(n=790)	(n=818)	(n=815)	(n=480)	(n=594)	(n=187)	(n=301)
Get an email containing the newsletter in the body of the email, %									
Willing to use this method	39.2	44.0	44.5	28.5[b]	42.8	25.9[c]	24.0[c]	21.2[c]	33.4[g]
Most prefers this method	21.6	22.6	25.5	16.0[d]	23.9	11.4[c]	13.3[c]	11.7[c]	17.3[g]
Get an email with a pdf attachment, %									
Willing to use this method	23.8	31.8	25.3[d]	16.0[b]	26.4	16.0[c]	12.4[c]	11.2[c]	15.5[c]
Most prefers this method	10.4	11.9	12.1	7.0[d]	11.8	6.7[e]	5.0[c]	1.4[c]	7.1[g]
Get an email with a link to a website, %									
Willing to use this method	24.0	32.2	25.2[d]	16.4[b]	26.3	14.9[c]	13.7[c]	14.2[c]	21.9
Most prefers this method	9.5	13.9	10.4	5.3[b]	10.5	5.5[e]	5.1[g]	4.8[g]	10.5
Get the newsletter in ≥1 of email types, %									
Willing to use this method	54.5	62.5	59.3	42.2[b]	59.3	37.2[c]	34.4[c]	30.0[c]	48.2[e]
Most prefers this method	38.4	44.0	44.2	26.6[b]	42.7	21.2[c]	22.1[c]	16.5[c]	32.0[e]
Get a print newsletter by regular mail, %									
Willing to use this method	65.9	62.0	60.5	75.8[b]	62.7	80.3[c]	77.8[c]	80.8[c]	68.1
Most prefers this method	58.7	51.9	52.3	71.7[b]	54.1	76.4[c]	76.6[c]	82.2[c]	65.1[e]

[a] Most preferred method restricted to people who indicated only one method or a most preferred method if >1 method was indicated. Cell percentages are based on weighted data for everyone in the age or race/ethnic group. Ns at top of columns are the unweighted number of respondents in that group. *P* values ≥.055 are not reported. See Multimedia Appendix 3 for detailed *P* values.

[b] Significantly differs (*P*<.001) from 65-69 age group after controlling for race/ethnicity and sex.

[c] Significantly differs (*P*<.001) from non-Hispanic white after controlling for age group and sex.

[d] Significantly differs (*P*<.05) from 65-69 age group after controlling for race/ethnicity and sex.

[e] Significantly differs (*P*<.01) from non-Hispanic white after controlling for age group and sex.

[f] Significantly differs (*P*<.01) from 65-69 age group after controlling for race/ethnicity and sex.

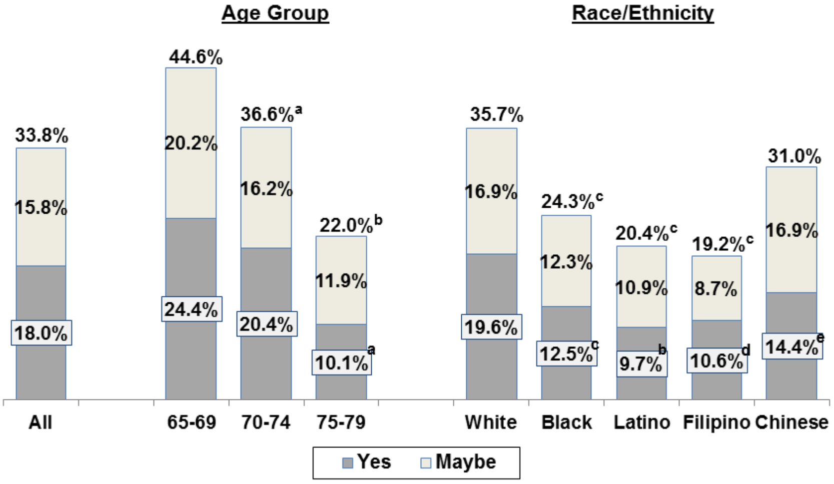
[g] Significantly differs (*P*<.05) from non-Hispanic white after controlling for age group and sex.

[h] Differs (*P*=.050) from non-Hispanic white after controlling for age group and sex.

[i] Restricted to people who completed the longer form of the questionnaire.

Willingness to go online to perform health-related tasks was significantly higher among those who could use the Internet on their own or with some help than in the overall senior population, with the same patterns of significant age group and race/ethnic differences as seen for other measures (see Table 8). However, even among those seniors who were able to use the Internet to get health information from websites or to communicate, many were not willing to perform health care–related tasks online. When we linked the subset of survey respondents who indicated being able to use the Internet (alone or with help) to evidence that they or a proxy had used at least one patient portal secure feature (sending a secure message, viewing lab test results online, ordering a prescription refill, or making an appointment) in 2013, we did not find significant age group differences (84.0%, 84.0%, and 80.3%, for the 65-69, 70-74, and 75-79 age groups, respectively) but did find significantly (*P*<.001) lower usage among black (60.0%), Latino (74.0%), and Filipino (72.3%) seniors than non-Hispanic white (85.3%) or Chinese seniors (85.7%), which remained even after adjusting for age and educational attainment.

Figure 1. Percentages of 65-79 year olds who would be willing to have a video visit if their doctor did not think it was necessary for them to be seen in person. (A video visit enables a patient and doctor to see each other while they are talking by using a smartphone, tablet, or webcam-enabled computer).



[a] Significantly differs (*P* = .019) from ages 65–79 after controlling for race/ethnicity and sex.

[b] Significantly differs (*P* < .001) from ages 65–79 after controlling for race/ethnicity and sex.

[c] Significantly differs (*P* < .001) from non-Hispanic whites after controlling for age group and sex.

[d] Significantly differs (*P* < .002) from non-Hispanic whites after controlling for age group and sex.

[e] Significantly differs (*P* < .047) from non-Hispanic whites after controlling for age group and sex.

Table 8. Willingness to perform health care–related tasks online[a].

Health care–related tasks	All	By age group			By race/ethnicity				
	65-79	65-69	70-74	75-79	Non-Hispanic white	Black	Latino	Filipino	Chinese
Currently communicates at least sometimes with doctor using secure messaging when not urgent, %									
All	58.2	70.0	58.7[b]	48.8[b]	63.6	33.8[c]	36.6[c]	32.2[c]	55.6[d]
Those who can use the Internet	71.8	77.9	70.3[b]	68.5[b]	74.6	51.0[c]	58.8[c]	58.1[c]	68.9
Currently views lab test results online at least sometimes, %									
All	54.4	64.9	55.4[e]	45.5[b]	58.8	31.1[c]	36.3[c]	33.5[c]	63.6
Those who can use the Internet	67.1	72.9	66.3[b]	63.2	69.0	47.4[c]	57.9[c]	60.0[c]	75.3
Currently orders prescription refills online at least sometimes [f] , %									
All	35.7	45.0	39.1	24.8[b]	39.7	20.0[c]	22.1[c]	12.8[c]	36.1
Those who can use the Internet	44.4	50.2	47.8	34.2[b]	46.8	29.9[c]	36.3[c]	22.8[c]	43.4
Willing to complete health questionnaires online, %									
All	49.1	59.1	52.0[g]	38.2[b]	54.5	28.3[c]	27.4[c]	21.1[c]	41.6[c]
Those who can use the Internet	61.5	66.6	63.5	53.7[b]	64.7	43.7[c]	45.3[c]	39.4[c]	51.5[c]
Willing to complete health questionnaires in the clinic using a tablet or touchscreen computer, %									
All	7.4	11.5	7.9	3.6[b]	7.8	6.7	5.1[d]	3.9[d]	6.3
Those who can use the Internet	9.1	13.0	9.4	5.1[b]	9.3	9.5	7.8	5.6	7.9
Willing to read health information online at health plan or other website, %									
All	35.4	42.4	38.4	26.4[b]	39.1	22.4[c]	20.5[c]	15.9[c]	28.3[g]
Those who can use the Internet	44.3	47.7	46.5	37.6[b]	46.4	34.0[c]	33.6[c]	29.8[c]	34.9[c]
Willing to watch health videos online at health plan website or another website like YouTube, %									
All	24.5	27.4	27.9	18.0[e]	26.7	17.5[c]	15.2[c]	11.6[c]	24.3
Those who can use the Internet	30.5	30.7	33.4	25.7	31.4	26.8	24.9[c]	20.2[c]	30.3
Willing to consider (“yes” or “maybe”) a video visit with doctor instead of an office visit, %									
All	33.8	44.6	36.6[e]	22.0[b]	36.5	24.8[g]	20.6[g]	19.3[g]	31.6
Those who can use the Internet	41.7	49.5	44.8	29.5[b]	42.8	37.7	32.8[g]	34.3[d]	36.0
Willing to get health care–related information by email (in body of email, pdf attachment, or link), %									
All	50.9	59.5	55.0	39.3[b]	54.8	36.0[c]	34.0[c]	30.7[c]	47.9
Those who can use the Internet	63.5	68.1	67.8	53.5[b]	65.1	56.3[c]	55.5[c]	52.9[c]	58.1

[a] Ability to use the Internet was assigned based on a “Yes” answer to the question “Can you use the Internet to get information from websites or to communicate with others?” Most senior Internet users were able go online on their own, but some indicated needing help or someone to go online for them. Ability to use email was assigned using the same type of question and responses. Cell percentages are based on weighted data for everyone in that age or race/ethnic group. Because percentages are based on responses to different questions, unweighted cell Ns vary. Most cell Ns can be ascertained from earlier tables, and they are also provided in Multimedia Appendix 4. *P* values ≥.055 are not reported. See Multimedia Appendix 3 for detailed *P* values.

[b] Significantly differs (*P*<.001) from 65-69 age group after controlling for race/ethnicity and sex.

[c] Significantly differs (*P*<.001) from non-Hispanic white after controlling for age group and sex.

[d] Significantly differs (*P*<.05) from non-Hispanic white after controlling for age group and sex.

[e] Significantly differs (*P*<.01) from 65-69 age group after controlling for age group and sex.

[f] Restricted to seniors who take medications for a chronic condition and do not rely totally on others to order their prescription refills.

[g] Significantly differs (*P*<.01) from non-Hispanic white after controlling for age group and sex.

Characteristics of Seniors Who Are Not Using the Patient Portal

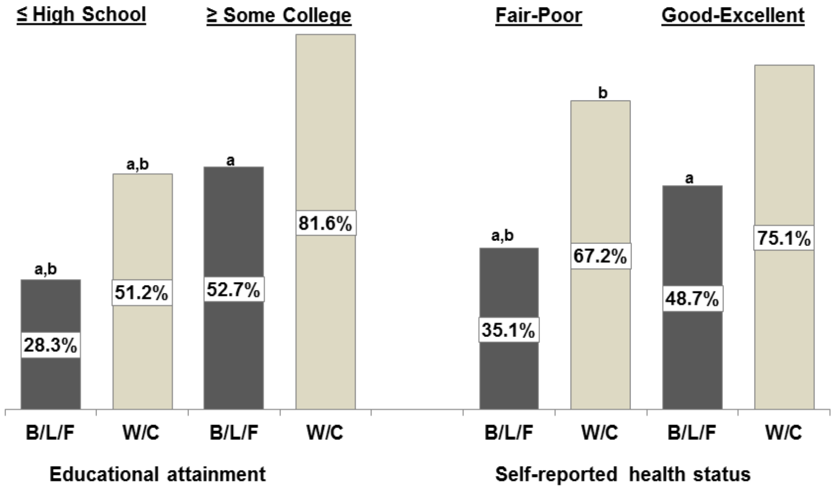
About 40.53% (93,667/231,080) of the seniors in the full study population did not use (or have a proxy use on their behalf) any of four patient portal features (secure message to a doctor, viewing lab test results online, ordering a prescription refill, or making a primary care or vision care appointment) in 2013. Of these non-portal users, 80.20% (75,120/93,667) were 70-79 years old (38.89%, 36,426/93,667, aged 75-79), and over half (56.49%, 52,911/93,667) had not registered for a patient portal account.

To learn more about nonusers of the patient portal, we linked survey respondents with their 2013 patient portal utilization data. We found that among those who had not used any of the four portal features in 2013, 56.6% did not use the Internet even with help, 12.8% used it but needed help or someone else to use it for them, and 30.6% were able to use it on their own. Latino and Filipino nonusers of portal features were significantly more likely than non-Hispanic white nonusers (70.1%, 73.5% vs 52.5%, respectively, *P*<.001) to be unable to use the Internet even with help, whereas black (56.1%) and Chinese (56.0%) nonusers of portal features did not significantly different from non-Hispanic whites. Seniors in the 75-79 age group who had not used the patient portal were significantly more likely than non-portal users aged 65-69 (65.2% vs 42.5%, *P*<.001) to be non-Internet users, with 54.1% of 70-74 year old non-portal users lacking ability to use the Internet. Over 40% (44.0%) of non-portal users had easy access to a device (desktop or laptop computer, netbook, tablet, or smartphone) that could be used to access the Internet. Yet, only one-third (34.3%) had gotten health information from a website in the previous 12 months, and only 24.7% thought that they could get to a website given a URL in printed material or an oral message even with help.

Seniors with a high school education or less were significantly less likely to have used any of the four patient portal features than those with at least some college or with a 4-year college degree (46.0% vs 71.6% and 81.6%, respectively, *P*<.001 for both comparisons). Seniors who considered their health to be fair or poor were significantly less likely than those with good to excellent health to have used these portal features (58.0% vs 71.0%, *P*<.001). Blacks, Latinos, and Filipinos had very similar rates of any portal use within the education and health status categories, as did non-Hispanic white and Chinese seniors, so we collapsed the five race/ethnic groups into two for comparison of education and health status by race/ethnicity. Black, Latino, and Filipino seniors were significantly less likely to use the portal than non-Hispanic white and Chinese seniors with and without formal education beyond high school (Figure 2). Black, Latino, and Filipino seniors who considered their health to be fair or poor were also significantly less likely than non-Hispanic white and Chinese seniors with similar health status to use patient portal features. They were also significantly less likely than black, Latino, and Filipino seniors with good to excellent health to use patient portal features. Use of any of the patient portal features did not significantly differ by health status for non-Hispanic white and Chinese seniors.

Of the 26% (288/843, unweighted) of non-portal users who expressed interest in learning how to use patient portal features, 50.4% were currently unable to use the Internet by themselves, and 25.3% did not have easy access to a digital device to go online.

Figure 2. Use of patient portal features in 2013 is significantly lower among seniors with ≤ high school education and in fair-poor health, and lower among Black, Latino, and Filipino seniors in these vulnerable groups.



B/L/F = Black, Latino, and Filipino; W/C = Non-Hispanic white and Chinese

[a]Significant ($P < .001$) race/ethnic difference within education or health status level after controlling for age and sex.

[b]Significant ($P < .001$) education/health status level difference within race/ethnic group after controlling for age and sex.

Impact of the Shift to Greater Use of Patient Portals and Online Communication

Seniors were asked whether, in their opinion, the health plan's shift toward using its website has made it easier or harder for them to perform five health care–related tasks (getting information about health plan benefits and costs, communicating with their doctor, getting lab test results, getting information about health conditions and treatments, and getting health education) and overall managing their health care. Results are shown in Table 9. Most seniors (47-75%) felt that these tasks had become easier, but a sizable minority (11-17%) thought that it had become harder. Seniors aged 75-79 were significantly more likely than 65-69 year olds, and black, Latino, and Filipino seniors were significantly more likely than non-Hispanic white seniors to think that it had gotten harder for them to do all of these tasks. Chinese seniors did not significantly differ from non-Hispanic whites. When we adjusted for ability to use the Internet by oneself, the race/ethnic differences became statistically insignificant, but the age group difference remained significant.

Table 9. Seniors' opinions on the effect of technology on ease of health care communication and education[a].

Health care–related tasks	All	By age group		By race/ethnicity				
	65-79	65-74	75-79	Non-Hispanic white	Black	Latino	Filipino	Chinese
Get information about your health plan benefits and costs, %								
Easier	46.8	50.2	38.9[b]	46.1	48.0	47.2	53.7	50.5
Harder	16.8	13.8	23.7[c]	15.0	20.9[d]	23.4[e]	29.8[f]	21.1[f]
Communicate with your doctor, %								
Easier	73.3	76.5	65.9[g]	76.1	58.2[f]	63.2[f]	61.4[f]	69.3
Harder	11.8	9.6	17.0[g]	10.1	16.7[d]	18.7[f]	24.4[f]	14.6
Ability to get lab test results, %								
Easier	74.8	77.5	68.6[b]	77.2	60.0[f]	65.6[f]	64.9[d]	74.8
Harder	11.1	9.1	15.7[b]	9.5	16.6[e]	17.1[f]	21.0[f]	14.2
Get information you want about health conditions and treatments, %								
Easier	59.5	62.6	52.4[b]	60.3	53.3[h]	57.3	56.4	62.0
Harder	12.9	10.6	18.2[g]	11.0	18.0[d]	18.4[d]	26.8[f]	18.3[h]
Get health education to help you improve your health or reduce risks, %								
Easier	57.6	61.5	48.2[g]	58.3	52.5	54.3	56.6	57.8
Harder	12.4	10.1	17.8[b]	10.5	16.8[d]	20.0[f]	25.6[f]	17.1[h]
Manage your health care, %								
Easier	61.7	66.2	50.8[g]	63.2	53.5[d]	56.5[i]	54.4[h]	61.7
Harder	12.1	10.0	17.3[b]	10.5	15.5[c]	19.0[f]	23.9[f]	15.4

[a] Seniors were asked whether the health plan's shift toward using its website and patient portal has made it easier or harder for them to obtain information and communicate with their doctors. Analyses were restricted to people who expressed an opinion (including that there had been no change) about their ability to perform this task. Cell percentages are based on weighted data for everyone in the age or race/ethnic group. Because people did not indicate opinions about all tasks, unweighted cell Ns vary; they are provided in Multimedia Appendix 4. *P* values ≥.055 are not reported. See Multimedia Appendix 3 for detailed *P* values.

[b] Significantly differs (*P*<.01) from 65-74 age group after controlling for race/ethnicity and sex.

[c] Significantly differs (*P*<.05) from 65-74 age group after controlling for race/ethnicity and sex.

[d] Significantly differs (*P*<.01) from non-Hispanic white after controlling for age group and sex.

[e] Significantly differs (*P*=.050) from non-Hispanic white after controlling for age group and sex.

[f] Significantly differs (*P*<.001) from non-Hispanic white after controlling for age group and sex.

[g] Significantly differs (*P*<.001) from 65-74 age group after controlling for race/ethnicity and sex.

[h] Significantly differs (*P*<.05) from non-Hispanic white after controlling for age group and sex.

[i] Significantly differs (*P*=.053) from non-Hispanic white after controlling for age group and sex.

Discussion

Principal Findings

Our study found that in 2013, nearly 80% of adults aged 65-79 in a large integrated health care delivery system in Northern California were able to use the Internet and email, had easy access to computers, mobile phones, and home Internet, and were using the health plan's patient portal. The percentages of Internet users in our three senior age groups were not much higher than those found in the 2012 Pew Internet Project national survey of seniors [22]. Significantly, both our patient portal utilization and survey results affirm that the shift to eHealth has the potential to limit access to two-way exchange of health information for segments of the older adult population who are already more vulnerable to chronic health problems, health care access barriers, and likely poorer outcomes.

Specifically, among seniors who had been health plan members for over 2 years, we documented age and race/ethnic disparities among KPNC members aged 65-79 in registration for and actual use of the health plan's patient portal secure features during the 2013 calendar year, even though all members were being actively encouraged at multiple touch points (eg, clinicians, receptionists, and electronic and mail media communications) to sign up for and use the patient portal. Using survey data linked to patient portal registration and utilization, we showed that race/ethnic disparities in use of the patient portal were present even among seniors who have the ability to use the Internet. We also showed that seniors with a high school education or less and those who were in fair or poor health were less likely to have used the patient portal than better educated and healthier seniors, respectively, and that within the more vulnerable groups, blacks, Latinos, and Filipinos were less likely to be portal users than non-Hispanic white and Chinese seniors. Previous studies have found similar race/ethnic and age-related disparities in the use of health plan patient portal features by seniors [24,32,33], but our study uses more current patient portal utilization data and focuses on differences within the senior age group.

Our research found significant differences between ethnic Filipino and Chinese seniors in their use of the health plan patient portal and their ability to use and preferences for using the Internet for health-related purposes, with ethnic Chinese seniors in most cases looking similar to non-Hispanic white, and ethnic Filipinos looking more similar to blacks and Latinos. These two ethnic groups are usually combined along with other Asian ethnicities into a broad "Asian" race/ethnic group. Our results suggest that doing so may be misleading for purposes of planning roll-outs of services and dissemination of health information, resulting in inequities across multiple Asian subgroups.

More importantly, we demonstrated that descriptive statistics about Internet access and preferences for digital engagement that are based on seniors as a group and not broken out by age cohorts and race/ethnicity within age cohorts can provide a deceptively optimistic picture of seniors' readiness to engage with patient portals and Web-based information than is the reality for certain segments of the senior population, specifically those who are older, non-white, less educated, and lower income. Evaluation of portal use among the population segments with lower ability/desire to use Internet-based communication will require that researchers pay attention to population sampling and post-stratification weighting of respondent data in the absence of data on the full population, such as we employed for our comparisons of account registration and utilization of patient portal features. In conducting our research, we also found that black, Latino, and Filipino seniors, especially those who had not signed up to use the health plan's patient portal, were significantly less likely to respond to our survey than non-Hispanic white and Chinese seniors, who were significantly more likely to be digitally connected and using the patient portal. This suggests that studies concerned with profiling eHealth engagement in multi-ethnic senior populations or specifically studying racial or ethnic differences need to employ stratified random samples that oversample these race/ethnic groups, not only because individually they tend to make up a smaller percentage of the total senior population, but also because seniors in these race/ethnic groups are much less likely to respond to a research survey. This also extends to evaluating Internet and eHealth use and preferences in populations that include other vulnerable subgroups, such as people with low income and low educational attainment.

Ability to use the Internet and having an email address are basic requirements for registering for a patient portal account that enables a member to access secure portal features, complete online health plan questionnaires that feed responses directly into the electronic medical record, and have secure email interactions with health care providers and other health plan staff. As more information and health care–related transactions become available through patient portals and health plan websites, and assumptions are made by health plan medical staff and workflow planners that most adult members will migrate to Web-based interactions, seniors who cannot or do not want to use their health plan's patient portal and website may find it harder to interact and access information and services. In our survey, less than half of seniors who had not used any of the four major patient portal features during the year prior to the survey were able to use the Internet or email even with someone's help and one fourth did not have access to a device that could be used to go online. In addition to disparities in Internet and email access, we found that the majority of black, Latino, and Filipino seniors and close to half of 75-79 year olds did not think they would be able to perform many of the most common health care–related tasks that could be done using the patient portal and health plan website. Further, we found that these race/ethnic and age group differences in perceived ability to use and preference for using the patient portal and website for these tasks persisted even among those seniors who were Internet users. This suggests that successful efforts to reduce race/ethnic- and age-related disparities among seniors in use of patient portals and other eHealth modalities and thus reduce the risk of exacerbating disparities in health and health care access will require more than increasing access to the Internet through community-based WiFi or increasing efforts to promote patient portal registration and use.

Although some seniors who were not using patient portal features or the health plan website say they would be willing to do so if required by the health plan, they also indicated that they needed to have a person (not a Web-based video or guide) provide instruction and support for using these Web-based tools. A 2013 survey from the Pew Research Center found that 66% of non-Internet-using seniors would require help from another person to go online [21]. The same survey also found that among non-Internet-using seniors, only 13% thought they would be knowledgeable enough to go online by themselves, and only 5% of seniors said they were likely to start using the Internet or email in the future [21]. While older adults have been found to have less trust in the Internet as a source of health information [44], trust is likely less of an issue with using a health plan website. A major barrier is that most seniors, and especially those aged ≥75, will be what Prensky has termed "digital immigrants” to Web-based health care interactions, having had limited, if any, experience using computers and the Internet during their school and work years [45]. In contrast, most websites and patient portals are created by “digital natives” for use by a majority “digital native” adult population—not for older and low eHealth-literate adults. Many age-related cognitive, physical, and psychomotor factors specific to older adults can make it difficult for them to use digital technologies in general and to feel that the effort required to learn to use a complex, hierarchically designed health plan website will outweigh the benefits of using it [22,46]. Morrow and Chin [46] make a number of evidence-based recommendations for how to design patient portals and websites to make them easier for older adults to use, including organizing information and tasks in a way that is consistent with older adults’ expectations, simplifying website navigation with shallow menus and quick links, making it simple to perform common portal tasks that help them manage their health and communicate with their providers, and using fonts and formats that are easy for older eyes to read. Many of the recommendations apply more generally to making the process of interacting with websites and patient portals easier for all patients with low eHealth literacy. Because older seniors are more likely to use a computer to go online than a smartphone or tablet [47], apps designed to make it easier to use patient portal functions with a smartphone or tablet will not work as well as a landing page with easily identifiable links to frequently used patient portal features and patient education resources for reducing navigation difficulties. A good example is the Permanente Medical Group’s My Doctor Online Physician Home Page, which was created to make it easier for Kaiser Permanente Northern California Region health plan members to access patient portal functions and patient education resources on the health plan’s complex website. (see Figure 3).

Advances in Web design, digital technologies, and greater availability of free Internet access outside the home are increasingly making it easier for older adults with poor eyesight, physical disabilities, and little computer and Internet experience to go online for health. Also, websites continue to improve based on user feedback. However, if seniors are not aware of these advances or do not receive the training and support they need, they may not attempt to use these tools, especially if they had negative experiences in the past. Watkins and Xie recommend tailoring eHealth literacy interventions to take into account known learning styles of different senior demographic subgroups as well as the starting level of experience in using the Internet rather than using a one-size-fits-all approach [48]. Evaluations of in-person eHealth training programs for seniors have shown positive changes in attitudes, skills, and use of Internet-based resources for obtaining health information [49,50]. Our study results suggest that training and ongoing support for those who want to use patient portals, websites, and other eHealth technologies will be easier for the majority of seniors to access if made available in the form of hardcopy (paper) handbooks, in-person workshops or tutorials, and toll-free call-in support, not just Web-based resources.

Some seniors in our survey who do not use the Internet expressed concern that they will miss important information that is readily available only on the website or via emails and that they will lose the ability to handle their health care-related tasks without having a relative or informal caregiver act as their intermediary. Some also indicated a fear that as Web-based health care interactions become more the norm, they are going to lose the in-person and phone-based interactions with their doctors and other staff that they feel are important to nurturing their relationships with their health care providers. This is consistent with “digital immigrants” having different expectations and preferences for how they want to interact with their health care providers and the health care system that may not align with what is not only acceptable to but desired by the “digital native” majorities of adult health plan members and health care providers. Our survey results suggest that the eHealth digital divide is already causing significant percentages of black, Latino, Filipino, and older seniors to feel that a shift toward website-based health communications on the part of their health plan has made it harder for them to access information and communicate with their doctors. This is especially concerning because as our study and other research [51] suggests, compared with non-Hispanic whites and Asians, higher proportions of black and Latino seniors have chronic health problems, poorer health, and greater disability [52] and also have low levels of health literacy [53].

Health care organizations and government programs will need to take into account differences in technology access and communication/transaction preferences when designing and implementing health and health care-related communication strategies for culturally and economically diverse adult populations with a wide age range. Although the Internet and other digital technologies offer convenience and access to a greater amount of health-related information, self-care resources, and services than people have had in the past and will play a major role in Health 2.0 [54], health care organizations will need to continue to make similar resources available in more low-tech modalities (print information, DVDs, phone, regular mail) for those who are unable or do not want to access these resources from websites and email.

Health care organizations should expect that some segments of the senior population will prefer not to become “digital immigrants” and want to continue to communicate about health-related matters and engage in other types of health care-related transactions in person, by phone, and using hardcopy print rather than electronic materials. Morrow and Chin suggest that in this regard, it is very important for health care providers to send a clear message to senior patients and their family members that patient portals, secure email, Web-based patient education resources, apps, and other eHealth modalities are meant to supplement, not supplant the modes of personal patient-provider relationship that many seniors value [46]. For example, leaving a voicemail message for a doctor should be as easy as emailing that doctor through the patient portal. Additionally, health care providers need to ensure that limited digitally proficient seniors do not feel pressure to arrange for a family member or friend act as their digital interpreter if they cannot or do not want to engage with their health care providers and health plan using a patient portal. Encouraging use of a digital interpreter not only risks undermining the sense of autonomy of otherwise cognitively competent seniors to manage their own care [55] but also raises many of the same communication-related concerns that have led to recommendations against using family members and friends as medical interpreters for patients with language barriers [56].

Figure 3. Screenshot of a Doctor Home Page developed by The Permanente Medical Group to make it easier for health plan members to use the health plan's website and patient portal.

My Doctor Online
The Permanente Medical Group

Search
English

Our Doctors | Staying Healthy | Español | Sign On

Stay Connected with Your Doctor

Manage & Schedule
Prescriptions
Appointments

View Information
Test results
Immunization record
Past visits
Hospital stays

E-mail Your Doctor
Compose message
View messages

Preventive Health Reminders
Screening tests and immunizations

Manage Your Family's Health
Learn how
Set up access

MD

Pediatrics

As your physician, I value my relationship with you. And I know that maintaining a good relationship means being able to communicate with each other. My colleagues and I have developed My Doctor Online so that we can stay in touch more easily. Because the better connected we are, the healthier you are.

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Walnut Creek Medical Center
Appt/Advice: 925-295-
See all office information »

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Colds and Flu in Children
Coughs in Children
Fever in Children
Immunizations
Strep Throat

ADDITIONAL TOPICS

Allergies and Asthma
Behavior, Development, and Parenting
Bones, Muscles, and Joints
Breastfeeding
Common Conditions
Digestive System
Ear, Nose, and Throat
Eating Disorders in Adolescence
Eyes
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For Teens
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Strengths

Our study had several strengths. First, the patient portal component of this study was done using an extremely large and diverse cohort of Medicare-age health plan members. The health plan itself represents an integrated health care delivery system with a highly developed website and patient portal. This enabled us to compare age-group and race/ethnic differences in patient portal use in a population where all members had received extensive encouragement to sign up for the patient portal over at least 2.5 years and had access to the same health care system and patient portal.

Second, by linking patients' electronic medical record data with use of patient portal features, we were able to restrict comparisons of use of the patient portal for online viewing of laboratory test results and online ordering of prescription refills to seniors who would have had cause to perform these tasks—something that has not been done in previous studies with this or other health plan populations.

Third, because of the size and diversity of the cohort, we were able to document significant age-group disparities and race/ethnic disparities within age groups in this Medicare-age population using directly observed percentages, not just odds ratios from logistic regression models. We were similarly able to document that these disparities persisted even among those who were registered to use the patient portal and among those with chronic health conditions who might be expected to have greater need for engaging with the health care system.

Fourth, our survey sample enabled us to compare access to and ability to use digital devices and the Internet, as well as experience with and preferences for performing health care–related tasks using digital technology across age cohorts and race/ethnic groups in a way that has not been done for a population of adults aged 65 and older. We were also able to link our survey data to patient portal registration and utilization data. This resulted in our discovery of a differential survey response rate by patient portal account creation status (our proxy for Internet access in the portal study component), which we subsequently incorporated into the survey weighting factor. This also made it possible for us to examine social determinants of use of a patient portal using real utilization data and self-reported social determinant variables such as education and Internet access.

Fifth, we were able to differentiate between patients' use of or willingness to use digital technology for health care–related tasks and their preferences for using these technologies in general.

Limitations

One limitation of the patient portal component of this study is that we did not have information for the full study population about overall Internet access practices and other factors such as education and income to determine whether disparities were due to these types of social determinants or to patient preferences. As a proxy for the propensity to use the Internet, we compared use of patient portal features among seniors who had created a patient portal account in 2013; this is similar to what has been used by other studies [13,18]. As described above, we also used survey data for a subset of this study population to examine whether disparities in patient portal utilization persisted within different levels of education, health status, and ability to use the Internet.

Although we were able to examine whether differences in use of secure features during the observation year persisted among those who had signed up to use the patient portal by the end of the year, we were not able to determine whether the need to obtain laboratory test results or refill prescriptions occurred before or after members created their patient portal account. We assumed that all members would have had the opportunity to use the portal to perform these tasks had they desired because everyone in this study population had, by design, been a member for at least 18 months before the study period and could have immediately activated their patient portal account when they created it.

The response rate to the survey was lower than we desired, especially among black, Latino, and Filipino seniors, which limited our ability to study race/ethnic differences within age groups. The small numbers in these groups may also limit generalizability. The numbers of Filipino and Chinese seniors included in the survey were also smaller than we would have liked because these ethnic groups had originally been selected only for pilot study purposes. Had the analysis of patient portal use in the full study sample been completed prior to the survey, we likely would have included comparable numbers of Filipinos and Chinese in the sample to increase the precision of our statistics and to have more statistical power to test for differences in access and preference between these two Asian ethnic groups.

We did not include a question about personal or family income in the survey because a large percentage of seniors had left the income question blank in previous health plan surveys or been disconcerted about being asked. We did ask whether cost was a factor in not having Internet at home and used self-reported education as a measure of socioeconomic status. We also used income data from a 2011 KPNC Member Health Survey to characterize income differences among the age and race/ethnic groups in this health plan, but we were not able to shed light on the joint effect of education and income on access to and preference for using eHealth technology.

Finally, no validated measures of health literacy were included in our survey, so we were unable to study the extent to which health literacy mediates differences in seniors' access to and preferences for using health information technology as part of their health care.

Conclusions

Our study documents digital disparities by age, race/ethnicity, and educational attainment within the senior age group with regard to access to digital devices, ability to use the Internet and email, and preferences for going online or using traditional telephones to interact with health care providers and the health care system in the United States. Our results suggest that the same subgroups of vulnerable seniors that have previously been shown to have difficulties with health care access may also be hampered by the eHealth digital divide from obtaining timely health information and advice, using digital monitoring devices as part of chronic disease self-management, and taking advantage of cost-saving Internet-based care options such as online purchase of prescription medications and medical equipment and having video visits with doctors and patient educators. Because well-known disparities in health status and health care access and use are being extended into the eHealth arena, we do not expect digital technologies to reduce socioeconomic gradients automatically.

In order to ensure that eHealth disparities do not increase health status and health care access disparities between more privileged and less privileged groups, eHealth initiatives should embed tracking systems and measures of disparities in their access and use. Health care delivery systems, government agencies, and other organizations that serve multiculturally, multilinguistically, multigenerationally, and socioeconomically diverse populations should analyze these data to identify access and use gaps for eHealth resources by seniors separately from the broader population. Most importantly, access to and use of eHealth resources should be monitored not only for the full senior population or the segment already known to be going online, but also by social determinants such as race/ethnicity, older age, low educational attainment, and low income. Government health agencies and quality assurance organizations focused on senior health and health care should hold health care providers and systems accountable for demonstrating that all patients are satisfied with the ease of communicating with their health care providers and the health care systems, their ability to get health and health care–related information and advice, and their ability to access reduced-cost services and products, regardless of whether they are able to go online.

Further research is needed to explore the extent to which age group and race/ethnic eHealth disparities affect patient-provider communication, use of patient education and disease management resources, and ultimately, health outcomes in different settings. Research is also needed to develop and evaluate the impact of improvements in the design of websites, patient portals, online patient education resources, self-monitoring tools, and eHealth devices that access Internet-based health resources aimed at reducing the physical, cognitive, psychomotor, emotional, and financial barriers that currently inhibit many seniors from using online resources for health-related purposes. Finally, more research is needed to develop and test interventions targeting seniors that aim to increase use of patient portals, eHealth devices, and other eHealth resources, including eHealth literacy programs, multimodal methods of providing website-specific training and support, and making home Internet more accessible to those on limited incomes.

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Authors' Contributions

NPG conceived and designed the study, developed the survey questionnaire, directed the survey used for the study, performed all analyses reported in the manuscript, and wrote the manuscript. MCH collaborated on the study design and questionnaire development, interpretation of the analyses, and the writing of the manuscript. Both authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Cell denominators for Tables 1 and 2.

[PDF File (Adobe PDF File), 39KB - jmir_v18i3e50_app1.pdf]

Multimedia Appendix 2

Survey questionnaire.

[PDF File (Adobe PDF File), 316KB - jmir_v18i3e50_app2.pdf]

Multimedia Appendix 3

Tables 1-9 showing exact P values for significance tests.

[PDF File (Adobe PDF File), 327KB - jmir_v18i3e50_app3.pdf]

Multimedia Appendix 4

Cell denominators for Tables 8 and 9.

[PDF File (Adobe PDF File), 37KB - jmir_v18i3e50_app4.pdf]

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Abbreviations

KPNC: Kaiser Permanente Northern California
non-LEP: non–limited English proficient

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Original Paper

Does Digital Ad Exposure Influence Information-Seeking Behavior Online? Evidence From the 2012 Tips From Former Smokers National Tobacco Prevention Campaign

Annice Kim[1], PhD; Heather Hansen[1], MPP; Jennifer Duke[1], PhD; Kevin Davis[1], MA; Robert Alexander[2], PhD; Amy Rowland[2], MSc; Jane Mitchko[2], MEd

[1]RTI International, Research Triangle Park, NC, United States

[2]Centers for Disease Control and Prevention, Office on Smoking and Health, Atlanta, GA, United States

Corresponding Author:
Annice Kim, PhD
RTI International
3040 E. Cornwallis Road
P.O. Box 12194
Research Triangle Park, NC,
United States
Phone: 1 919 316 3972
Fax: 1 919 541 6683
Email: akim@rti.org

Abstract

Background: Measuring the impact of online health campaigns is challenging. Ad click-through rates are traditionally used to measure campaign reach, but few Internet users ever click on ads. Alternatively, self-reported exposure to digital ads would be prone to recall bias. Furthermore, there may be latency effects whereby people do not click on ads when exposed but visit the promoted website or conduct campaign-related searches later. Online panels that unobtrusively collect panelists' Web behavior data and link ad exposure to website visits and searches can more reliably assess the impact of digital ad exposure. From March to June 2012, the Centers for Disease Control and Prevention aired the national Tips From Former Smokers (Tips 2012) media campaign designed to encourage current smokers to quit. Advertisements ran across media channels, and the digital ads directed users to the Tips 2012 campaign website.

Objective: Our aim was to examine whether exposure to Tips 2012 digital ads influenced information-seeking behaviors online.

Methods: ComScore mined its panelists' Web behavior data for unique codes that would indicate exposure to Tips 2012 ads, regardless of whether panelists clicked the ad or not. A total of 15,319 US adults were identified as having been exposed to a Tips 2012 campaign ad. An equal number of unexposed adults (N=15,319) were identified and matched on demographics and Internet use behavior to the exposed group. Panelists' Web behavior data were mined for up to 4 weeks after initial Tips 2012 ad exposure to determine whether they visited the Tips 2012 campaign website or other cessation-related websites (eg, nicotine replacement therapy site) or conducted searches for campaign-related topics (eg, quit smoking).

Results: The proportion of exposed adults visiting the Tips 2012 sites increased from 0.4% in Week 1 to 0.9% 4 weeks after ad exposure, and these rates were significantly higher than in the unexposed group (0.1% in Week 1 to 0.4% in Week 4, $P<.001$) across all weeks examined. The proportion of exposed panelists visiting other cessation websites increased from 0.2% in Week 1 to 0.3% 4 weeks after initial ad exposure, and these rates were significantly higher than in the unexposed group (0.0% in Week 1 to 0.2% in Week 4, $P=.001$ to $P=.019$) across all weeks examined. There were no significant differences in searches for campaign-related topics between the exposed and unexposed group during most of the weeks examined.

Conclusions: These results suggest that online ad exposure is associated with confirmed visits to the Tips 2012 campaign sites and visits to other cessation websites and that these information-seeking behaviors occur up to several weeks after ad exposure. Web behavior data from online panels are useful for examining exposure and behavioral responses to digital campaign ads.

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KEYWORDS

tobacco cessation; health; Internet; monitoring and evaluation

Introduction

Smoking is the leading cause of preventable deaths in the United States, accounting for approximately 480,000 deaths annually [1]. An extensive body of research demonstrates that mass media campaigns are an effective strategy to encourage smoking cessation that contributes to reductions in adult smoking prevalence rates [2-4]. Historically, campaigns have placed advertisements on traditional broadcast media, such as television and radio, to inform target audiences about the dangers of tobacco use and to encourage use of cessation resources, such as a telephone quitline. Increasingly, campaigns have added digital advertising to reach audiences online and to drive visits to the campaign websites with cessation resources. While much is known about the impact of television ads on cessation-seeking behaviors with best practice recommendations to guide media strategy and planning of television and radio campaigns [5], very little is known about the impact of digital ads on health information-seeking behaviors online.

In 2012, the Centers for Disease Control and Prevention (CDC) launched Tips 2012 From Former Smokers (Tips 2012)—the first federally funded, national tobacco paid-media education campaign. The Tips 2012 campaign advertisements aired nationally from March to June 2012 on cable television, radio, online, print, and outdoor media (eg, billboards). Campaign ads featured former smokers sharing their stories about the daily challenges of living with smoking-related illnesses. To provide smokers with resources and information about quitting, Tips 2012 television ads promoted the 1-800-QUIT-NOW telephone quitline portal and the National Cancer Institute’s (NCI) Smokefree website [6]. The digital campaign consisted of display, video, mobile, and search ads that were intended to reach online audiences and to direct them to the Tips 2012 website [7]. The campaign also disseminated cessation information to audiences via CDC’s Tobacco Free Facebook page [8] and Twitter handle [9] and CDC’s StreamingHealth YouTube channel [10]. The Tips 2012 campaign was effective in changing tobacco-related knowledge, beliefs, and intentions to quit smoking [11]. Further, it influenced an estimated 1.64 million smokers to make a quit attempt and 100,000 smokers to remain abstinent permanently [12]. Additionally, calls to the quitline increased by 132%, and the number of unique visitors to the Smokefree.gov cessation website increased 428% during the campaign [13].

The purpose of this study is to examine the impact of the Tips 2012 digital advertisements on cessation information-seeking behaviors online. Traditionally, the impact of campaign ad exposure on short-term tobacco-related outcomes like information-seeking behaviors and awareness of campaign messages has been examined by linking gross rating points (ie, reach x frequency of ad exposure) as an exogenous observational measure of television ad exposure to survey responses (eg, [3,14-16]). However, self-reported survey responses may not accurately measure the potential impact of digital ad exposure on information-seeking behavior online because they rely on participant recall of the promoted website and campaign-related topics that may be prone to recall bias.

Measuring the impact of digital campaign advertisements is challenging. Ad impressions and click-through rates (CTRs) are traditionally used to measure message reach, but they are limited because only a small fraction of Internet users ever click on ads [17], and CTRs are not linked to behavioral outcome data, such as online information-seeking behavior. Even if ads are not clicked, incidental ad exposure can affect brand/campaign awareness [18,19]. Furthermore, there may be latency effects whereby people do not click on ads at the time of exposure but visit the promoted website or conduct searches on campaign-related topics later [17]. Website analytics programs (eg, Google Analytics, Adobe SiteCatalyst) provide some insights into the impact of online ads (eg, what proportion of traffic originated from clicks on paid search ads), but not for all ad types (eg, video paid ads) and it does not link online ad exposure to website visits. An alternative approach would be to assess self-reported exposure to digital ads via surveys. However, this approach would especially be prone to recall bias given the extensive diversity of websites users may visit on any given day, the different types of ads (eg, display, search, video, social), and the manner in which users may access the Internet (via computer vs mobile devices) that may influence the number and type of ads delivered and viewed.

A more accurate approach to measuring digital ad exposure and behavioral impact is needed. A panel-based method that unobtrusively collects Web behavior data and can link ad exposure to online information-seeking behaviors at the individual level may be a more reliable method for measuring online campaign effects [20]. Several companies (eg, comScore [21], Nielsen [22]) have Web-based panels in which members agree to install a software on their computers that unobtrusively captures data about their online behavior, including websites visited, searches conducted, and whether a specific ad was delivered on a site they visited, regardless of whether they clicked on the ad or not. In this study, we used comScore’s Web panel of approximately 1 million US adult Internet users to identify those who were exposed to the campaign and to assess whether exposure to the Tips 2012 digital ads was associated with (1) visits to the Tips 2012 campaign website, the Smokefree.gov cessation site, and other non-campaign-related cessation sites and (2) searches for campaign-related topics and general information about cessation.

Methods

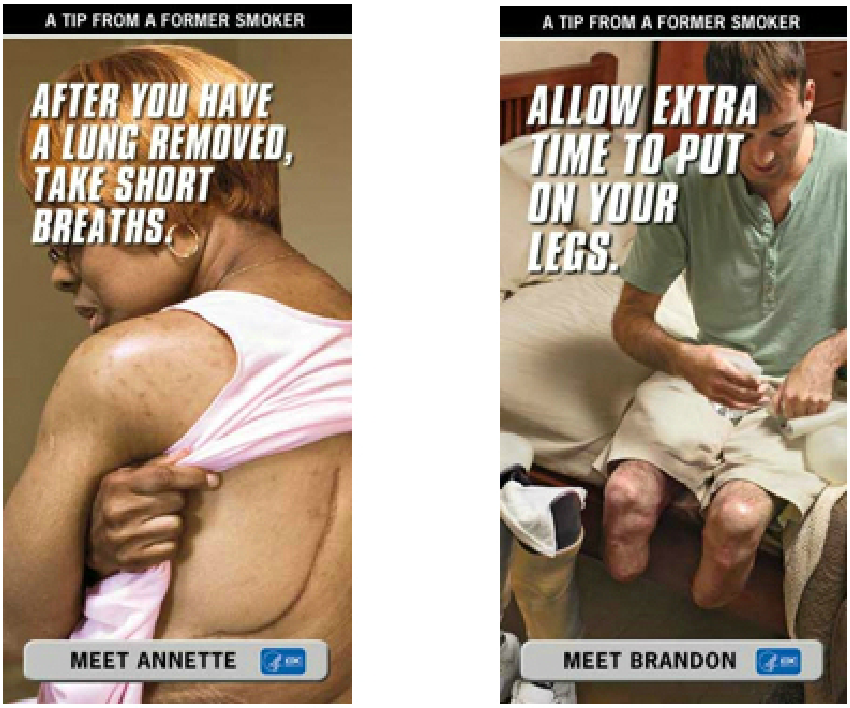
Tips 2012 Digital Advertising

The digital campaign consisted of display, video, mobile, and search ads that were intended to reach the target audience of adult smokers aged 18-54 and to direct them to the Tips 2012 website. All digital ads ran from March 19-June 10, 2012. Display ads were animated or static and appeared at the top or sidebar of popular websites, such as weather.com, to attract target audiences. The display ads were placed on select websites and ad networks and highlighted the stories of former smokers Annette, Brandon, Shawn, Roosevelt, Suzy, and Terrie (see examples in Figure 1). The campaign also featured a cessation support ad of formers smokers who had quit (“Cessation”) and the “Asthma” ad, which highlighted the harmful effects of exposure to secondhand smoke. Display ads were tagged with the CDC Tips 2012 website so that viewers who clicked on the ad were directed to the Tips 2012 site. Approximately 372 million impressions of digital ads were served, and they generated 489,000 clicks for a CTR of 0.13%, which exceeds the industry standard of 0.08% for display ad CTRs [23].

Video ads are generally shown before or after other video content, such as an online television show or music video. Video ads ran on 29 websites and featured the same 30-second ads that ran on television. Video ads were tagged with the CDC Tips 2012 website so that viewers who clicked on the ad were directed to the Tips 2012 site. For video ads, approximately 407 million impressions were served, and these ads generated 4.2 million clicks for a CTR of 1.05%, which exceeded industry standards of 1.03% for video ad CTRs [24].

Search ads appear at the top and sidebar of search results so that when consumers type in any of the paid search terms (eg, how to quit smoking), the top result retrieved is the Tips 2012 site. Tips 2012 search ads were purchased for the two top search engines, Google and Yahoo. For search ads, 22.6 million impressions were delivered via search ads, and these ads generated 224,811 clicks for a CTR of 1.0%, which was equal to the industry standard of 1.0% [25] for search ad CTRs.

Figure 1. Provides examples of CDC Tips 2012 campaign-related advertisements.



Panel Data

The data for this analysis came from comScore, a market research company that unobtrusively collects Web behavior data on 1+ million US Internet users to measure trends in consumer behaviors online. Panelists download tracking software on their computers that enables comScore to track their Web behavior, including every website they visit, searches they conduct, purchases they make, and ads that are delivered on sites visited, regardless of whether the ads are clicked or not. These data are then aggregated and weighted to provide national estimates on consumer behaviors online. The panel is a convenience sample with panelists largely recruited via nonprobability-based sampling methods (eg, online ads, partner websites). However, a subsample is recruited via random-digit-dialing to calibrate the post-stratification weights that comScore uses to project its estimates to the US Internet population. Panelists are provided incentives for participation such as free online games and charitable donations on panelists’ behalf.

Measures

Exposure to Tips 2012 Digital Display and Search Ads

The Tips 2012 campaign’s media contractor provided the “tags” (hash identification code, hypertext markup language source code) to each of the Tips 2012 digital display ads. Using this information, comScore mined its panelists’ Web behavior data for these display ad tags and exposure to sponsored links (search ads) to identify individuals who were exposed and not exposed to the Tips 2012 digital campaign from March 19-June 10, 2012. Video and mobile ad exposure was not examined in this study. Among comScore’s approximately 1 million US adults who were active panelists (ie, tracking software was installed and sending data) during the March 19-June 10, 2012 time period, 15,319 panelists were identified as having been “exposed” to the Tips 2012 digital display and/or search ads. For a control group, an equal number of “unexposed” adults (N=15,319) were matched to the exposed group on demographics and Internet use behavior (eg, time spent online) using propensity score matching nearest neighbor approach (Table 1). comScore uses propensity score matching to balance exposed and unexposed groups in order to isolate the effects of digital campaign ad exposure (eg, [17]). Propensity score matching has been widely used to adjust for selection bias in estimating campaign exposure effects (eg, [26]). Information about panelists' smoking status was not available. Once the exposed and unexposed groups were identified, panelists' Web behavior data, including websites visited and searches conducted, were mined for up to 4 weeks after initial Tips 2012 ad exposure.

Table 1. Demographic characteristics of exposed and unexposed panelists.

Demographic	Exposed panelists, % (N=15,319)	Unexposed panelists, % (N=15,319)
Age		
18-24	15	11
25-34	18	20
35-44	20	21
45-54	24	25
55-64	14	15
65+	9	8
Race/Ethnicity		
White	46	50
Black	22	20
Asian	13	13
Other	19	17
Geography (United States)		
North East	20	19
North Central	20	20
South	37	40
West	23	21
Annual household income, USD		
Less than $25K	30	29
$25K-50K	25	24
$50K to <75K	21	23
$75K to <100K	12	13
More than $100K	12	10
Children in household	27	28

Visit to Tips 2012 Campaign Websites

We examined whether panelists in the exposed and unexposed groups visited any of the campaign sites listed in Table 2, which includes the main Tips 2012 site and social media pages (CDC Tobacco Free Facebook page, CDC Tobacco Free Twitter handle, and CDC's StreamingHealth YouTube channel) used to disseminate Tips 2012 messages. A visit was captured if the panelist clicked on the display ad (which sent them directly to the Tips 2012 website) or used other methods, such as clicking on search results, typing in the uniform resource locator (URL) directly into the browser, or clicking on a hyperlink from another site.

The Tips 2012 television ads directed audiences to NCI's Smokefree.gov website because it offers extensive cessation resources. As a result, awareness of the Smokefree.gov website may be high and people may associate this site with the Tips 2012 campaign. Therefore, we also examined visits to NCI's Smokefree.gov, its associated websites (Smokefree Women and Smokefree Espanol), and social media pages.

Table 2. Tips 2012 campaign and non-campaign websites.

Website	URL
Campaign websites	
CDC Tips 2012	
CDC Tips 2012 campaign website	cdc.gov/tobacco/campaign/Tips 2012/
Tobacco Free Facebook page	facebook.com/cdctobaccofree
Tobacco Free on Twitter (@CDCTobaccoFree)	twitter.com/CDCTobaccoFree/
CDC StreamingHealth YouTube Channel	youtube.com/user/CDCStreamingHealth
NCI Smokefree	
NCI Smokefree website	Smokefree.gov
Smokefree.gov on Twitter (@SmokefreeGov)	twitter.com/smokefreegov
Smokefree Women website	women.smokefree.gov
SmokefreeWomen onTwitter (@SmokefreeWomen)	twitter.com/SmokefreeWomen
Smokefree Women YouTube Channel	youtube.com/SmokefreeWomen
Smokefree Women Facebook page	facebook.com/smokefree.women
Smokefree Espanol website	espanol.smokefree.gov
Other non–campaign-related cessation sites	
Cessation-related [a]	
HealthWays cessation service	quitnet.com
Alere cessation service	quitnow.net
Legacy cessation service	becomeanex.org
American Cancer Society cessation resources	cancer.org/Healthy/StayAwayfromTobacco/GuidetoQuittingSmoking/index
American Lung Association cessation resources	lung.org/stop-smoking/
Nicotine Related Therapy (NRT)-related	
Nicoderm CQ patch	nicodermcq.com
Nicotrol inhaler	nicotrol.com/
Nicorette gum/lozenge/mini	nicorette.com
Habitrol patch	habitrol.com
State cessation program websites [a]	
Make Smoking History—Massachusetts	Makesmokinghistory.org
Tobacco Free Florida	tobaccofreeflorida.com
Tobacco Free Florida—Facebook	facebook.com/TobaccoFreeFlorida

[a] These are examples only, not the entire list. In total, 101 cessation sites were examined, including 10 national cessation-related sites, 4 NRT sites, and 87 state cessation program sites. This list of sites were compiled and reviewed by tobacco control researchers at Research Triangle Institute and CDC.

Visit to Other Non–Campaign-Related Cessation Websites

We also examined visits to key national cessation sites (eg, [27]), state tobacco cessation sites (eg, [28]), and nicotine replacement therapy (NRT)-related sites (eg, [29]) (see Table 2). We examined panelists' visits to these non-campaign-related cessation websites because websites with similar content may see increased visits through content-related searches by the exposed group when a campaign has low brand awareness. Additionally, seeing the Tips 2012 ad may trigger people's recall of an existing state cessation program or NRT options they were intending to seek out.

Search for Campaign-Related Topics

To determine whether exposure to Tips 2012 online ads influenced audiences to seek out additional information about the campaign, panelists' search behavior data were mined for the occurrence of specific (eg, Tips 2012, Terri ad) and general (eg, quit smoking) campaign-related search queries on major search engines (eg, Google, Bing) as well as general websites with search functions (eg, YouTube). A list of 2270 potential search terms were examined based on top external keywords from Adobe SiteCatalyst for the CDC Tips 2012 website and Google Analytics for NCI's Smokefree.gov site, as well as top keywords used in the digital ad campaign.

Analysis

For each time period, we calculated the proportion of panelists in the exposed and unexposed groups who (1) visited the Tips 2012 campaign-related websites, (2) visited Smokefree-related websites, (3) visited other non–campaign-related cessation websites, and (4) conducted searches for any campaign-related key terms. Proportions were calculated separately for the exposed and unexposed groups and at each weekly time period (Week 1, Week 2, Week 3, and Week 4) after initial ad exposure. Results for Week 1 represent the proportion of exposed and unexposed groups who visited campaign sites or conducted searches within 1 week after first campaign ad exposure. Results for Week 2 represent the proportion of exposed and unexposed groups who visited campaign sites or conducted searches within Weeks 1 and 2 after first campaign ad exposure, and similarly Week 3 represent Weeks 1-3 after first campaign ad exposure, and Week 4 represent Weeks 1-4 after first campaign ad exposure. We conducted *t* tests to determine whether differences in proportions between the exposed and unexposed groups at each time period were statistically significant.

Results

Did Exposure to Tips 2012 Digital Ads Influence Visits to the Tips 2012 Campaign Sites and NCI Smokefree Sites?

Figure 2 summarizes the proportion of exposed and unexposed panelists who visited any of the Tips 2012–related campaign sites. The proportion of exposed panelists visiting Tips 2012 sites increased from 0.4% in Week 1 to 0.9% in Week 4 after initial ad exposure. Unexposed panelists also visited Tips 2012 sites but at significantly lower rates from 0.1% in Week 1 to 0.4% at Week 4 (see Table 3). Significantly more panelists who were exposed to the Tips 2012 digital ads visited the campaign website compared to unexposed panelists at 1, 2, 3, and 4 weeks after initial ad exposure (*P*<.001). Very few panelists visited the Smokefree websites (0.1%), with no difference between the exposed and unexposed groups (data not shown).

Figure 2. Shows the change in visits to CDC Tips 2012-related websites over the course of the campaign by digital ad exposure.

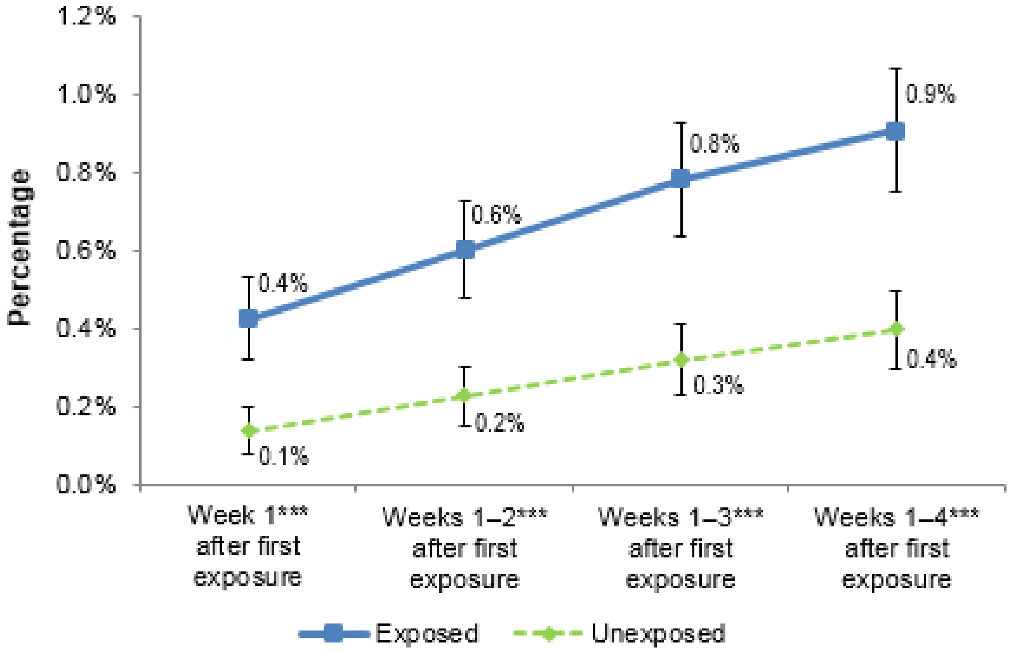


Table 3. Visits to CDC Tips sites.

	Week 1	Weeks 1-2	Weeks 1-3	Weeks 1- 4
Exposed, % (95% CI)	0.4 (0.32-0.53)	0.6 (0.48-0.72)	0.8 (0.64-0.93)	0.9 (0.75-1.07)
Unexposed, % (95% CI)	0.1 (0.08-0.20)	0.2 (0.15-0.30)	0.3 (0.23-0.41)	0.4 (0.30-0.50)
t statistic	4.672	5.012	5.294	5.339
P value	<.001			

Did Exposure to Tips 2012 Digital Ads Influence Visits to Other Cessation Websites?

Figure 3 summarizes the proportion of exposed and unexposed panelists who visited any of the non–Tips 2012 cessation sites, including NRT sites, general cessation information sites, and state-specific cessation sites. The proportion of exposed panelists visiting other cessation websites increased from 0.2% in Week 1 to 0.3% in Week 4 after initial ad exposure. Unexposed panelists also visited other cessation websites but at lower rates, ranging from 0.0% in Week 1 to 0.2% at Week 4 (see Table 4). Significantly more panelists who were exposed to the Tips 2012 digital ads visited other cessation websites compared to unexposed panelists at 1, 2, 3, and 4 weeks after initial ad exposure (*P*=.001 to *P*=.019).

Figure 3. Shows the change in visits to cessation-related websites over the course of the campaign by digital ad exposure.

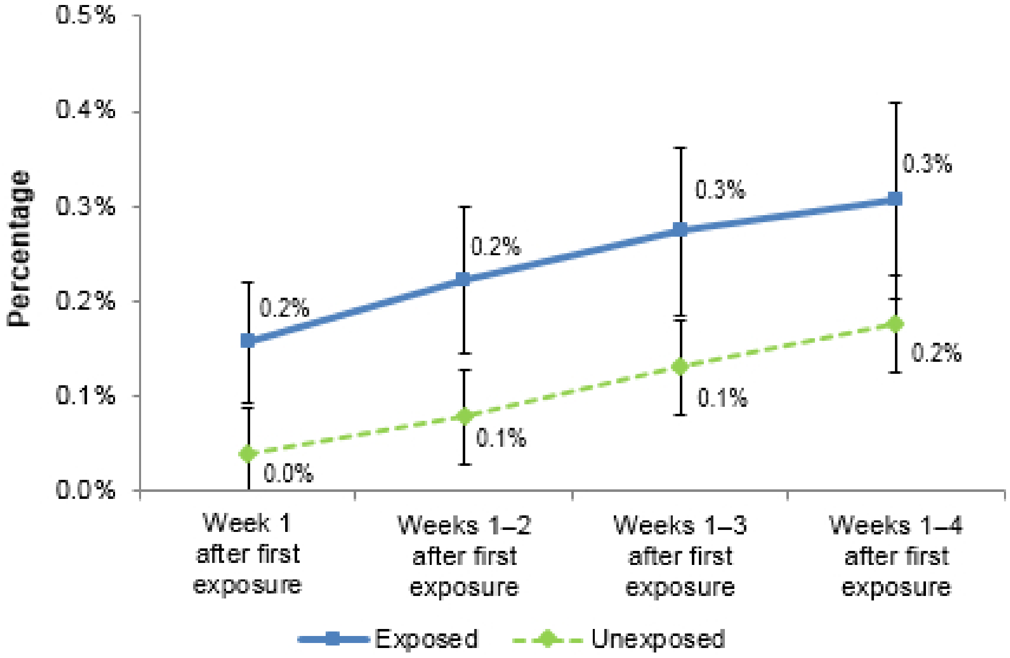


Table 4. Visits to other cessation sites (national, state, NRT).

	Week 1	Weeks 1-2	Weeks 1-3	Weeks 1- 4
Exposed, % (95% CI)	0.2 (0.09-0.22)	0.2 (0.14-0.30)	0.3 (0.19-0.36)	0.3 (0.20-0.41)
Unexposed, % (95% CI)	0.0 (0.00-0.08)	0.1 (0.03-0.13)	0.1 (0.07-0.20)	0.2 (0.10-0.26)
t statistic	3.135	3.053	2.560	1.973
P value	.001	.001	.005	.019

Did Exposure to Tips 2012 Digital Ads Influence Searches for Campaign-Related Topics?

Figure 4 summarizes the proportion of exposed and unexposed panelists who conducted searches on any of the campaign-related terms. The proportion of exposed panelists searching for cessation-related information increased from 0.2% in Week 1 to 0.7% in Week 4 after initial ad exposure. Unexposed panelists also conducted searches but at slightly lower rates from 0.2% in Week 1 to 0.5% at Week 4 (see Table 5). Rates of search behavior between exposed and unexposed panelists were only significantly different at 3 weeks after initial ad exposure (*P*=.032) and not at Weeks 1, 2, or 4.

Figure 4. Shows the change in CDC Tips 2012 campaign-related searches over the course of the campaign by digital ad exposure.

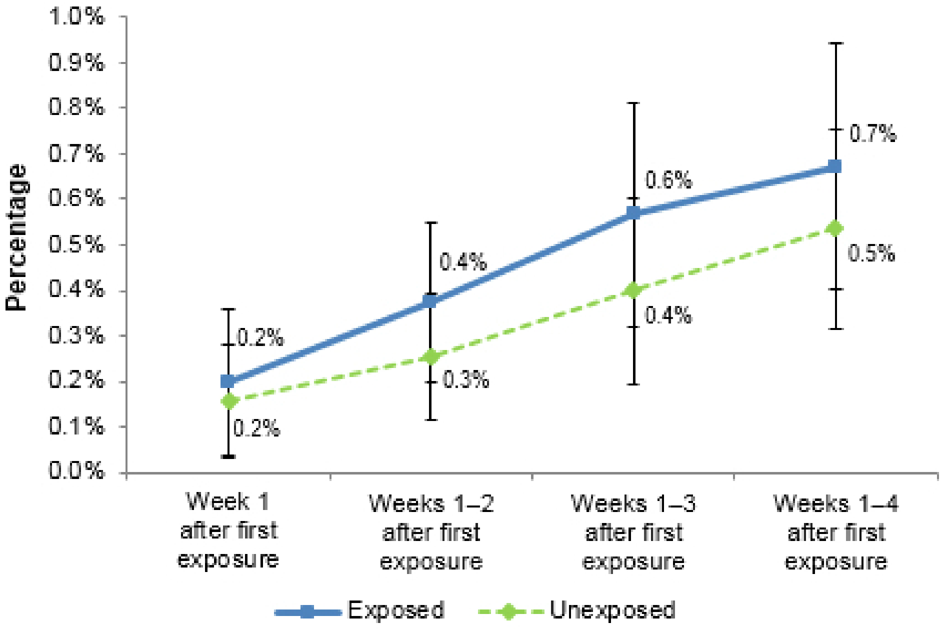


Table 5. Search for any cessation terms.

	Week 1	Weeks 1-2	Weeks 1-3	Weeks 1- 4
Exposed, % (95% CI)	0.2 (0.04-0.36)	0.4 (0.20-0.55)	0.6 (0.32-0.81)	0.7 (0.40-0.94)
Unexposed, % (95% CI)	0.2 (0.03-0.28)	0.3 (0.12-0.39)	0.4 (0.19-0.60)	0.5 (0.32-0.75)
t statistic	0.377	1.033	1.037	0.773
P value	.414	.066	.032	.122

Discussion

Principal Findings

In summary, exposure to Tips 2012 digital display and search ads influenced visits to the Tips 2012 campaign-related websites, with visits occurring even up to 4 weeks after initial ad exposure. The total proportion of exposed panelists who visited the Tips 2012 website was higher than the total CTRs for digital display ads over the entire campaign period (0.9% vs 0.1%), suggesting that CTRs alone may underestimate campaign reach. These results are consistent with findings from a previous study that used a similar methodology to examine the influence of digital display ad exposure on visits to Florida state tobacco cessation website and social media pages [20]. Visits by comScore panelists to the Smokefree.gov website were low overall, with no differences by Tips 2012 digital ad exposure. This is likely due to the fact that Tips 2012 digital ads showed the Tips 2012 website URL and linked directly to the Tips 2012 website rather than Smokefree.gov, which was promoted only in broadcast television ads. Additionally, the Tips 2012 website was optimized in greater detail than the Smokefree.gov website to pick up traffic from searches (ie, search engine optimization), which may have also accounted for the fewer visits to Smokefree.gov relative to Tips 2012.

Interestingly, exposure to Tips 2012 digital ads influenced other information-seeking behavior online. The increased visits to other cessation sites (eg, NRT sites, quitnet) among those exposed to the Tips 2012 ads suggest that the campaign had an added benefit of driving traffic to other cessation sites. Therefore, state programs could leverage the timing of a national campaign like Tips 2012 and supplement it with additional local ad buys to drive target audiences to seek cessation resources. Those exposed to the Tips 2012 digital ads were not consistently more likely to search for campaign-related cessation information than those unexposed. This may be because both groups were exposed to messages from other channels (eg, Tips 2012 television/radio ads) that may have influenced similar patterns of information-seeking behavior online. In this study, we were not able to control for exposure to campaign messages from other media channels. However, since consumers are increasingly using multiple media devices simultaneously (eg, nearly 40% of Americans use their tablets or smartphones while watching television [26]), future studies should examine the relative influence of advertising exposure across media platforms on information-seeking behavior. Although digital advertising has historically been viewed as a competitor to television advertising, media companies like Nielsen increasingly believe that given the “reality of today’s consumers and their cross-platform habits, the two forms [of advertising] should be viewed as complementary rather than competing” ([30], p. 6). There may be cross-media platform effects, so future studies need to assess how television and digital ads can be optimized to achieve synergies in the intended behavioral outcome.

We saw an increase in the proportion of panelists visiting the Tips 2012 campaign site over time, but we cannot be sure whether this was due to a latency effect (ie, panelists remembering the campaign ad and visiting the site later) or increased exposure to multiple Tips 2012 ads during the post ad exposure 4-week follow-up period. In this study, we examined only first exposure to Tips 2012 digital display ad, but future studies should assess whether there is a dose-response relationship between the amount of digital advertising exposure and information-seeking behaviors online. Future studies should also examine the relative effectiveness of different types of digital ads (ie, display ads vs video ads vs mobile ads) on information-seeking behavior as we were able to examine exposure only to display and sponsored link search ads in this study.

While we found statistically significant differences in website visits and campaign-related searches between the exposed and unexposed groups, overall, the magnitude of the visits and searches and the difference between the groups were small. It is challenging to put these findings in context given the paucity of research on the effects of digital ad campaigns. Further research is needed to build the evidence base for digital media campaign effects.

Strengths and Limitations

This study has several strengths. First, Web behavior data were collected unobtrusively, and ad exposure was measured regardless of whether the ad was clicked or not. Prior studies [32-36] have relied on self-reported survey data, the use of cookies, session identifiers, online ad campaign tracking (eg, Google AdWords), or website analytics tools (eg, Google Analytics), which have limitations such as recall bias or users deleting cookies that affect the accuracy of measuring campaign reach and exposure. Second, by matching unexposed and exposed groups on key demographics and online behavior, we were able to isolate the influence of digital ad exposure and minimize potential confounders. Third, we examined a comprehensive set of cessation websites (n=101) and search terms (n=2269) and were able to examine search behavior on major search engines like Google as well as any websites with search capabilities (eg, YouTube). To date, very few studies have examined how to measure online ad exposure and its effects on health information-seeking behavior online. To our knowledge, this is the first study that examines the impact of a national tobacco prevention campaign's digital advertising strategy on information-seeking behaviors online. We chose to examine information-seeking behavior because studies have shown that it is associated with health knowledge and behavior choices [37,38]. However, we acknowledge that behavior change is a complex process and therefore information-seeking may not directly lead to health behavior change. Future studies should examine whether online information seeking influences behavior change by linking respondents' Web visitation and search data to self-reported surveys.

This study also has limitations. First, we were unable to determine whether the increased visits to the campaign website were due to latency effects, increased level of digital ad exposure, or exposure to campaign content from other media channels. Future studies should examine the level and timing of ad exposure across media platforms to better understand dose-response relationships and cross-media effects. Second, we examined the influence only of display and search ad exposure, so we cannot determine whether these results would also translate to video or mobile ad exposure. Video ads may be more effective than display ads because advertisers can deliver more engaging and longer content in video formats and place these ads on sites like YouTube, which generate substantial traffic. Third, comScore's panel is a convenience sample, and although estimates are weighted to the online population, results may not generalize to the US adult population. Fourth, we were unable to examine how smokers specifically responded to campaign ads because information on panelists' smoking behavior was not available for this study. It is possible that panelists who were exposed to the digital ads were more likely to be smokers interested in quitting and therefore engaged in more information-seeking behavior online than the unexposed panelists. In this study, panelists were matched on demographic characteristics to isolate the influence of digital ad exposure, but future studies should investigate the impact of digital ad campaigns on specific subgroups. The audience that responds to digital ads is likely to be demographically and behaviorally different from the audience that responds to television ads. Therefore, understanding who is being reached can help campaign planners optimize media purchases across channels to reach target audiences most effectively. Finally, due to the confidential nature of proprietary data collected from comScore, we were unable to obtain detailed information about their methods (eg, specifics of data mining procedure) that may be needed to replicate studies of similar scope in the future. This is a common limitation when using data from digital analytics companies like comScore. For this reason, the national Media Rating Council conducts detailed audits of media industry companies to ensure that audience measurement services are valid, reliable, and ethical [39]. comScore's methodology has been reviewed and accredited by the Media Rating Council [40]. We used comScore data because they are an industry leader in monitoring consumer online behavior, and collecting this type of passive Internet activity data from a large population based panel would have been cost prohibitive on our own. As we increasingly turn to data from digital analytics companies to understand online health behaviors, a broader discussion is warranted around the tradeoffs of using proprietary data with confidentiality restrictions and disclosing sufficient level of details needed to evaluate and replicate this research.

Conclusions and Implications

The results of this study show that exposure to digital display and search ads is associated with confirmed visits to the campaign website up to several weeks after initial ad exposure regardless of whether the ad was clicked or not. Results also suggest that these ads may cue audiences to seek other cessation-related websites. Web behavior data from online panels are useful for examining exposure and behavioral responses to digital campaign ads because they provide a more comprehensive assessment of campaign impact than relying on ad impressions and CTRs alone. Future studies should examine the optimal dose needed to achieve information-seeking behaviors, the relative impact of different types of digital ads, cross-platform influences and synergies, and impact on specific subgroups like smokers. Digital advertising is a potentially powerful tool for motivating audience's information seeking around behaviors that are targeted in campaign messages. Researchers and practitioners have an opportunity to harness the vast volume of digital data to provide a more evidence-based approach to designing and evaluating digital media campaigns and to help inform best practices.

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Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
CTR: click-through rate
NCI: National Cancer Institute
NRT: nicotine replacement therapy
URL: Uniform Resource Locator

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Original Paper

Electronic Health Record Patient Portal Adoption by Health Care Consumers: An Acceptance Model and Survey

Jorge Tavares[1*], MSc; Tiago Oliveira[1*], PhD

NOVA Information Management School (IMS), Universidade Nova de Lisboa, Lisboa, Portugal

[*] all authors contributed equally

Corresponding Author:
Jorge Tavares, MSc
NOVA Information Management School (IMS)
Universidade Nova de Lisboa
Campus de Campolide
Lisboa, 1070-312
Portugal
Phone: 351 917330943
Fax: 351 213828611
Email: d2012072@novaims.unl.pt

Abstract

Background: The future of health care delivery is becoming more citizen centered, as today's user is more active, better informed, and more demanding. Worldwide governments are promoting online health services, such as electronic health record (EHR) patient portals and, as a result, the deployment and use of these services. Overall, this makes the adoption of patient-accessible EHR portals an important field to study and understand.

Objective: The aim of this study is to understand the factors that drive individuals to adopt EHR portals.

Methods: We applied a new adoption model using, as a starting point, Ventkatesh's Unified Theory of Acceptance and Use of Technology in a consumer context (UTAUT2) by integrating a new construct specific to health care, a new moderator, and new relationships. To test the research model, we used the partial least squares (PLS) causal modelling approach. An online questionnaire was administrated. We collected 360 valid responses.

Results: The statistically significant drivers of behavioral intention are performance expectancy (beta=.200; *t*=3.619), effort expectancy (beta=.185; *t*=2.907), habit (beta=.388; *t*=7.320), and self-perception (beta=.098; *t*=2.285). The predictors of use behavior are habit (beta=0.206; *t*=2.752) and behavioral intention (beta=0.258; *t*=4.036). The model explained 49.7% of the variance in behavioral intention and 26.8% of the variance in use behavior.

Conclusions: Our research helps to understand the desired technology characteristics of EHR portals. By testing an information technology acceptance model, we are able to determine what is more valued by patients when it comes to deciding whether to adopt EHR portals or not. The inclusion of specific constructs and relationships related to the health care consumer area also had a significant impact on understanding the adoption of EHR portals.

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KEYWORDS

UTAUT2; technology adoption; eHealth; health care consumers; electronic health records; technology acceptance

Introduction

Overview

Our study focuses on a specific type of eHealth technology, the patient-accessible electronic health record (EHR) portals [1-5]. To better understand the definition of EHR portals it is important to have a clear view of the technologies that support them. First are the patient portals, health care-related online applications that allow patients to interact and communicate with their health care providers [3,5]. The second is the EHR, meaning a repository of patient data in digital form, stored and exchanged securely. EHR systems are the software platforms that physician offices and hospitals use to create, store, update, and maintain EHRs for patients [2]. By definition, an EHR portal is a Web-based application that combines an EHR system and a patient portal, not only for patients to interact with their health care providers, but also to access their own medical records and medical exam results [2-7].

EHR portals may help patients carry out self-management activities, thereby making the use of the health care system more effective and sustainable, not only from the patient care standpoint, but also from a financial perspective due to rising health care costs and budgets in many countries [8-11]. A recent survey of US health care providers shows that 57% of health care institutions already have a portal in place and 71% value the integration of the EHR system within the patient portal by choosing a product (ie, patient portal interface) from their EHR vendor [7]. In Europe, not only health care providers, such as hospitals and clinics, provide EHR portals, but also governmental institutions make these platforms available to patients [8,12].

This concept of a national-level patient portal progressed into a trans-European initiative, the European Patients Smart Open Services (epSOS). epSOS concentrates on developing a practical eHealth framework, and an information and communication technology (ICT) infrastructure that enables secure access to patient health information among different European health care systems [13]. The pilot stage of this project, which ended in June 2014, focused on cross-border eHealth services in the following areas: patient summary and cross-border use of electronic prescriptions [13]. In the United States, a new guidance was issued by the Centers for Medicare & Medicaid Services (CMS) called Stage 2 meaningful use [5,14]. This guidance requires that the eligible professionals and hospitals that participate in the Medicare & Medicaid EHR Incentive Programs must give their patients secure online access to their health information, including EHRs [5,7,14]. Stage 2 meaningful use boosted the development of new integrated EHR portals in the United States by health care providers that, according to the new guidance, must not only implement it but also demonstrate effective use by the patients [5,7,14]. According to the literature, the most used features in EHR patient portals are as follows: scheduling medical appointments, email messaging, requesting prescription refills, and checking of patients' medical exams [1,3,15].

The aim of this study is to identify a set of determinants in the adoption of electronic health record portals by health care consumers. In our study, we examine these determinants in the field of eHealth technology use and acceptance by health care consumers. We then propose a new research model based on Venkatesh's Unified Theory of Acceptance and Use of Technology in a consumer context (UTAUT2) by integrating a new construct from the health care area, self-perception (SP), and a new moderator, chronic disability (CD) [2,16-18].

In this paper, we first review the literature concerning information technology (IT) adoption models regarding consumer health care. We then present a research model to analyze EHR portals for the health care consumer. Finally, we discuss the issue and present conclusions.

Theoretical Background

There have been several theoretical models developed from theories in psychology, sociology, and consumer behavior employed to explain technology acceptance and use [18]. The goal of this study is to focus specifically on EHR portal adoption from the perspective of the health care consumer, so it is of the utmost importance to review the literature in this particular field. Adoption of eHealth technologies by patients is clearly a very important topic in information systems (IS) in health care. The adoption of eHealth technologies by health care consumers still requires more attention and research due to the limited number of studies reported in the literature to date [2,19-22]. The use of the UTAUT2 model might be beneficial to eHealth adoption due to its consumer-specific constructs like price value [21].

When studying eHealth and health care adoption by health care professionals, the most common adoption models used are the technology acceptance model (TAM) [23,24] and the unified theory of acceptance and use of technology (UTAUT) [25-29]. Evaluating the studies published in the field of consumer health IT adoption, and more specifically in the use and adoption of eHealth tools by the health care consumer, most studies use TAM or extensions of TAM [19,30-34]. TAM was designed and tailored in IS contexts to predict information technology acceptance and usage on the job. TAM uses three dimensions: perceived usefulness (PU), that is "the degree to which a person believes that using a particular system would enhance his or her job"; perceived ease of use (PEOU), that is "the degree to which a person believes that using a particular system would be free of effort"; and attitude toward technology use [32,35,36]. PU and PEOU together affect the attitude toward technology use, which in turn influences behavioral intention to adopt [32,36]. UTAUT formulates a unified model that integrates elements of eight models in the field of IT acceptance, including from TAM, which incorporates the concept of PU as performance expectancy and PEOU as effort expectancy [35]. Apart from these two constructs from TAM, UTAUT also uses two other constructs, social influence and facilitating conditions (FC). All of these are joined together in the model along with four moderators—age, gender, experience, and voluntariness of use. The model and its relationships are illustrated in Figure 1 [35]. The R^2 obtained with UTAUT was superior to those of any of the individual models, including TAM, making a synthesis of the different theories by bringing together into the model the constructs that have a significant impact [18,35]. For example, with UTAUT it is possible to measure the impact of social influence on behavioral intention, something that was not measured with TAM [18,35]. Although UTAUT provides better results than TAM and other IS adoption models, the focus of UTAUT is also the employee technology acceptance at the individual level, which is not the focus of our paper because our target group is health care consumers [18].

Ideally, we need a model tailored to the consumer use context, and in this specific field, UTAUT2 was developed with this goal, obtaining very good results [18,21]. This new model includes the same four UTAUT constructs, but which are moderated differently. The constructs are now moderated only by age, gender, and experience [18]. The moderator *voluntariness of use* was dropped since the target population was not obliged to use the technology [18]. UTAUT2 also introduces three new constructs (ie, specific consumer adoption constructs): hedonic motivation, price value, and habit. Hedonic motivation and price value explain behavioral intention, while habit explains behavioral intention and use behavior [18]. Compared to UTAUT, the extensions proposed in UTAUT2 that are consumer specific produced a substantial improvement in the variance explained in behavioral intention (from 56% to 74%) and technology use (from 40% to 52%) [18]. Including these three new constructs made UTAUT2 a more suitable model for consumer-centered technologies [18]. Figure 2 explains the UTAUT2 model. The definitions of the different constructs used in the UTAUT and UTAUT2 models are provided in the Research Model section of this paper. Most of the existing UTAUT2 literature focuses on other types of technologies, such as online purchasing, mobile banking, and Web-based services [18,37-39]. A recently published study used UTAUT2 in health and fitness apps, which is not exactly the same technology scope and type of eHealth service as EHR portals, but obtained the following results: performance expectancy, hedonic motivation, price value, and habit were significant predictors of intention of continued usage [40].

Table 1 summarizes some of the studies performed in the area of eHealth, the theory or theories behind the studies, the dependent variable that is being explained by each study, and the most important findings. The target population in all studies was patients and the technologies have similarities with EHR portals [2,16,30,31,41,42].

Figure 1. Unified Theory of Acceptance and use of Technology (UTAUT) model adapted from Venkatesh et al [35]. Notes: 1. Moderated by age and gender; 2. Moderated by age, gender, and experience; 3. Moderated by age and experience; 4. Moderated by age, gender, experience, and voluntariness of use.

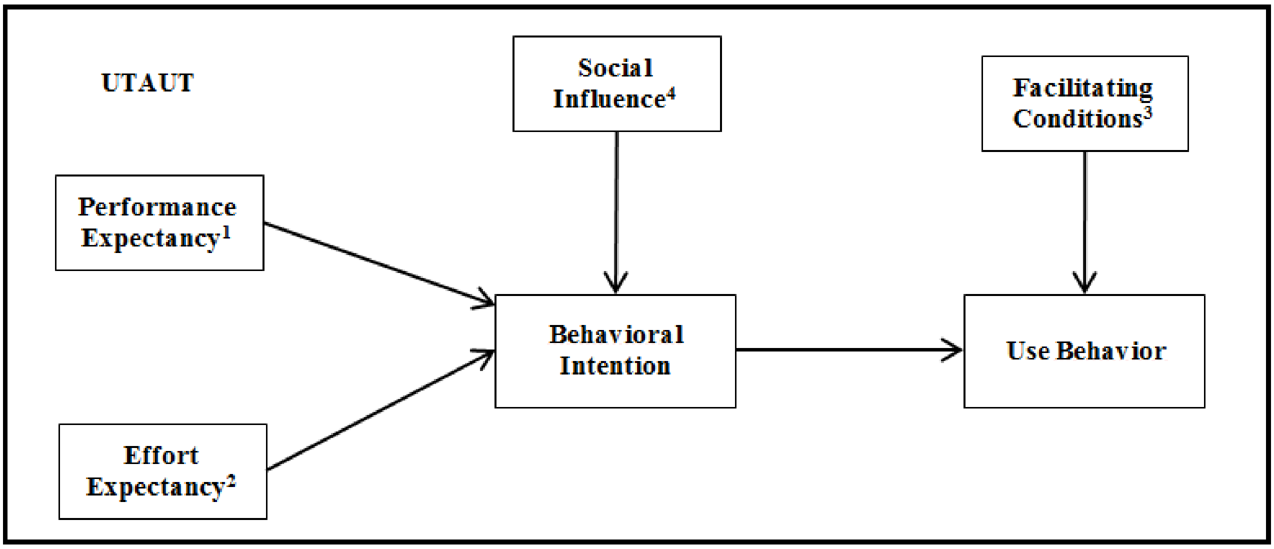


Figure 2. Unified Theory of Acceptance and use of Technology in a consumer context (UTAUT2) model adapted from Venkatesh et al [18]. Notes: 1. Moderated by age and gender; 2. Moderated by age, gender, and experience; 3. Effect on behavioral intention is moderated by age, gender, and experience. Effect on use behavior is moderated by age and experience; 4. Moderated by experience.

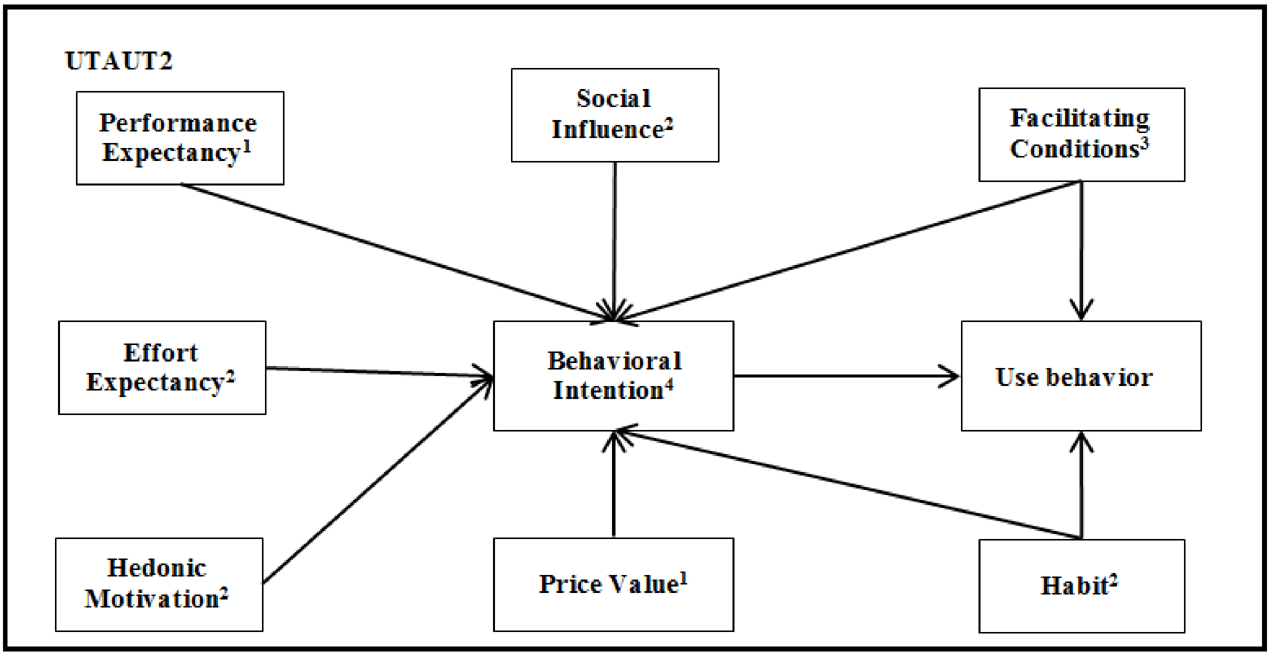


Table 1. eHealth adoption models.

Theory	Dependent variable	Findings	Reference
TAM[a], motivational model (MM), integrated model (IM)	eHealth behavioral intention	Users' perceived ease of use (PEOU), users' perceived technology usefulness (PU), intrinsic motivation (IM), and extrinsic motivation (MM) have a significant positive influence on behavioral Intention. IM does not have a better performance than TAM or MM when predicting behavioral Intention.	[30]
Elaboration likelihood model (ELM), concern for information privacy (CFIP)	EHR[b] behavioral intention	Positively framed arguments and issue involvement generate more favorable attitudes toward EHR behavioral intention. CFIP is negatively associated with likelihood of adoption.	[2]
TAM (qualitative study)	eHealth services behavioral Intention	PU seemed to be important. PEOU did not seem to be an issue. Although experience is not a TAM construct, it seemed to have influenced behavioral Intention.	[41]
TAM, plus several other constructs	Internet use behavior as a source of information	PU, importance given to written media in searches for health information, concern for personal health, importance given to the opinions of physicians and other health professionals, and the trust placed in the information available are the best predictors to use behavior.	[42]
Personal empowerment	Internet use behavior as a source of information	There are three types of attitudes encouraging Internet use to seek health information: professional, consumer, and community logic.	[16]
Extended TAM in health information technology (HIT)	HIT behavioral intention	PU, PEOU, and perceived threat significantly impacted health consumers' behavioral intention.	[31]

[a] TAM: technology acceptance model.

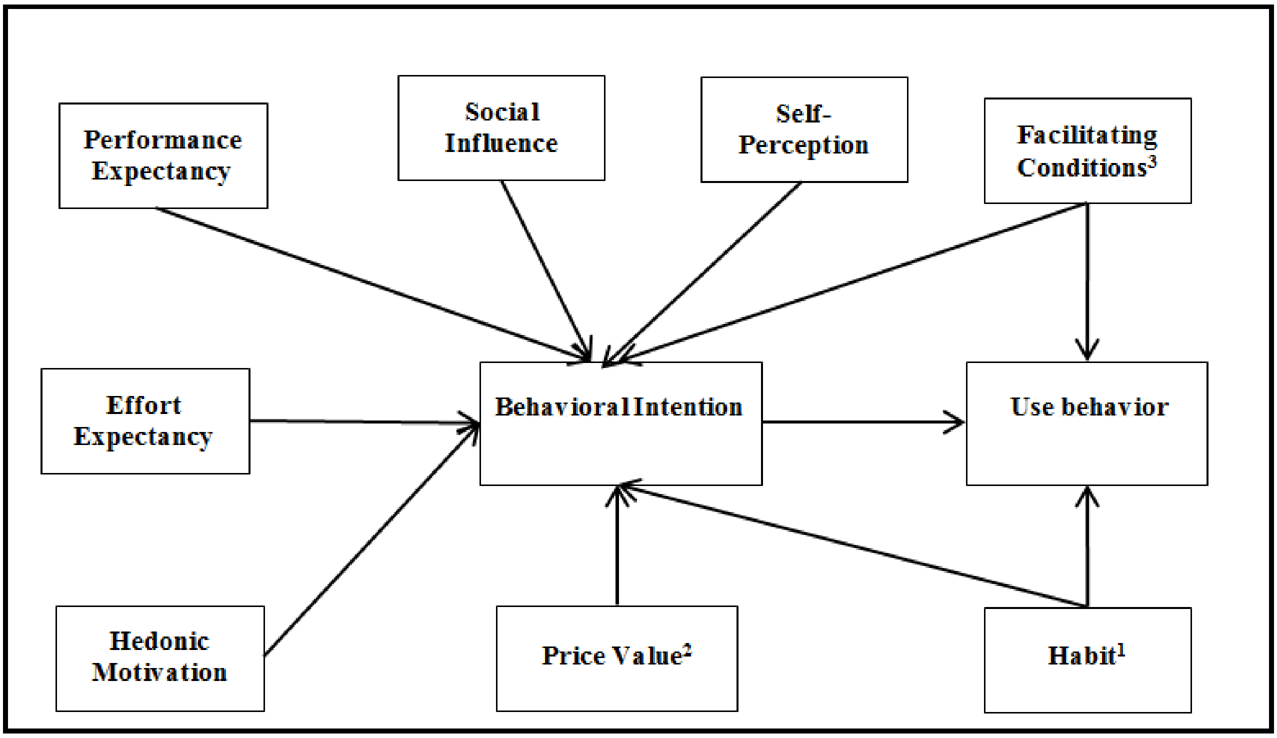
[b] EHR: electronic health record.

Research Model

UTAUT2 was developed as an adoption model providing the general factors of IT adoption in consumer use. However, according to Venkatesh et al [18], in certain situations in which the technology may be influenced by specific factors it may be necessary to extend the model with new constructs, moderators, and relationships. We therefore identified key additional constructs and relationships based on the literature review that are specific to IT health care adoption to be integrated into UTAUT2, thus tailoring it to the eHealth consumer context, with the special aim of studying the adoption of EHR portals. We did this by (1) identifying a key construct from earlier research in health care—self-perception—and by (2) adding a new moderator specific to health care use—chronic disability.

Published studies suggest that patients with chronic illness, severe illness, or disability are more likely to use eHealth technologies if they have the resources and support available [17,43,44]. A national survey in the United States shows that 86% of people living with disability or chronic illness with Internet access have looked online for information about health topics, compared with 79% of Internet users with no chronic conditions [44]. A recent study using a TAM extended version with the health belief model (HBM) measured the perceived health risk to chronic diseases [32]. Using chronic disability with UTAUT2 in the field of EHR portals is not only a new approach, but also one that takes advantage of the existence of the construct facilitating conditions—defined as the individual perception of the support available for using a technology activity [35]—that can be moderated by chronic disability, something that can be more properly tested with UTAUT2 than with TAM [18]. Recent studies tackled the need to study the variables that can drive the patients to be more active in their own health management [8,21]. Self-perception in health [45-47], called the self-perception construct, considers that the perceived, rather than the real, severity of the health complaint could be the propelling force behind the action in health care [45,47,48]. EHR portals are interfaces that links patients with health care professionals, and this construct is relevant to understanding if the patient's awareness about her/his own health status can be a driver to adopt EHR portals. Other studies using the health belief model with TAM [31,32] incorporated other constructs related to the health belief model concept. One such study was by Kim and Park [31], who studied health-related constructs like health belief and concerns or perceived health status, conceptually similar to self-perception, that have been shown to have an indirect effect on the behavioral intention to use health information technology [31]. This shows the importance of measuring this dimension in our study with a consumer-centered adoption model. Figure 3 illustrates the new research model.

Figure 3. The research model. Notes: 1. Moderated by age or gender; 2. Moderated by age; 3. Moderated by chronic disability on use.



Research Model: Extended Unified Theory of Acceptance and Use of Technology in a Consumer Context Model

Performance expectancy is defined as the degree to which using a technology will provide benefits to consumers in carrying out certain activities [35,49]. Our literature review indicates that health care consumers tend more to adopt eHealth technologies that provide clear benefits, such as obtaining an electronic medical prescription via EHR portals [8,50,51]. *Hypothesis 1* (H1) states that performance expectancy will positively influence behavioral intention.

Effort expectancy is the degree of ease related to consumers' use of technology [35]. The easier it is for consumers to understand and use an eHealth technology, the greater is the probability that they will adopt it [8,51]. *Hypothesis 2* (H2) states that effort expectancy will positively influence behavioral intention.

Social influence is the extent to which consumers perceive that others who are important to them (eg, friends and family) believe they should use a particular technology [18]. In the case of eHealth, this can also be an important construct since people who share the same diseases (eg, multiple sclerosis) or the same health condition (eg, obesity) tend to be influenced by others having the same condition [20,52]. *Hypothesis 3* (H3) states that social influence will positively influence behavioral intention.

The construct, facilitating conditions, is defined as the individual perception of the support available for using a technology activity [35]. One of the barriers to consumers' use of health services over the Internet is the consumers' lack of resources to access these platforms [51], suggesting that users with better conditions to use eHealth technologies favor EHR portals adoption. *Hypothesis 4 (a)* (H4 [a]) states that facilitating conditions will positively influence behavioral intention.

Chronic disability is an incapacitating situation (eg, chronic illness) that affects a patient permanently or for long-term periods. Our literature review reveals that patients with chronic illness or disability are more likely to use eHealth technologies if they have the resources and support available (ie, facilitating conditions) [17,20]. *Hypothesis 4 (b)* (H4 [b]) states that chronic disability will moderate the effect of facilitating conditions on use behavior, such that the effect will be stronger for chronically disabled people.

Hedonic motivation is defined as intrinsic motivation (eg, enjoyment) and has been included as a key predictor in much of the reported consumer behavior research [18]. Obtaining and dealing with information about our health status by using eHealth technologies may be an enjoyable process, or in some cases may not be when a patient has, for example, an incurable disease [53]. Nevertheless, in a recent study with UTAUT2 in eHealth, hedonic motivation was found to have a significant impact on behavioral intention [40]. We then propose that this specific construct may have a significant impact in predicting EHR portal use. *Hypothesis 5* (H5) states that hedonic motivation will have a positive influence on behavioral intention.

Price value in a consumer use environment is also a relevant factor as, unlike workplace technologies, consumers must bear the costs related with the purchase of devices and services [18]. If a patient can obtain her/his medical prescription via an EHR portal, she/he can save transportation costs by avoiding a trip to a health center or hospital. The better the perception a health care consumer has about the *price value* of an eHealth technology (ie, that it can help save money), the more likely it is that she/he will adopt it [8,11]; older people tend to give more importance to price in eHealth [21]. *Hypothesis 6* (H6) states that age will moderate the effect of price value on behavioral intention, such that the effect will be stronger for older people.

Habit can be defined as the extent to which people tend to execute behaviors automatically because of learning [18]. We can expect that habit will positively influence eHealth adoption, as it does in other IT adoption fields, since habit is a concept that should not be specific to an IT technology [18]. The literature review indicates that in eHealth, younger people and women tend to have the habit to use more eHealth technologies [17,20]. *Hypothesis 7 (a1)* (H7 [a1]) states that age will moderate the effect of habit on behavioral intention, such that the effect will be stronger for younger people. *Hypothesis 7 (a2)* (H7 [a2]) states that gender will moderate the effect of habit on behavioral intention, such that the effect will be stronger for women. *Hypothesis 7 (b1)* (H7 [b1]) states that age will moderate the effect of habit on use behavior, such that the effect will be stronger for younger people. *Hypothesis 7 (b2)* (H7 [b2]) states that gender will moderate the effect of habit on use behavior, such that the effect will be stronger for women.

Behind the concept, self-perception, is the health belief model. The model assumes that subjective health considerations determine whether people perform a health-related action, such as consulting their physician [45]. For example, the health belief model considers the perceived, rather than the real, severity of the complaint to be the propelling force behind the action [45].

Studies about patients that look for information online seem to confirm the concept of the health belief model; the results show that a larger proportion of respondents who described their health as poor indicated that they looked for health-related information online “often” compared with those who described their health as fair or better [54]. We therefore add self-perception as a predictor of health consumer behavioral intention to use a technology. *Hypothesis 8* (H8) states that self-perception will positively influence behavioral intention.

The role of intention as a predictor of usage is critical and has been well established not only in IS in general, but also in health care and eHealth, with the literature suggesting that the driver of using specific eHealth platforms is preceded by the intention to use them [18,22,30,31,35,45]. *Hypothesis 9* (H9) states that behavioral Intention will positively influence use behavior.

Methods

Measurement

All of the items were adopted from Venkatesh et al [18], Wilson and Lankton [30], and Vandekar et al [45] with small modifications in order to adjust to EHR portal technology. The items are shown in Multimedia Appendix 1. The questionnaire was administered in Portuguese through a Web hosting service after being translated by a professional translator. In order to ensure that the content did not lose its original meaning, a back-translation was made from the Portuguese instrument to English, again by a professional translator, and compared to the original [55].

The scales’ items were measured on a 7-point Likert scale, ranging from *strongly disagree* (1) to *strongly agree* (7). Use was measured on a different scale. The scale from UTAUT2—from *never* to *many times per day*—was adapted to *never* to *every time I need*, since EHR portal usage is not as regular as mobile Internet usage. Demographic questions about age and gender were also included; age was measured in years and gender was coded as a dummy variable (0 or 1), with women represented by 0. Chronic disability was coded as a dummy variable (0 or 1), with its absence represented by 0.

Before the respondents could see any of the questions, an introduction was made explaining the concept of EHR portals (see Multimedia Appendix 1). The aim of this introduction was to ensure that respondents were aware of this concept and had prior knowledge and contact with EHR portals, because the absence of this prior knowledge is an exclusion criterion.

Data Collection

A pilot survey was conducted to validate the questions and the scale of the survey. From the pilot survey, we had 30 responses demonstrating that all of the items were reliable and valid. The data from the pilot survey were not included in the main survey.

According to the literature, the technology that we are studying (EHR portals) is being used by less than 7% of the total number of health care consumers or patients [5,7,56]. We are therefore sampling a group of people that could be defined as a rare population, as it constitutes a small proportion of the total population, and specific sample strategies can be used that are suitable in this case [57,58]. We have a disproportionate stratification of our target population compared with the general population, because according to the literature, users and early adopters of these types of platforms have significantly higher education [19,43,59]. As a result, we focused our sampling strategy in places where our target population—users of EHR portals—are more concentrated [57,58]; thus, we selected educational institutions.

The survey, via hyperlink, was sent by email in October 2013 to a total of 1618 people at three institutions that provide educational services, from which we obtained 350 responses. NOVA Information Management School (IMS) approved and verified the ethical compliance of the questionnaire before its use. All participants were informed by email about the study purpose, confidentiality protection, and the anonymity of the information collected. A reminder was sent 2 weeks after the first email, only to those who had not responded to the first email, in order to improve the response rate. Following the reminder, we had a total of 465 respondents out of 1618 (28.74% response rate). After removing the invalid responses, the final sample consisted of 360 respondents. A questionnaire was considered invalid if not all questions were answered. According to our statistical modelling method, we cannot use incomplete questionnaires [60,61].

Data Analysis

To test the research model, we used the partial least squares (PLS) method, which is a causal modelling approach that represents a variance-based technique of path modelling [60]. Our main reasons for choosing this method were the complexity of the model (ie, many moderators) and the fact that the PLS method is oriented to explain variance of the research model and to identify key constructs [60-62]. We used the software program SmartPLS version 2.0.M3 (SmartPLS GmbH) [63] to estimate the PLS. Before testing the structural model, we examined the measurement model to assess construct reliability, indicator reliability, convergent validity, and discriminant validity.

Results

Sample Characteristics

Our sample characteristics are shown in Table 2.

The literature mentions that users of EHR portals are younger than the population average and have significantly higher education [19,43,59]; the results shown in Table 2 are aligned with the literature findings.

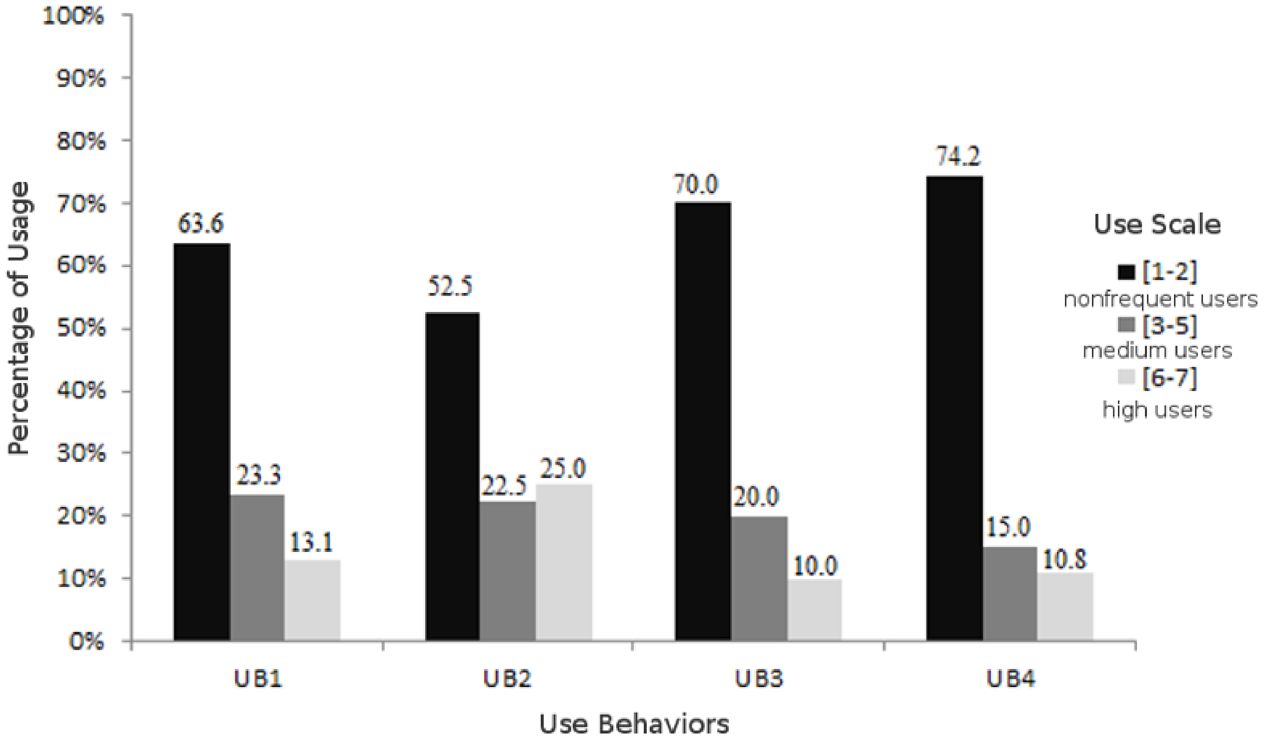
Usage Results

Use was measured on a scale that ranges from *never* (1) to *every time I need* (7). In Figure 4, we grouped the results by nonfrequent users of a particular EHR portal feature (scale from 1 to 2), medium users (scale from 3 to 5), and high users (scale from 6 to 7). These results show that the fact that people know about the technology and enter and register in these portals does not make them frequent users. Our study results are aligned with those of earlier studies and reports [3,12,17]; also, the results from our study show that only 30% of users use a portal regularly to check their EHR. Medical appointment scheduling is the feature with the highest usage.

Table 2. Sample characteristics (n=360).

Variable and category		Frequency, n (%)
Age in years		
	18-20	69 (19.2)
	21-24	75 (20.8)
	25-30	76 (21.1)
	31-40	89 (24.7)
	>40	51 (14.2)
Gender		
	Male	142 (39.4)
	Female	218 (60.6)
Chronic illness/disability		
	No	308 (85.6)
	Yes	52 (14.4)
Education		
	Undergraduate	132 (36.7)
	Bachelor’s degree	87 (24.2)
	Postgraduate	70 (19.4)
	Master’s degree or more	71 (19.7)

Figure 4. Types of usage patterns of electronic health record (EHR) portals. UB: use behavior; UB1: management of personal information and communication with health providers; UB2: medical appointment schedule; UB3: check their own EHR; UB4: request for medical prescription renewals.



Measurement Model

The results of the measurement model are shown in Tables 3, 4, and 5 and in Multimedia Appendix 2. To evaluate construct reliability, one can use Cronbach alpha or the composite reliability coefficient (CR). Although Cronbach alpha is more often used, CR is more appropriate for PLS since it prioritizes indicators according to their individual reliability and takes into account that indicators have different loadings, unlike Cronbach alpha [64]. Table 3 reports that all constructs have a CR greater than .70, showing evidence of internal consistency [60,65].

Table 3. Cronbach alpha, composite reliability, and average variance extracted.

Construct	Cronbach alpha	Composite reliability coefficient (CR)	Average variance extracted (AVE)
Performance expectancy	.90	.94	.83
Effort expectancy	.91	.94	.79
Social influence	.98	.98	.96
Facilitating conditions	.80	.87	.63
Hedonic motivation	.93	.96	.88
Price value	.93	.96	.88
Habit	.74	.85	.66
Self-perception	.67	.81	.52
Behavior intention	.90	.94	.83

In order to have good indicator reliability, it is desired that the latent variable explain more than half of the indicators' variances. The correlation between the constructs and their indicators should ideally be greater than .70 ($\sqrt{.50} \approx .70$) [60,65]. However, an item is recommended to be eliminated only if its outer standardized loadings are lower than .40 [66]. The measurement model has issues with two indicators' reliabilities—SP3 and SP5—which were removed; FC4, SP4, and SP6 are lower than .70, but still greater than .40 (see Multimedia Appendix 2).

In order to assess the convergent validity, we used average variance extracted (AVE). The AVE should be greater than .50, so that the latent variable explains, on average, more than 50% of its own indicators [64,67]. As shown in Table 3, all of the indicators respect this criterion. Finally, discriminant validity can be evaluated with the Fornell-Larcker criterion [67]. This criterion claims that a latent variable shares more variance with its indicators than with the other latent variables, so that the square root of AVEs should be greater than the correlations between the construct [60,67]. As seen in Table 4, all diagonal—square root of AVEs—are greater than the correlation between constructs—off-diagonal elements. In addition, another criterion can be assessed, although it is a more liberal one [60]. For each construct, we also examined if loadings are greater than all of its cross-loadings [61,68]. This criterion is also met, as seen in Multimedia Appendix 2.

Table 4. Correlations[a] and square root of average variance extracted[b].

	PE[c]	EE[d]	SI[e]	FC[f]	HM[g]	PV[h]	HT[i]	SP[j]	BI[k]	UB[l]	Age	Gender	CD[m]
PE	.91												
EE	.47	.89											
SI	.31	.24	.98										
FC	.25	.57	.23	.79									
HM	.47	.44	.31	.32	.94								
PV	.42	.33	.34	.26	.42	.94							
HT	.43	.29	.55	.26	.48	.46	.81						
SP	.04	-.08	.15	-.06	.08	.08	.16	.72					
BI	.50	.43	.43	.29	.44	.35	.61	.17	.91				
UB	.23	.18	.39	.24	.17	.23	.41	.10	.44	N/A[n]			
Age	-.01	-.04	.13	-.03	-.01	.08	.09	.08	.08	.20	N/A		
Gender	-.02	-.04	.05	0	-.08	.05	0	.05	-.03	0	.11	N/A	
CD	-.08	-.10	.02	-.08	-.06	-.02	.03	.24	.01	.13	.18	.09	N/A

[a] Off-diagonal elements are correlations.

[b] Diagonal elements are square roots of average variance extracted.

[c] PE: performance expectancy.

[d] EE: effort expectancy.

[e] SI: social influence.

[f] FC: facilitating conditions.

[g] HM: hedonic motivation.

[h] PV: price value.

[i] HT: habit.

[j] SP: self-perception.

[k] BI: behavioral intention.

[l] UB: use behavior.

[m] CD: chronic disability.

[n] N/A: not applicable, because they are not reflective constructs.

Use, which was modelled using four formative indicators, is evaluated by specific quality criteria related to formative indicators. As seen in Table 5, the variance inflation factors are all below 5, suggesting that multi-collinearity is not an issue [64]. In addition, the indicators comply with the criterion of being statistically significant or, if not significant, its outer loading must be higher than .50 [64].

Table 5. Formative indicators' quality criteria.

Indicators	VIF[a]	Weights	*t* (weights)	Outer loadings	*t* (loadings)
UB1[b]	2.609	.861	4.70[c]	.949	21.08[c]
UB2	1.707	.354	2.27[d]	.746	8.41[c]
UB3	3.237	.127	0.57	.741	8.46[c]
UB4	2.472	-.329	1.66	.543	4.50[c]

[a] VIF: variance inflation factor.

[b] UB: use behavior.

[c] $P<.01$.

[d] $P<.05$.

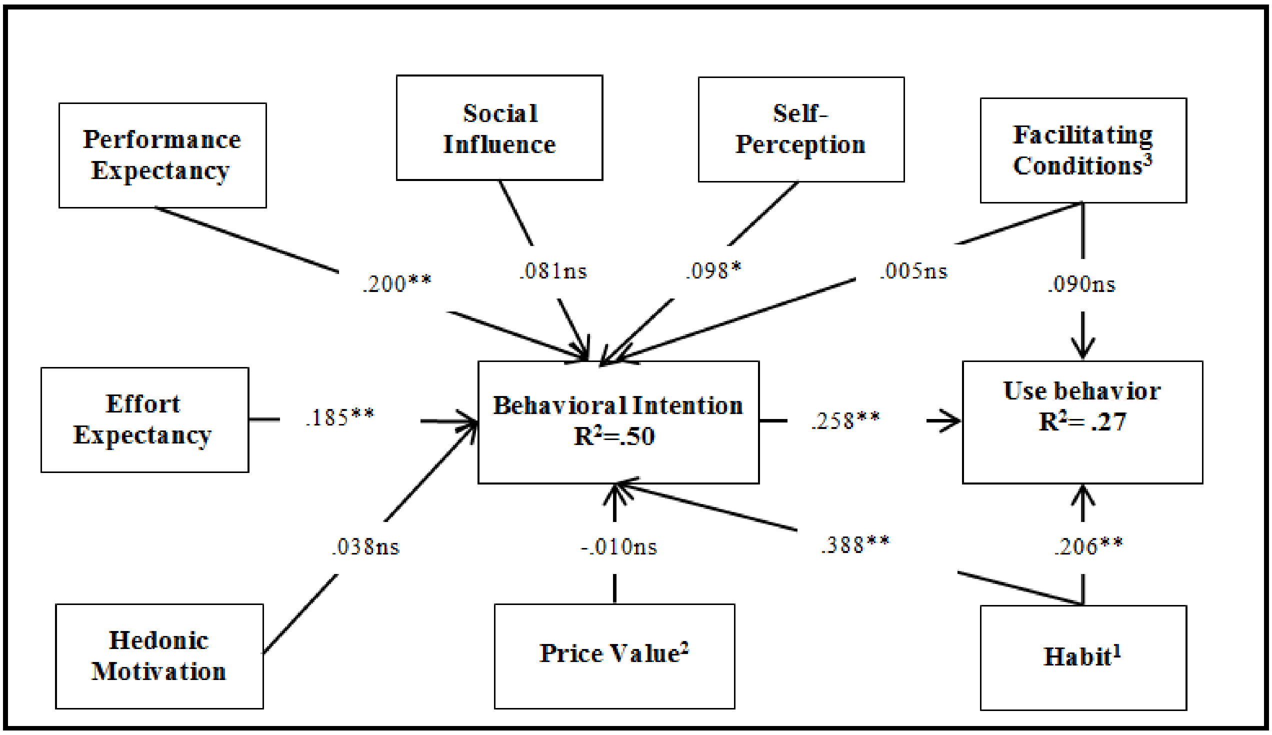
In sum, all assessments are satisfactory. This means that the constructs can be used to test the conceptual model.

Structural Model

The structural model path significance levels were estimated using a bootstrap with 5000 iterations of resampling to obtain the highest possible consistency in the results. The R^2 was used to evaluate the structural model. Overall, the model explains 49.7% and 26.8% of the variance in behavioral intention and use behavior, respectively (see Figure 5).

Table 6 presents a summary of all the hypotheses tested and their support (or not) based on statistical tests. As Table 6 shows, the predictors of behavioral intention are performance expectancy (beta=.200; *t*=3.619), effort expectancy (beta =.185; *t*=2.907), habit (beta =.388; *t*=7.320), and self-perception (beta = .098; *t*=2.285). The predictors of technology use behavior are habit (beta =.206; *t*=2.752) and behavioral intention (beta =.258; *t*=4.036). Age also has a positive and significant effect on use behavior. This finding suggests that older individuals use EHR portal technologies more than do younger individuals.

Figure 5. Structural model results. Notes: 1. Moderated by age or gender; 2. Moderated by age; 3. Moderated by chronic disability on use; **P*<.01; ***P*<.05; ns: nonsignificant.



We also tested the mediating role of behavioral intention between the independent variables and use behavior (see Table 7). To test if behavior intention mediated the independent variables on use behavior, we followed the Preacher and Hayes [64] approach. Initially, we check if only direct effects—without mediator (ie, behavior intention)—are statistically significant in explaining use behavior. Based on this (Step 1) we concluded that habit, facilitating conditions, and social influence are statistically significant, meaning that any of these factors might mediate behavior intention. Then in Step 2, we include the mediator variable (ie, behavior intention) in order to test if indirect effect of habit, facilitating conditions, or social influence are significant on use behavior. Only the indirect effect of habit is statistically significant (*P*<.01; *t*=3.472). Because of this fact, we compute the variance accounted for (VAF). The VAF is .38, meaning that behavior intention is a partial mediator of habit on use behavior [64]. Another important finding from this analysis is that in future studies it may be worth including a new relationship between social influence and use behavior, supported by a good literature background. This relationship is not foreseen in the UTAUT2 model.

Table 6. Summary of findings regarding hypotheses.

Dependent variables	Independent variables	Hypotheses (H)	Beta	*t*	R^2
Behavioral intention					49.7%
	PE[a]	H1 (supported)	.200	3.619[l]	
	EE[b]	H2 (supported)	.185	2.907[l]	
	SI[c]	H3 (not supported)	.081	1.544	
	FC[d]	H4 (a) (not supported)	.005	0.112	
	HM[e]	H5 (not supported)	.038	0.678	
	PV[f]	N/A[g]	-.010	0.203	
	PV x age	H6 (not supported)	.026	0.563	
	HT[h]	N/A	.388	7.320[l]	
	HT x age	H7 (a1) (not supported)	.033	0.584	
	HT x gender	H7 (a2) (not supported)	.010	0.183	
	SP[i]	H8 (supported)	.098	2.285[m]	
	Age	N/A	.065	1.408	
	Gender	N/A	.052	0.454	
	Gender x age	N/A	-.087	0.078	
	CD[j]	N/A	-.002	0.049	
Use behavior					26.8%
	FC		.090	1.755	
	FC x CD	H4 (b) (not supported)	.076	0.391	
	HT	N/A	.206	2.752[l]	
	HT x age	H7 (b1) (not supported)	.060	0.621	
	HT x gender	H7 (b2) (not supported)	.066	0.704	
	BI[k]	H9 (supported)	.258	4.036[l]	
	Age	N/A	.170	2.387[m]	
	Gender	N/A	-.013	0.092	
	Gender x age	N/A	.005	0.031	
	CD	N/A	-.081	0.476	

[a] PE: performance expectancy.

[b] EE: effort expectancy.

[c] SI: social influence.

[d] FC: facilitating conditions.

[e] HM: hedonic motivation.

[f] PV: price value.

[g] N/A: not applicable.

[h] HT: habit.

[i] SP: self-perception.

[j] CD: chronic disability.

[k] BI: behavioral intention.

[l] *P*<.01.

[m] *P*<.05.

Table 7. Mediating role of behavior intention on independent variables.

Step 1			Step 2			VAF[a]
Paths	Beta	*t*	Paths	Beta	*t*	
			PE[b]→BI[c]	.200	3.673[l]	
			EE[d]→BI	.188	2.844[l]	
			SI[e]→BI	.082	1.616	
			FC[f]→BI	.007	0.161	
			HM[g]→BI	.036	0.659	
			PV[h]→BI	-.007	0.131	
			HT[i]→BI	.392	7.313[l]	
			SP[j]→BI	.105	2.521[m]	
PE→UB[k]	.075	1.281	PE→UB	.067	1.125	
EE→UB	-.023	0.481	EE→UB	-.026	0.451	
SI→UB	.223	3.733[l]	SI→UB	.228	3.389[l]	
FC→UB	.124	2.609[l]	FC→UB	.132	2.578[m]	
HM→UB	-.107	1.617	HM→UB	-.112	1.629	
PV→UB	.012	0.192	PV→UB	.019	0.312	
HT→UB	.278	3.733[l]	HT→UB	.276	3.801[l]	
SP→UB	.065	1.122	SP→UB	.050	0.869	
			BI→UB	.271	3.746[l]	
			(FC→BI)×(BI→UB)	.003	0.256	
			(SI→ BI)×(BI→UB)	.021	1.390	
			(HT→BI)×(BI→UB)	.106	3.472[l]	.38

[a] VAF: variance accounted for.

[b] PE: performance expectancy.

[c] BI: behavioral intention.

[d] EE: effort expectancy.

[e] SI: social influence.

[f] FC: facilitating conditions.

[g] HM: hedonic motivation.

[h] PV: price value.

[i] HT: habit.

[j] SP: self-perception.

[k] UB: use behavior.

[l] *P*<.01.

[m] *P*<.05.

Discussion

Principal Findings

The results suggest that using our research model in a health-related area—EHR portal acceptance by health care consumers—yields good results, explaining 49.7% of the variance on behavioral intention and 26.8% of the variance in technology use [2]. The most important contributors with significant impact on behavioral intention are performance expectancy, effort expectancy, habit, and self-perception. The predictors of use behavior are habit and behavioral intention. The inclusion of a specific construct—self-perception—related to the health care consumer area had a significant impact on understanding the adoption of EHR portals, revealing the usefulness of integrating it into our research model. Age also had a positive and significant effect on technology use. This finding suggests that older individuals use EHR portal technologies more than do younger individuals, a belief that is found in the literature. There, it is mentioned that as age increases, the need for health care services also increases, and that this is reflected in more frequent access to health care services [8,69]. Our results were not able to support the finding that patients with chronic illness or disability are more likely to use EHR portals if they have the resources and support available. Our study had a lower proportion of people who mentioned having a chronic disability or illness compared with other studies [17,44]. This fact, together with the fact that our sample was also younger than those from other studies [17,44] and previous findings that older people usually require more support in using technologies [17,21,44], may explain why chronic disability did not achieve statistical significance as a moderator.

Theoretical Implications

Concerning our results, some of our hypotheses were supported and others not; both H1 and H2 were supported. In studies that have addressed similar problems, including those studying patient portals [19,30,31], both performance and effort expectancy, originally from TAM [36], also had a significant positive impact. In our study, social influence did not show a significant effect on behavioral intention, thereby not supporting H3. Although the literature mentions the potential impact of social influence on the adoption of eHealth technologies [20,52], another recent study using UTAUT2 in health and fitness apps found no significant impact of social influence on behavioral intention [40], which is aligned with our study results. The rejection of the facilitating conditions hypothesis, H4 (a), suggests that the subjects in our sample consider that the resources or knowledge to use EHR portals are not an issue. This can be explained by the facility of having access to a computer and the Internet [4,12] and agrees with recent literature findings in eHealth [40].

Our results were also not able to confirm that patients with chronic illness or disability are more likely to use EHR portals if they have the resources and support available, as stated in H4 (b). This stands at odds with findings reported in the literature [17,44]. Earlier studies that addressed the concept behind H4 (b) included older people and those with a higher proportion of chronic disease or disability in the sample [17,44]. This may account for the difference in the results between our study and those reported in the literature. Future studies could address the degree or type of chronic disability.

Hedonic motivation also has no significant impact on behavioral intention (H5). Hedonic motivation is defined as intrinsic motivation (eg, enjoyment) for using EHR portals. Patients seem not to perceive the use of EHR portals as an enjoyment. This is probably because much of the use of portals is driven by the presence of a disease or a health problem, and the need for the portal is associated with that unfortunate fact—something that does not promote enjoyment [53,70]. Hedonic motivation had a positive impact on behavior intention in an eHealth study about health and fitness apps that promote balanced lifestyles [40]. These apps potentially have a greater impact on a person's hedonic motivation than the motives leading patients to use EHR portals. H6 was not verified. In Europe, access to the majority of eHealth services is free of charge [1,9], so the value that is given to the patients is to enable them to perform certain tasks more effectively online. Unfortunately, that fact is not being perceived by the patients.

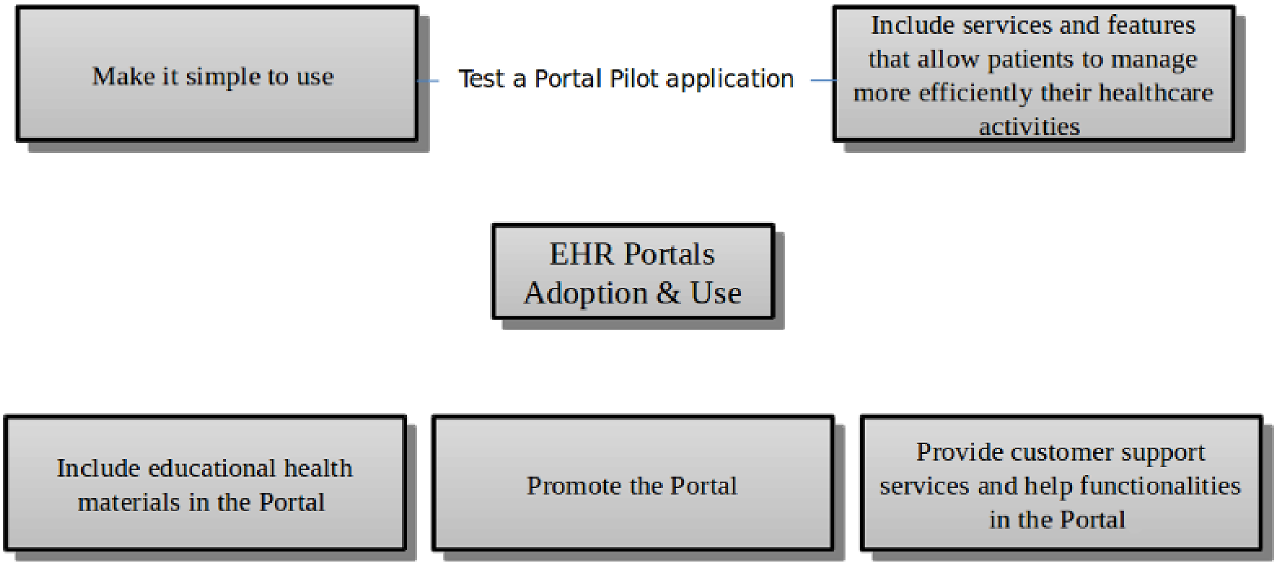
The impact of habit in behavioral intention and use behavior was not moderated by age or gender; H7 (a1), H7 (a2), H7 (b1), and H7 (b2) were therefore not supported. However, the construct habit has a significant impact on both behavioral intention and use behavior, in line with findings from literature that mention habit as a predictor of behavioral intention and use behavior [18,40]. Self-perception, a construct related to health care, has a significant impact on behavioral intention, supporting H8. People who have a greater perception that they have health problems are more likely to use EHR portals. Our study's findings are in line with other studies in this regard [31,47]. H9—behavioral intention will positively influence use behavior—was also supported. Literature suggests that using specific eHealth platforms is preceded by the intention to use them [18,22,30,31,35,45].

Overall, we were able to demonstrate that habit, a construct specific to consumer technology acceptance, and self-perception, which is related to the area of knowledge we are testing, are both very important in understanding the acceptance of EHR portals. Specific tailor-made models that incorporate specific changes related to the study's topic may be an effective option for studying complex areas of knowledge, such as IT health care.

Managerial Implications

The findings of this study have valuable managerial implications for the conceptualization, design, and implementation of an EHR portal. We found that performance expectancy and effort expectancy have a significant impact on the adoption of EHR portals. Earlier studies using TAM identified these constructs as being relevant for the adoption of patient portals [30,41]. One of these studies adopted a qualitative TAM approach to evaluate patient portals [41], and the opinion of health care consumers in that study was that the design of these platforms should be simple and easy to use [41]. It is very important when designing or redeploying an EHR portal to make it easy and simple to use, and we therefore suggest that a pilot application of the platform be tested by the potential users so that improvements can be made during the development stage to increase the platform's acceptance [71,72]. Our results suggest that there is a significant impact of health care consumers' habit on EHR portal use. In addition to the direct and automatic effect of habit on technology use, habit also operates as a stored intention path to influence behavior [18]. This demands greater marketing communication effort to strengthen both the stored intention and its link to behavior [18]. Promotional strategies should therefore be implemented not only on the Internet, but also in the health care institutions that the patient usually goes to [56]. Because habit has been defined as the extent to which people tend to perform behaviors automatically because of learning [18], it is critical that EHR portals have client support services to help users with the platform. Another important finding is that the construct that is specific to health care—self-perception—also has a significant impact on the intention to use EHR portals. Self-perception relates to the fact that the perceived, rather than the real, severity of the health complaint is the propelling force behind the action [45]. Health care interventions that make the patient more aware of her/his health condition(s) may also promote the use of the EHR portal. Having a population that is better educated and more aware about health status could lead to a greater adoption of eHealth services, especially EHR portals. Overall, the managerial implications mentioned here are important not only for increasing the adoption of EHR portals, but also for increasing the frequency of usage of current users, who in most cases are not frequent users (see Figure 4). Figure 6 summarizes the managerial implications.

Figure 6. Managerial implications. EHR: electronic health record.



Limitations and Future Research

We acknowledge that this research is limited by the geographic location, as it pertains to only one country and to only a sample of educational institutions. According to the literature, the technology that we are studying—EHR portals—is being used by less than 7% of the total number of health care consumers or patients [5,7,56]. The literature also mentions that users and early adopters of these types of platforms are younger than the population average and have significantly higher education [19,43,59]. Using a sampling strategy suitable to low-prevalence populations [57,58], we focused our sampling on educational institutions, where our target population is more concentrated [57]. It is also common to find studies that evaluate eHealth portals, addressing the users of a particular portal [16,19,30]. This is also a good strategy to target rare populations, but is also potentially biased as it reflects the opinions of only the users of a certain portal [19,57]. Another important fact that we acknowledge as a limitation in this study is that we were not able to collect the answers at more than one point in time. As a result, we could not use experience as a moderator in this study. Difficulties targeting the user population and the sensitivity of the topic related to EHRs [2] contributed to this limitation. The impact of chronic disability/illness as a positive moderator of facilitating conditions to explain technology use—pointed out as a possibility in the literature [17,44]—was not detected in our study. Nevertheless, only a small proportion of our sample (14.4%) mentioned having a chronic disability or illness and we did not collect information about its type or degree. Future studies might investigate this issue in greater depth.

Regarding the model tested, the inclusion of a health-related construct with significant positive impact demonstrates that it is relevant and that its inclusion is warranted. It also reveals the value of adding specific constructs related to the area in which the technology is used to existing frameworks. For future studies, it may also be advantageous to include other constructs (eg, confidentiality) that are not specific to health care but which, according to the literature, may be influential in eHealth adoption [2,19], or new relationships such as the one between social influence and use behavior. Some constructs from UTAUT2, notably hedonic motivation, do not seem to be relevant for EHR portal adoption and, in fact, self-perception seems to be a better motivational predictor. Future studies may therefore exclude this construct in order to avoid adding redundant complexity to the model. Another interesting future contribution is to evaluate mediated moderation in the research model.

Conclusions

EHR portal adoption is a new and growing field of study that is an important topic in government-level discussions in the European Union and the United States. In our study, we used a new model in which we identified key additional constructs and relationships based on the literature review that are specific to IT health care adoption and integrated them into UTAUT2. The research model was tested and was found to explain 49.7% of the variance in behavioral intention and 26.8% of the variance in EHR portal technology use. Of all the constructs tested, performance expectancy, effort expectancy, self-perception, and habit had the most significant effects on behavioral intention. Habit and behavioral intention had a significant effect on technology use. Two specific constructs—habit (consumer related) and self-perception (health care)—were very significant in explaining the adoption of EHR portals, showing how important it is to use specific adoption models that include constructs specific to the area. The impact of chronic disability as a moderator of facilitating conditions to explain use behavior was not supported in our study. Not only is the adoption of EHR portals still low, but most current users of these platforms use them only infrequently. We used the results obtained in this study to provide managerial insights that may increase the adoption and usage of EHR portals.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire items.

[PDF File (Adobe PDF File), 172KB - jmir_v18i3e49_app1.pdf]

Multimedia Appendix 2

Partial least squares (PLS) loadings and cross-loadings.

[PDF File (Adobe PDF File), 38KB - jmir_v18i3e49_app2.pdf]

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Abbreviations

AVE: average variance extracted
BI: behavioral intention
CD: chronic disability
CFIP: concern for information privacy
CMS: Centers for Medicare & Medicaid Services
CR: composite reliability coefficient
EE: effort expectancy
EHR: electronic health record
ELM: elaboration likelihood model
epSOS: European Patients Smart Open Services
FC: facilitating conditions
H1: hypothesis 1
H2: hypothesis 2
H3: hypothesis 3
H4 (a): hypothesis 4 (a)
H4 (b): hypothesis 4 (b)
H5: hypothesis 5
H6: hypothesis 6
H7 (a1): hypothesis 7 (a1)
H7 (a2): hypothesis 7 (a2)
H7 (b1): hypothesis 7 (b1)
H7 (b2): hypothesis 7 (b2)
H8: hypothesis 8
H9: hypothesis 9
HBM: health belief model
HIT: health information technology
HM: hedonic motivation
HT: habit
ICT: information and communication technology
IM: integrated model
IMS: Information Management School
IS: information systems
IT: information technology
MM: motivational model
N/A: not applicable
ns: nonsignificant
PE: performance expectancy
PEOU: perceived ease of use
PLS: partial least squares
PU: perceived usefulness
PV: price value
SI: social influence
SP: self-perception
TAM: technology acceptance model
UB: use behavior
UTAUT: unified theory of acceptance and use of technology
UTAUT2: unified theory of acceptance and use of technology in a consumer context
VAF: variance accounted for
VIF: variance inflation factor

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Original Paper

Personal Health Record Use in the United States: Forecasting Future Adoption Levels

Eric W Ford[1*], PhD; Bradford W Hesse[2*], PhD; Timothy R Huerta[3], MA, PhD

[1]Department of Health Policy and Management, Johns Hopkins University, Baltimore, MD, United States
[2]National Cancer Institute, Bethesda, MD, United States
[3]College of Medicine, Departments of Family Medicine and Biomedical Informatics, The Ohio State University, Columbus, OH, United States
[*]these authors contributed equally

Corresponding Author:
Eric W Ford, PhD
Department of Health Policy and Management
Johns Hopkins University
624 N Broadway
Baltimore, MD, 21205
United States
Phone: 1 806 787 3267
Fax: 1 410 555 1212
Email: ewford@gmail.com

Abstract

Background: Personal health records (PHRs) offer a tremendous opportunity to generate consumer support in pursing the triple aim of reducing costs, increasing access, and improving care quality. Moreover, surveys in the United States indicate that consumers want Web-based access to their medical records. However, concerns that consumers' low health information literacy levels and physicians' resistance to sharing notes will limit PHRs' utility to a relatively small portion of the population have reduced both the product innovation and policy imperatives.

Objective: The purpose of our study was 3-fold: first, to report on US consumers' current level of PHR activity; second, to describe the roles of imitation and innovation influence factors in determining PHR adoption rates; and third, to forecast future PHR diffusion uptake among US consumers under 3 scenarios.

Methods: We used secondary data from the Health Information National Trends Survey (HINTS) of US citizens for the survey years 2008, 2011, and 2013. Applying technology diffusion theory and Bass modeling, we evaluated 3 future PHR adoption scenarios by varying the introduction dates.

Results: All models displayed the characteristic diffusion S-curve indicating that the PHR technology is likely to achieve significant market penetration ahead of meaningful use goals. The best-performing model indicates that PHR adoption will exceed 75% by 2020. Therefore, the meaningful use program targets for PHR adoption are below the rates likely to occur without an intervention.

Conclusions: The promise of improved care quality and cost savings through better consumer engagement prompted the US Institute of Medicine to call for universal PHR adoption in 1999. The PHR products available as of 2014 are likely to meet and exceed meaningful use stage 3 targets before 2020 without any incentive. Therefore, more ambitious uptake and functionality availability should be incorporated into future goals.

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KEYWORDS

personal health records; electronic health records; patient participation; technology diffusion; Bass modeling; PHR Adoption Forecasts

Introduction

The 2009 US Health Information Technology for Economic and Clinical Health (HITECH) Act called for the creation of a meaningful use (MU) incentive program to distribute significant financial support to providers and health systems adopting electronic health record (EHR) technologies [1,2]. The program has been successful in boosting EHR adoption rates at least in the short term by applying exogenous incentives to a market that had otherwise been stalled. This was considered by many policy makers to be a necessary first step in establishing the infrastructure that could eventually be leveraged to improve the quality of care delivery and to encourage patients' engagement in improving their own health outcomes. In an external review led by the Robert Wood Johnson Foundation [3], reviewers observed that while the overall impact of HITECH and its many programs may not yet be clear, "the pace of adoption of technologies by the public is likely to continue at a rapid pace." Furthermore, the reviewers concluded, "Consumer engagement with technology is likely to bring further pressure to bear on health care organizations as patients seek ways to use these devices to track and transmit their own data and interact with health care health professionals."

This notion that consumer involvement would be a key to the success of HITECH in bringing about improved health outcomes was central to the formulation of the MU incentive program. In a report by the National Research Council (National Academies of Sciences, Engineering, and Medicine of the United States) released in 2009, a task force of informatics scientists noted that, for computational technology to be effective in health care improvement, it must provide functionality and cognitive support that is of value to providers, patients, and their caregivers [4]. Stage 2 of the MU incentive program requires the active engagement of patients and their families with patient portal technologies in managing their own health information and care coordination [5-7]. Stage 3 MU recommendations (originally scheduled for implementation in 2017 but now under policy reconsideration) state that patients should be able to (1) communicate electronically using secure messaging, (2) access patient education materials on the Internet, (3) generate health data into their providers' EHRs, and (4) view, download, and transmit their provider-managed EHRs. Taken together, these requirements outline the basic functionalities of a consumer-managed personal health record (PHR) [8].

PHRs offer a tremendous opportunity to generate consumer support in pursuing the triple aim of reducing costs, improving health outcomes for populations, and improving the experience of care for patients and their families [9-13]. Moreover, surveys have indicated that consumers want Web-based access to their medical records [14,15]. Nevertheless, diffusion of full patient access to their EHR-tethered portal or personally controlled PHR has been slow historically. Reasons given have included worries on the patients' side that full and open access to personal medical information could bring up privacy concerns; worries on the providers' side that the technical nature of Web-based medical information could create a health literacy burden; and concerns on the business side that MU stage 2-certified EHRs are not set up to support fully interoperable data exchange [16].

These concerns notwithstanding, a set of converging trends may be pushing consumer access to PHR functionality toward a patient-driven health information economy. Nearly two-thirds of the American public own mobile phones and have become accustomed to interactive services related to personal data in other facets of their lives. As reimbursement models change, health care providers will need to incorporate data from multiple sources in order to get a better picture of the total patient's preventive health needs [17]. For these reasons, there is an emerging need for more research into consumer engagement [9,14]. Given the current state of consumer usage levels, and observations associated with the diffusion of innovations in other settings, it should be possible to forecast PHR adoption uptake and explore how imitation and innovation factors are influencing the pattern.

The purpose of our study was to estimate the future uptake of PHR functionalities among the US population. We analyzed the Health Information National Trends Survey (HINTS), a nationally representative survey conducted by the US National Cancer Institute, to assess consumers' current use of Web-based apps to store personal health information and communicate with providers [18]. We also used the data to forecast the future adoption of these PHR apps.

Understanding the trajectory of PHR uptake by consumers is important for policy makers, providers, and technology vendors. For policy makers, setting PHR usage targets based on quantified estimates rather than normative goals will ensure that targets are set at optimal levels to accelerate uptake, but not be unachievable. The provider community has been resistant to health information sharing. Having evidence that consumers are not only willing, but also able, to effectively use such tools may lower this resistance. In addition, having an active and growing market for PHR technologies should spur health information technology vendors to invest in research and development to take advantage of this burgeoning market.

Methods

Data Source, Variables, and Sample

We analyzed 3 iterations of the HINTS version 4 survey of US adults (survey years 2008, 2011, and 2013). A calculated variable based on survey responses to 2 questions measured PHR functionality: (1) "In the last 12 months, have you used the Internet to keep track of personal health information such as care received, test results, or upcoming medical appointments?" and (2) "In the last 12 months, have you used email or the Internet to communicate with a doctor or a doctor's office?" These items capture 2 critical requirements for effective use of a PHR: storing clinical data electronically and communicating with a care provider over the Internet. We considered respondents answering yes to both items to be using basic PHR functionalities as described in the Centers for Medicare & Medicaid Services' MU program for EHRs. Data were weighted according to specifications provided by the National Cancer Institute to make the data representative of the United States overall. Adoption rates were calculated for use in the Bass model analysis.

Bass Modeling and the Technology Diffusion Model

Rogers [19] developed the technology diffusion theory that describes how innovators' (ie, first adopters), early adopters', early majority, late majority, and laggards' adoption patterns occur over time. Subsequently, Bass [20] developed the first commercial applications of such diffusion models, predicting the uptake of consumer products based on the influence of various types of advertising campaigns and motivations internal to the customer. The Bass model predicts how many customers will eventually adopt a new product, and when they will do so, based on early market penetration rates.

The model has several attractive properties. Empirical research by Bass [20] identified the latent factors that predict a technology's diffusion pattern as a function of external and internal influences. The *external influence coefficient*, represented by the letter p in the empirical model, represents the impact of innovation and advertising and the environmental context in which the innovation is embedded. In contrast, the *internal influence coefficient*, represented by the letter q, reflects the impact of relationships on diffusion, and is therefore often referred to as the imitation coefficient, the word-of-mouth effect, or social contagions in the diffusion literature [21].

The parameters p and q provide information about how a new technology will diffuse in the future. A high external influence coefficient (p) indicates that the diffusion has a quick start but also tapers off quickly. A high internal influence coefficient (q) indicates that the diffusion starts slowly and accelerates later as the product's benefits are spread, typically by word-of-mouth.

In concert, these variables interact to create diffusion dynamics. For example, when the internal influence coefficient (q) is larger than external influence coefficient (p), the cumulative number of adopters follows the type of S-curve often observed for high-risk, innovative products that take extended time frames to become widely used. When the internal influence coefficient (q) is smaller than the external influence coefficient (p), the cumulative number of adopters follows an inverse J-curve trajectory, often observed in less-risky innovations, such as new consumer durables (eg, washers and dryers).

Analysis

We conducted a sensitivity analysis to test the Bass model's parameters and create a possible range of future PHR uptake by varying the technology introduction year [22]. The oldest estimates for PHRs entering the market place with the minimum functionalities described above puts their introduction around the year 2001 [23]. Halamka et al [24] documented the developmental period for the first PHRs and identified 2007 as being the first year that clinically based apps accessed through providers' systems, rather than Web-based technologies managed by consumers (eg, HealthVault and WebMD), were widely available to the public. Similarly, Kaiser Permanente, a US managed care provider, made its clinically linked PHR available to all members in 2007 [25]. Therefore, we used 2001 and 2007 as potential PHR innovation start dates. Additionally, we analyzed 2004 as a midpoint to assess model fit.

We conducted the statistical analyses and forecasts using linear optimization in Microsoft Excel for Mac 2011 (Microsoft Corporation). The model was constrained to ensure that the theoretical model fit within 2% of actual data throughout the estimates. The models were analyzed using both generalized reduced gradient algorithm for nonlinear functions and the evolutionary algorithm for assessing discontinuous change. The generalized reduced gradient algorithm identified better model fits in every instance and they are the only results we report for this study. As an additional model reliability assessment, we reran the models with their last year of data omitted to assess how the trends would vary under different amounts of input.

Results

Over the survey years, consumers were increasingly using electronic media for both storing health data and communicating with their clinical providers (see Table 1). Based on survey weighting, approximately 8 million people were using the 2 basic PHR functionalities tracked in 2008 (eg, storing data on the Internet and communicating electronically with a clinical provider). Similar to other Internet-based social media, the PHR functionality uptake among consumers grew rapidly and exceeded 31 million users in 2013 [26].

In addition to the rapid growth in the number of individuals using the two technologies that are at the core of the PHR together, there was a steady growth in the number of consumers using one of the tools to manage the flow of health information. In particular, the use of technology to communicate directly with clinicians has been growing rapidly.

The PHR adoption scenario that used a 2001 technology introduction date had the tightest constraints and generated estimates that most closely approximated the observed experiences to date (see Table 2). The 2004 start date performed next best, with the 2008 and 2013 estimates slightly understating the observed rates of PHR use. The 2007 start date's estimates performed in a similar pattern to the 2004 version, albeit in a slightly more exaggerated fashion. These differences are caused by the internal and external coefficients that underlie the models' operations moving to more extreme values.

The external (p) and internal (q) coefficients for the 2001 and 2004 PHR introduction dates are consistent with results from a wide range of other products' diffusion patterns that have been studied using the Bass model [27]. The sensitivity analysis shows that the PHR diffusion models with a 2004 start date provide a motivation coefficient ratio (q/p=30.092) that is the most similar to prior studies from other domains. Assessing the 2004 model's stability by omitting the last year's data did not significantly change the forecasts, and the estimate for year 2020 was within seven-tenths of 1% of the model using data from the 3 years 2008, 2011, and 2013.

The internal coefficient (q) for 2007 is lower than in most prior studies but is still plausible. The external coefficient (p) for the 2007 start date is within the normal range (see Table 3). Moreover, all 3 Bass models suggest that PHR-like, Internet-based personal health information management innovations will make significant gains in future.

Table 1. Extracted response rates for items of interest measuring PHR[a] functionality based on HINTS[b] weightings.

Responses to items[c]	Survey year 2008	2011	2013
Yes to both PHR items, n (%)	7,878,118 (5.16%)	15,407,840 (9.80%)	31,220,465 9 (17.17%)
Yes to clinician communication item only, n (%)	12,881,980 (8.44%)	14,665,440 (9.32%)	22,880,580 (12.58%)
Yes to tracked personal health information item only, n (%)	13,897,188 (9.11%)	14,761,217 (9.39%)	19,969,109 (10.98%)
No to both PHR items, n (%)	117,944,796 (77.29%)	112,444,964 (71.49%)	107,794,014 (59.27%)
Total number of responses	152,602,082	157,279,461	181,864,168

[a] PHR: personal health record.

[b] HINTS: Health Information National Trends Survey. Data are reweighted to create a nationally representative sample.

[c] Questions regarded whether respondents used (1) Internet-based health information storage and (2) Internet-based communication with physicians in the past year.

Table 2. Differences between HINTS[a] survey results and Bass modeling estimates for personal health record adoption among US consumers.

	Observed uptake rate (survey results)	Technology introduction start date 2001 Bass	 Difference	2004 Bass	Difference	2007 Bass	Difference
HINTS year							
2008	5.16%	4.54%	–0.623	4.36%	–0.800	3.96%	–1.20
2011	9.80%	10.50%	0.700	10.60%	0.800	11.00%	1.20
2013	17.17%	17.17%	0.000	16.82%	–0.352	16.41%	–0.76
Mean difference			0.020		0.117		0.253

[a] Health Information National Trends Survey (HINTS) for 2008, 2011, and 2013 serve as the known observations. Bass estimates are based on the first year when various experts identify a minimally functioning personal health record being available in the marketplace.

Table 3. Sensitivity analyses for internal and external coefficients.

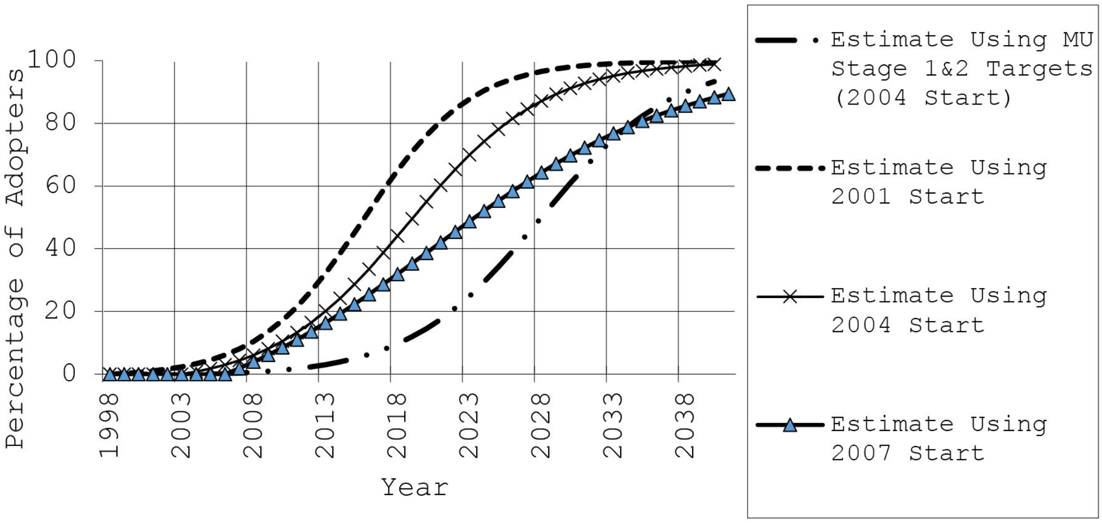
	External coefficient (p)	Internal coefficient (q)	Motivation coefficient ratio (q/p)
Innovation introduction start date			
2001	0.002	0.268	117.040
2004	0.007	0.214	30.092
2007	0.018	0.095	5.181
MU[a] targets	0.002	0.217	148.44

[a] MU: meaningful use incentive program of the US Health Information Technology for Economic and Clinical Health (HITECH) Act. The start date for personal health record availability for the MU model is 2004.

The MU model estimates a diffusion curve based on personal health record adoption targets set by policy. The resultant curve suggests the diffusion of these innovations if we assume the MU minimum targets for the diffusion trajectory. Notably, the external coefficient (p=.002) of the MU policy targets creates an expectation of diffusion that is very low compared with most other research on technology adoption. We found that MU policy targets create a diffusion pattern similar to what we might find if we had started this policy in 2001 with a much lower social contagion effect (q/p=148.44). The net result for the MU stage 2 and 3 targets is a diffusion pattern of much lower consumer uptake of PHR functionalities than would occur under conditions without an intervention.

Graphing the PHR diffusion models, all the versions display the characteristic S-curve of a product adoption that will be sustainable (see Figure 1). Both the 2001 and 2004 start-date forecasts indicate that a plurality of the US population will be using key PHR functionalities by 2020 in excess of the MU goals. Only the 2007 start-date curve indicates that there will be a diffusion rate that will not meet most proposed MU program objectives for PHR adoption.

Figure 1. Projected diffusion patterns for Internet-based personal health record adoption in the United States, by year of introduction. MU: meaningful use incentive program of the US Health Information Technology for Economic and Clinical Health (HITECH) Act.



Discussion

The diffusion of PHR-like apps among US consumers is proceeding rapidly. Based on the high values for the internal coefficient (*q*) on the best-performing model (ie, 2004 PHR introduction date), the diffusion rate is following the trajectory associated with the long-term adoption of consumer-driven technologies. Moreover, the adoption trajectories for all of the observed models exceed the policy targets articulated for MU stages 2 and 3.

With respect to PHR policy incentives, the MU program has included inducements for health systems and providers to make PHR functionalities available to consumers [28]. MU stage 2 requires EHR systems to allow patients to see their medical records, transmit their records to others, and communicate with their provider through a secure portal. Specifically, 5% of patients must be using the provider communication functionality by 2014 for the provider to be eligible for reward payments. These are minimal capability and engagement targets, and no specific populations are identified as being most likely to benefit [29,30]. As described in the regulation, the record sharing does not require an interoperable record that would allow another provider to bring data into its own system in a structured fashion. This results in data exchange with limited utility for patients using a third-party's or other provider's PHR app.

MU stage 3 has slightly higher thresholds for consumer engagement than stage 2. The percentage of consumers who must communicate electronically with their provider rises from 5% under stage 2 (target date of 2014) to 10% under stage 3 (target date of 2017). The percentage of consumers who must have access to their entire record under stage 3 targets is 50%. Neither stage 2 nor stage 3 requires the downloaded PHR be interoperable with other providers' health information technology systems.

The MU model's slower consumer adoption rate is driven by a low external coefficient (*p*=.002) relative to the 2004 technology introduction forecasts (*p*=.007). The low external coefficient suggests that the MU program may be having the opposite of its intended effect by slowing innovation. This is likely explained by 2 factors. First, health information technology system vendors and providers may be making the minimum PHR functionalities available instead of adopting the higher-level capabilities available in nonclinical contexts that attract consumers to engage with these tools. For example, the user experience of some personal health tracking tools is much better and stylized than the current PHR tools. While numerous groups, as well as the US government, have explored potential design options for improving the user experience in this context, those innovations have not found their way into the current generation of PHRs.

Second, care providers may be creating barriers to technology adoption through bureaucratic and administrative burden, although most have attested to exceeding the MU standards [31]. There is a significant concern about the liability of releasing PHR data outside the institutional firewall. The result is significant adoption costs, especially in terms of time, for patients using PHRs. The internal coefficient (*q*=.217) for the MU program forecast is comparable with the other models, suggesting that, under any circumstance, consumer demand for PHR functions will remain strong. Using the stage 2 and 3 consumer engagement targets as diffusion forecasts yields the lowest consumer uptake rates of any model. The internal to external coefficient ratio (*q*/*p* = 148.44) is the highest of any forecast, suggesting that consumers' desire for the product, rather than ongoing product innovations, will be the primary driver of PHR diffusion rates under this scenario.

Limitations

The research described herein has 3 main limitations. First, the HINTS instrument provides valuable insights into consumer behavior; however, the questions asked in earlier iterations did not explicitly refer to PHR technologies. Therefore, the results are only an approximation of the actual phenomenon. Second, a limitation inherent in the HINTS instrument is that it does not account for other people managing someone else's health information. In many households, one individual manages the care for other family members, including children and parents. The extent to which this is being carried out electronically was not measured. Thus, the actual prevalence of PHR use may be higher. Third, it is likely that new PHR functionalities will fundamentally change the technology and be, in effect, a new product. The release of a "new" product versus an "updated" iteration means there will be a new start date for the PHR introduction, which will change the curve profiles. A better understanding of what constitutes a new product in this marketplace merits discussion.

Conclusion

Consumers' PHR use is growing in both the numbers of people engaged and the degree of technological functionality they can manage [32]. As organizations identify ways to make these tools more widely available, sophisticated PHR technologies would move from the domain of early adopters to the widespread use among a majority of consumers in the market. As this occurs, the primary factor limiting PHR functionalities' diffusion may well be health care vendors' and providers' reticence to deploy these tools in a manner that resonates with the patient. It is *not* the consumer who is unwilling to use these tools, but the deployment and barriers they face that limits their adoption.

Vendors and providers are not the only component slowing adoption. MU goals on this issue may have the same problems in PHR adoption that they experienced in EHR adoption: the standards of engagement are low enough to allow for incremental approaches to adoption as opposed to incentivizing transformative targets. Policy discussions in a "post-meaningful use" world would benefit from insights provided through these types of data-based diffusion analyses, especially as the emphasis shifts away from applying endogenous incentives for adoption, to driving innovation to curry the interest of engaged consumers [33]. Robert Wachter, in his book *The Digital Doctor: Hope, Hype, and Harm at the Dawn of Medicine's Computer Age*, summed up the future prospects of health information technology this way: "The real action—and the money—will shift to creating innovative tools to allow patients to stay healthy and to manage chronic illness" [34].

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Abbreviations

EHR: electronic health record
HINTS: Health Information National Trends Survey
HITECH: Health Information Technology for Economic and Clinical Health
MU: meaningful use
p: external influence coefficient
q: internal influence coefficient
PHR: personal health record

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Original Paper

The Impact of Personality Factors and Preceding User Comments on the Processing of Research Findings on Deep Brain Stimulation: A Randomized Controlled Experiment in a Simulated Online Forum

Insa Feinkohl[1], PhD; Danny Flemming[1], Dipl.-Psych.; Ulrike Cress[1,2], Dr rer soc, Dipl.-Psych.; Joachim Kimmerle[1,2], Dr rer nat, Dipl.-Psych.

[1]Leibniz-Institut für Wissensmedien | Knowledge Media Research Center, Knowledge Construction Lab, Tuebingen, Germany

[2]Department of Psychology, University of Tuebingen, Tuebingen, Germany

Corresponding Author:
Joachim Kimmerle, Dr rer nat, Dipl.-Psych.
Leibniz-Institut für Wissensmedien | Knowledge Media Research Center
Knowledge Construction Lab
Schleichstr. 6
Tuebingen, 72076
Germany
Phone: 49 7071 979 363
Fax: 49 7071 979 100
Email: j.kimmerle@iwm-kmrc.de

Abstract

Background: Laypeople frequently discuss medical research findings on Web-based platforms, but little is known about whether they grasp the tentativeness that is inherent in these findings. Potential influential factors involved in understanding medical tentativeness have hardly been assessed to date.

Objective: The research presented here aimed to examine the effects of personality factors and of other users' previous contributions in a Web-based forum on laypeople's understanding of the tentativeness of medical research findings, using the example of research on deep brain stimulation.

Methods: We presented 70 university students with an online news article that reported findings on applying deep brain stimulation as a novel therapeutic method for depression, which participants were unfamiliar with. In a randomized controlled experiment, we manipulated the forum such that the article was either accompanied by user comments that addressed the issue of tentativeness, by comments that did not address this issue, or the article was accompanied by no comments at all. Participants were instructed to write their own individual user comments. Their scientific literacy, epistemological beliefs, and academic self-efficacy were measured. The outcomes measured were perceived tentativeness and tentativeness addressed in the participants' own comments.

Results: More sophisticated epistemological beliefs enhanced the perception of tentativeness (standardized β=.26, P=.034). Greater scientific literacy (stand. β=.25, P=.025) and greater academic self-efficacy (stand. β=.31, P=.007) were both predictors of a more extensive discussion of tentativeness in participants' comments. When forum posts presented in the experiment addressed the issue of tentativeness, participants' subsequent behavior tended to be consistent with what they had read in the forum, $F_{2,63}$=3.66; P=.049, η_p^2=.092.

Conclusions: Students' understanding of the tentativeness of research findings on deep brain stimulation in an online forum is influenced by a number of character traits and by the previous comments that were contributed to the forum by other users. There is potential for targeted modification of traits such as scientific literacy, epistemological beliefs, and academic self-efficacy to foster critical thinking in laypeople who take part in online discussions of medical research findings.

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KEYWORDS

medical news; online forum; scientific literacy; epistemological beliefs; academic self-efficacy; tentativeness

Introduction

The resources made available to medical research have seen a steady increase over the past century [1,2]. Health and disease are better understood than ever, and novel technologies for diagnosis and therapy are continuously being developed. The mass media landscape has undergone a kind of evolution that parallels this development. Following what has been termed "scientific malnutrition" during the 20th century [3], mainstream media have increasingly begun to report on findings from medical research studies [4,5]. With the rise of online media and subsequently of Web 2.0, which allows readers to "share" news items among their associates, the global distribution of health news items now reaches vast dimensions [6,7].

Like all scientific research, that in the medical domain is affected by the inherently uncertain, temporary, and revisionary nature of scientific findings [8,9], which is referred to in the literature as the "tentativeness" [8,10,11] of science. This tentativeness is characterized by the fact that research findings are frequently quite controversial and that they are contradictory or inconsistent [8,10]. Usually, scientific findings are provisional and they cannot readily be generalized.

When confronted with medical research findings in the media, it is important for non-professionals to detect and to understand this tentativeness [10,12] because the perception of medical research has an impact on making personal decisions related to health. Coverage of health-related topics in the media, for instance, is correlated with the frequency of online searches for that topic [13]. Understanding and appreciating the tentativeness of medical research findings are important for applying critical thinking to the medical context [14].

The Impact of Web 2.0 on Perceiving Media Content

Laypeople's understanding of tentativeness has gained relevance with the rise of Web 2.0. With the term laypeople, we refer to all Internet users who are not medical experts but nevertheless are interested in reading and understanding online newspaper texts about medical topics. So with laypeople, we mean casual readers of science journalistic texts who do not necessarily have to be patients or individuals with the same medical condition as described in the text. Readers of science journalistic articles often have an academic background and are therefore not representative of the average population. The role of laypeople has changed, since they are no longer mere recipients of information from journalists. Nowadays, anybody with Internet access may receive medical information and personal opinions from other non-professionals [15-17]. Facilitated by the commenting functions on Internet platforms such as online news outlets and social media websites, laypeople have the opportunity to become active producers of medical media content [18,19].

Since evidence suggests that about 85% of those people who read online news articles also read associated user comments [20], readers' decisions related to health are likely to be influenced not only by the article itself, but additionally by user comments. In contrast to news items, these sources are not subject to any formal gatekeeping [21], and so users have to independently evaluate the unfiltered information in order to decide whether to accept or reject its content [8]. Consequently, research into the processes that are at play in the interaction of laypeople on online platforms is essential, particularly in regard to the extent to which the tentativeness of medical research findings is grasped. But currently such research lags way behind the continuous technological advancement of Web 2.0. Interindividual determinants of critical thinking in the context of medical information in particular are under-researched, despite the fact that such determinants have been identified previously in conventional environments [22].

Determinants of Understanding Tentativeness

Factors related to scientific understanding and scientific knowledge are known to have an impact on people's ability to critically deal with scientific information. Accordingly, we assume that such factors may also play a role when it comes to understanding the tentativeness of medical research findings presented in the media. One such factor is scientific literacy [23], previously defined as the ability to "use evidence and data to evaluate the quality of science information and arguments put forth by scientists and in the media" [24], or as having "a basic vocabulary of scientific terms and constructs; and […] a general understanding of the nature of scientific inquiry" [25]. Accordingly, a range of tests is available to tap a person's scientific literacy. One approach is to assess their ability to understand the Tuesday science section of the *New York Times* [25]; another is to use open-ended questions such as "What is a molecule?" Using the latter approach, Miller [26] found that scientific literacy among adults has seen a substantial increase during the latter part of the 20th century. It is even higher among those in the younger generation, which suggests a future trend for continuation of the improvement in scientific literacy in the population [25]. At the same time, however, evidence suggests that intervention programs targeting this ability may be of only limited success [27]. On the basis that scientific literacy is closely related to critical thinking aptitude [28], its effect on the ability to understand tentativeness in medical research is plausible from a theoretical and empirical point of view.

Another factor that has an impact on how critically people handle scientific information and that, as a consequence, is supposed to influence whether they grasp the tentativeness of medical research findings is a person's beliefs about the nature of knowledge, which is referred to in the literature as epistemological beliefs [29-31]. People align on a spectrum spanning simple epistemological beliefs, meaning beliefs that knowledge is static and absolute, to sophisticated epistemological beliefs that see knowledge as a complex and dynamic concept [32]. Epistemological beliefs are considered as character traits and are domain-specific. Sophisticated epistemological beliefs, such as those related to the medical domain in particular, have been shown to influence learning strategies, learning outcomes [33], and information seeking behavior including source choice [32].

Finally, academic self-efficacy, meaning a belief in one’s own competence to be able to work effectively in an academic context [34] also has an impact on how people deal with scientific information and, thus, may also play a role in understanding the tentativeness of medical research findings. Academic self-efficacy is associated with personality-type variables such as social orientation or proactive personality, as well as with motivational factors [35,36] and learning-related emotions [37]. Given that academic self-efficacy specific to the science domain has been shown to correlate with actual academic success in science subjects [37,38], we assume an influence of this factor on the ability to grasp the tentativeness of medical research findings.

Previously, scientific literacy, epistemological beliefs, and academic self-efficacy have all been associated with the ability to apply critical thinking in traditional psychological experiments [22,39,40]. They have not been investigated concurrently, however, and even less with respect to influences on the critical evaluation of medical research findings on an online platform.

In addition to these three personality factors, we were also interested in the impact of a potentially relevant situational aspect because in Web-based discussion forums people are not at all limited to the mere critical reception of information. Interactive functions of Web 2.0 also allow active contributions, and so Web-based forums are typically characterized by a vigorous exchange of opinion, personal support, and guidance [41-43]. Users also frequently make reference to preceding posts in their contributions [16,44]. We therefore expect that when given the opportunity to post in a user forum dealing with medical research, people will be influenced by the comments that have already been posted by other forum users. It is well known that users tend to adjust their own contributions to that of others [45], and we assume that they will also adjust their own contributions according to the extent to which the issue of tentativeness has been addressed in preceding user comments. A previous analysis of traditional print media found that the perception of medical tentativeness depended on the salience of that issue in the text [46]. A potential extension of this effect to online forum settings is worth studying. Given the popularity of online platforms, a systematic investigation of the dynamic and multidirectional processes that result from effects of situational aspects of such salience of information is overdue.

This Study

In a laboratory study, we presented students, who were laypeople with respect to the neurosurgical procedure of deep brain stimulation (DBS), with an online medical news article on that procedure. DBS involves the implantation of remote-controlled electrodes into the brain and has been used in experimental studies to alleviate symptoms of depression. Although its effectiveness is promising, it remains as yet unproven [47]. DBS was selected as the topic of the article because findings from studies of the procedure are characterized by great inconsistencies and an overall high level of tentativeness [47-49]. In addition, prior knowledge of DBS is uncommon among laypeople [46]. Also, based on a relatively high prevalence of depression in the population [50], any findings on the effectiveness of the procedure may be very relevant to a substantial proportion of the general public. Specifically, the article used in this study described a patient suffering from a severe case of depression, for whom DBS led to the restoration of a “normal” life. An online forum with commenting function associated with the article was simulated for the study.

We examined the relationships between scientific literacy, epistemological beliefs, academic self-efficacy, and people’s understanding of the tentativeness of the findings reported in the article, as well as potential effects of topics from preceding users’ comments on that same outcome. We examined participants’ perceived tentativeness of the case study findings reported in the online medical news article (measured by a questionnaire) and the extent to which they took tentativeness into consideration in their own comments in the forum (addressed tentativeness).

We posited the following hypotheses:

H1: Greater scientific literacy will enhance perceived tentativeness (H1a) and addressed tentativeness (H1b).

H2: More sophisticated epistemological beliefs in the medical domain will enhance perceived tentativeness (H2a) and addressed tentativeness (H2b).

H3: Greater academic self-efficacy in the science domain will enhance perceived tentativeness (H3a) and addressed tentativeness (H3b).

H4: Addressed tentativeness will depend on the degree to which comments by other users also address this issue.

Relationships between perceived tentativeness and addressed tentativeness were also explored.

Methods

Study Design

In a randomized controlled experiment, participants were randomly allocated to one of three experimental conditions. In all three conditions, they were asked to write a comment in response to an online newspaper-style text, elaborating on their views as extensively as possible. Conditions differed in terms of the “user” comments purportedly made previously, which participants could see in the simulated online forum. In control condition A, no comments were present. In condition B, previous comments were present but did not address the tentativeness of the findings reported in the article. In condition C, previous comments addressed the issue of tentativeness. Scientific literacy, epistemological beliefs, and academic self-efficacy were the trait variables measured. The outcome variables identified and measured were perceived tentativeness and actively addressed tentativeness in participants’ own comments.

Sample

We recruited 70 participants aged 18-35 years from a university-wide pool of volunteers who confirmed upon study entry that they had no prior knowledge of DBS; 19 participants were male (27.1%) and 49 were female (70.0%). Two participants chose not to disclose their sex. Data were complete for all other measured variables. All participants were university students and all except one had obtained general qualification for university entrance. None of these participants was excluded from the study. Twenty-four participants were randomly assigned to condition A, 23 to condition B, and 23 participants to condition C. All gave full written informed consent and received 6€ for participating in a session that lasted approximately 45 minutes.

Materials and Instruments

All participants received the same online newspaper-style article reporting a case study of a female patient with depression. The article was constructed in part on the basis of actual newspaper articles; the case study itself was fictional. It described a case in which a patient, following unsuccessful treatment with psychotropic drugs and psychotherapy, experienced substantial improvements in her quality of life after the application of DBS. The article was fabricated for the study in the style typical of mainstream media. It pointed out that the use of DBS in the patient was only experimental but did not explicitly stress the tentativeness of the content in the report.

Subsequent to reading the newspaper article, participants in the two comments conditions saw five fictitious comments by previous "users." The "user" comments were designed to be similar in both groups in terms of word count (total of 276 and 306 words across comments for conditions B and C respectively). In addition, the comments were identical with regard to the (relatively neutral) attitude toward DBS that was expressed. The comments in both groups differed only in that for condition B the comments focused on the content of the text without addressing the tentativeness of the findings (eg, by relating the case study to the user's own experiences with depression). For condition C, the five comments explicitly discussed the issue of tentativeness (eg, by pointing out that long-term effects of DBS were not identifiable on the basis of the case study, that the success described in the study may be due to chance or placebo effects, or that alternative explanations for the patient's improved condition might exist).

We performed a test of the experimental material after completion of the main study to confirm that our manipulation of the level of tentativeness conveyed by the comments had been successful. For this purpose, 24 university students aged 19-30 years (mean age 22.4 years [SD 3.0]; 83% female) were presented with all 10 comments in random order and for each rated their agreement with the statement, "The comment communicates that the findings are preliminary and should be interpreted with care" on 7-point Likert scales. The five comments in condition B received an average rating of 1.53 (SD 0.39); those of condition C received an average rating of 5.35 (SD 0.63). As expected, the sum scores across the five comments for condition B (mean 7.67, SD 1.95) were significantly lower than for condition C (mean 26.75, SD 3.17), t_{23}=24.32; P<.001. This shows that our manipulation was indeed successful as different levels of tentativeness were conveyed by these two groups of comments.

A total of four questionnaires were administered. Participants' level of scientific literacy was measured by the Nature of Science Assessment (NoS), which has been used previously to measure scientific literacy in a student sample [51]. For each of the 7 items in the questionnaire, 4 response options were displayed. Single correct responses with no other options ticked were counted and contributed to a sum score (possible range 0-7).

Epistemological beliefs specific to the medical domain were assessed using the 24-item Connotative Aspects of Epistemological Beliefs (CAEB) Questionnaire [52]. On 7-point semantic differential scales, pairs of adjectives represented simpler versus more sophisticated beliefs in response to the statement, "Medical knowledge of psychiatric and psycho-motor diseases and their treatment is…" Scores were reversed as appropriate and summed, before the scale was adjusted to start at "0" (possible range of 0-144; higher scores indicating more sophisticated epistemological beliefs).

The level of participants' academic self-efficacy in the science domain was measured using a 4-item scale [53], which in similar form has been shown previously to have good internal consistency [54]. Responses were made on 5-point Likert scales spanning from "do not agree at all" to "completely agree" (see Table 1). Scores were reversed as appropriate, before sum scores were calculated and the scale was adjusted to start at "0" (possible range 0-16).

Table 1. Items measuring academic self-efficacy.

Number	Item
1	"I am usually able to understand scientific content."
2	"If I put enough effort into it, I succeed in gaining a good overview of the natural sciences."
3	"If I have questions related to the field of science, I am usually able to help myself."
4	"Without help, I am not able to deal with scientific topics at all." (reversed item)

Participants' perceived tentativeness of the findings presented in the journalistic article was measured by a 6-item scale (see Table 2), which has been used previously [46]. Agreement with each of the items was rated on 7-point Likert scales spanning from "not true at all" to "absolutely true." Scores were reversed as appropriate and summed up. The scale was adjusted to start at 0, resulting in a possible score range of 0-36 (higher values indicating higher perceived tentativeness).

Table 2. Items measuring perceived tentativeness.

Number	Item
1	"The findings of the study are not very definite."
2	"On the basis of this study, our understanding of DBS in depression is not complete yet."
3	"The study is conclusive." (reversed item)
4	"The findings are reliable." (reversed item)
5	"The study offers a solid basis on which to decide on the future use or non-use of DBS in depression." (reversed item)
6	"The findings of the study should be seen as preliminary only."

Addressed tentativeness in participants' comments was coded independently by 2 raters who were naïve to the research questions and blind to the experimental conditions. Prior to viewing the comments, a list of aspects of tentativeness relating to the newspaper article was set up and used to rate the extent to which tentativeness was addressed by the participants in their comments (score 0-6; resulting from one point for each of the 6 following aspects of tentativeness that were addressed by the participants: "uncertain long-term effects," "single case study," "lack of control condition," "potential for placebo effect," "inability to draw conclusions on all patients with depression on basis of study," "need for further studies"). Before rating the participants' comments, the 2 raters first became familiarized with the scoring procedure using five training comments. Following completion of the coding of all 70 comments for addressed tentativeness by the 2 raters and subsequent calculation of interrater reliability (see below), the average of the scores assigned by the raters was calculated for each comment and was used for the purpose of analyses.

Demographic information was obtained using a standard self-report questionnaire with items on age, sex, and the main subject of study.

Procedure

The study was performed on laptops in the laboratory. Initially, participants read the newspaper article presented on the screen in their own time. On the next screen, the "user" comments on the article were presented for the two comments conditions (B and C) in a simulated forum (condition A did not receive any "user" comments), and participants in all three conditions were asked to write their own comments in a space provided on that same page. Instructions were non-specific, with the request to simply comment on the article in any way. No time limits or limits to a word count were imposed. Subsequently, the tentativeness questionnaire, the NoS scale, the CAEB scale, and the academic self-efficacy questionnaire, as well as demographic information were completed.

Statistical Analysis

Scales were initially assessed for internal consistency, and interrater reliability for addressed tentativeness scores was calculated. Bivariate Pearson correlations explored associations among all predictor and outcome variables. In order to investigate the relationship of the trait variables with perceived and addressed tentativeness scores, a linear regression model was calculated for each of the two outcome measures. Scientific literacy (NoS), epistemological beliefs (CAEB), and academic self-efficacy scores were all entered concurrently into the models in order to evaluate the independence of associations. Each of the two models controlled for experimental condition. The model on addressed tentativeness additionally controlled for word count on the basis that participants who wrote longer comments had a relatively greater chance of obtaining high scores on that measure compared with participants who wrote shorter comments. Finally, an analysis of covariance (ANCOVA) with adjustment for word count and for all three trait variables compared addressed tentativeness scores among the three experimental conditions. All statistical analyses were two-tailed.

Ethical Approval

The study had ethical approval from the Institutional Ethics Committee (approval reference: LEK 2014/001).

Results

Scales and Sample Characteristics

Internal consistencies for the CAEB (Cronbach alpha=.88), academic self-efficacy (alpha=.86), and perceived tentativeness (alpha=.74) scales were found to be good. Agreement between the 2 raters on addressed tentativeness was very good (intraclass correlation coefficient=.90). The average of the addressed tentativeness score was negatively skewed, with 24 participants (34.4%) receiving a score of 0, meaning that these individuals did not address the issue of tentativeness in their comments at all. Nonetheless, we decided not to transform the variable, given that the transformation of count data such as these may lead to a bias in results when used in parametric analyses [55]. All of the remaining variables were normally distributed. Overall sample characteristics are presented in Table 3.

Table 3. Sample characteristics.

Characteristics	Values and scores
Age (years), mean (SD)	24.50 (3.95)
Female sex, n (%)	49 (70.0)
Subject of study, n (%)	
The humanities	23 (32.9)
Natural sciences	10 (14.3)
Pedagogics	6 (8.6)
Economics	6 (8.6)
Law	6 (8.6)
Other	19 (27.1)
Scientific literacy (NoS) (possible range 0-7), mean (SD)	2.36 (1.46)
Epistemological beliefs (CAEB) (possible range 0-144), mean (SD)	75.41 (16.38)
Academic self-efficacy (possible range 0-16), mean (SD)	11.09 (2.88)
Perceived tentativeness (possible range 0-36)	24.07 (5.57)
Addressed tentativeness (average of 2 raters; possible range 0-6), median (IQR)	1.0 (0.0-2.0)
Comment word count (range 38-383), mean (SD)	165.0 (73.2)

Evaluation Outcomes

Two-tailed Pearson correlation analyses (see Table 4) revealed that participants who obtained higher scientific literacy scores referred to tentativeness to a greater extent in their comments. A higher epistemological beliefs score was associated with higher perceived tentativeness, and higher academic self-efficacy was linked to greater addressed tentativeness. The positive association of addressed tentativeness with perceived tentativeness was relatively modest, though highly significant.

Table 4. Pearson correlations among measured variables.

	r (*P* value)					
	Age	Scientific literacy	Epistemological beliefs	Academic self-efficacy	Addressed tentativeness	Perceived tentativeness
Scientific literacy	.09 (.474)					
Epistemological beliefs	.10 (.433)	.07 (.583)				
Academic self-efficacy	.03 (.794)	.12 (.335)	-.09 (.480)			
Addressed tentativeness	.18 (.134)	.24 (.017)[a]	-.03 (.798)	.28 (.019)[a]		
Perceived tentativeness	.25 (.035)[a]	-.03 (.828)	.25 (.037)[a]	.14 (.406)	.39 (.001)[a]	
Word count	.05 (.698)	-.05 (.668)	-.01 (.932)	.01 (.962)	.22 (.063)	.10 (.416)

[a] *P* values are significant.

In order to further investigate the findings from the univariate analyses presented in Table 4, we calculated two linear regression models. For each of the two outcomes (perceived tentativeness and addressed tentativeness), all predictors were entered concurrently into a single model that controlled for experimental condition and—in the case of addressed tentativeness—also for word count (see Table 5). Epistemological beliefs were identified as a statistically significant predictor of perceived tentativeness, with higher CAEB scores associated with greater perceived tentativeness. This association supported H2a and was independent of participants' scientific literacy, their academic self-efficacy, and experimental condition. The reverse pattern of findings was observed for addressed tentativeness. Here, both higher scientific literacy (H1b) and higher academic self-efficacy (H3b) predicted a more elaborately addressed tentativeness in participants' comments; these effects were independent of one another and of experimental condition and word count. The remaining hypothesized associations (H1a, H2b, H3a) were not supported by these analyses.

Table 5. Models of perceived tentativeness and addressed tentativeness on scientific literacy, epistemological beliefs, and academic self-efficacy[a].

	Perceived tentativeness		Addressed tentativeness	
	Standardized β (standard error)	*P* value	Standardized β (standard error)	*P* value
Scientific literacy	-.06 (.46)	.603	.25 (.09)[b]	.025
Epistemological beliefs	.26 (.04)[b]	.034	-.05 (.01)	.631
Academic self-efficacy	.14 (.24)	.238	.31 (.05)[b]	.007

[a] Findings from two linear regression models (for perceived and addressed tentativeness, respectively) with all predictor variables entered in a single step. Both models controlled for experimental condition; the analysis of addressed tentativeness additionally controlled for word count. Total $r^2$for model of perceived tentativeness=.08. Total $r^2$for model of addressed tentativeness=.27.

[b] Values are significant.

In order to evaluate the effect of experimental condition on addressed tentativeness, an ANCOVA with adjustment for the word count of the participants' own comments as well as for their scientific literacy, epistemological beliefs, and academic self-efficacy assessed mean addressed tentativeness in the three experimental conditions. As expected in H4, there was an overall effect of condition on addressed tentativeness, $F_{2,63}$=3.66; *P*=.049, η_p^2=.092. Post-hoc pairwise comparisons revealed that this effect was driven by a statistically significant difference in addressed tentativeness between the control condition A and condition C where the preceding comments discussed tentativeness; adjusted means in condition A 0.73, 95% CI 0.28-1.18; standard error 0.23 versus adjusted means in condition C 1.54, 95% CI 1.09-1.99; standard error 0.23; *P*=.015. The remaining pairwise comparisons of group differences in addressed tentativeness did not reach statistical significance (both *P*>.10).

Discussion

Main Findings

This study investigated the roles that science-related interindividual character differences and themes discussed in other people's online forum contributions play in the critical evaluation of an online medical news article by students who were laypeople with respect to the topic of the article. To our knowledge, this is the first study to assess the extent to which users discuss medical tentativeness in their comments on a medical topic in a simulated online forum.

Results of the measurements carried out in the study showed that participants with greater scientific literacy and those with higher academic self-efficacy actively addressed the issue of tentativeness to a relatively greater extent than participants who had lower scores in these dimensions. Importantly, the findings for scientific literacy and academic self-efficacy were independent of one another. Epistemological beliefs were not a predictor of addressed tentativeness. However, in line with our expectation, we found evidence showing that participants who believed medical knowledge to be relatively more complex (ie, had more sophisticated epistemological beliefs) perceived the tentativeness in the article's research findings to a higher degree. Neither scientific literacy nor academic self-efficacy was related to perceived tentativeness (it should be noted here that in a previous study [56] general self-efficacy—not academic self-efficacy—was even negatively associated with perceived tentativeness).

The finding that people with more sophisticated epistemological beliefs demonstrate a greater ability to detect tentativeness in medical research is consistent with the literature on epistemological beliefs and critical thinking in science in general [39] and in the domain of medical research [46]. On the basis of this association in the literature in the medical research domain in particular, our expectations extended to an effect of epistemological beliefs on the degree to which the tentativeness issue was actively addressed in users' own comments. This was found not to be the case in the sample we used for this study, and we can only speculate as to potential underlying reasons. It is possible that people with more sophisticated epistemological beliefs did successfully identify tentativeness in the less demanding information processing that occurred in answering questions in a questionnaire but did not make any effort to actively engage in the discussion of the issue in their own contributions.

The association of higher scientific literacy and higher academic self-efficacy with greater addressed tentativeness is consistent with previous investigations that had identified relationships of these factors with critical thinking ability [28,40]. We have extended this previous evidence by showing that this same association applies to the active evaluation of medical research in an online forum. Higher academic self-efficacy and greater scientific literacy may have each promoted deeper levels of processing of the information that was provided in the article. The absence of a correlation between scientific literacy and academic self-efficacy was somewhat surprising, considering that both essentially measured scientific knowledge. A degree of disparity between the self-perception of ability (academic self-efficacy) and actually measured ability (scientific literacy) has frequently been reported in the research literature on self-perception [57] and may be a plausible explanation for the lack of this correlation in our study.

We had also expected that participants who were exposed to comments already appearing in the forum that addressed the issue of tentativeness would be influenced in the content of their contributions. A difference was indeed found between the experimental conditions insofar as participants in the condition receiving comments that mentioned tentativeness (condition C) scored higher on addressed tentativeness compared to the participants in the control condition (condition A). With this finding, we have extended previous evidence that had identified salience of tentativeness in a journalistic article as predictive of perceived tentativeness [46], by demonstrating a similar effect of that salience when it is presented in user comments in an online forum. The relatively modest size of the effect may have been due to the fact that complex processes were at play. For instance, reading existing comments by other users that addressed the issue of tentativeness may have led to individuals' wishing to discuss that same issue too, but at the same time may have decreased their discussion due to the notion that tentativeness had already been addressed sufficiently by other users.

Limitations, Future Work, and Recommendations

In the past, online forum posts on medical topics have mainly been used for thematic language analyses [19]. There is little control over potential influential factors and ethical issues associated with the lack of informed consent in actual online forums [58]. Our use of a simulated forum for comment has now avoided these ethical issues by enabling us to obtain consent by participants [59]. Moreover, it allowed the experimental manipulation of a specific situational aspect as well as the determination of what impact personality variables would have that are usually obscured in the anonymity of the World Wide Web. Our findings are further strengthened by the use of a topic that participants had no prior knowledge or opinion of, ruling out any effects by interindividual differences in these aspects on their activity in the simulated forum.

However, the somewhat artificial setting of the forum that included researcher-generated comments and text-based experimental manipulation in a single session is a potential shortcoming of this study. Our findings are further limited by the fact that analyses were based on a sample of university students. Future laboratory studies should consider using non-specific samples in order to determine whether the effects identified here extend to the general, including non-student, population. Around one third of the student sample presented here failed to address tentativeness at all in their comments, despite being equipped with at least basic scientific education in secondary school that should provide them with the capacity to deal with scientific material and with the aptitude to apply critical thinking. Accordingly, laypeople in the general population would be expected to address tentativeness even less than was reported here.

We further used only one topic in the current study (DBS), and our findings may not generalize to other scientific topics, including medical research topics. It may be the case that the effects seen in this study in fact would be different if participants were to deal with tentative research findings in other domains. Future studies should therefore aim to extend the present results by evaluating other scientific topics. Nonetheless, by focusing on DBS, we have highlighted a field of medical research that may warrant particular care in the communication of research findings to the general population. Researchers working on DBS and who interact with science journalists and university media outlets may be advised to consider the online dissemination of their findings. Online forums in particular may represent one useful way to influence the perception of DBS research and to increase knowledge in the general population of this often life-saving procedure.

In addition to the manipulation of other possible situational factors that could influence people's behavior in online forums, future studies should make use of real-life forums to investigate health-related thinking and behavior in patients and laypeople [60]. Findings from such studies could then directly feed into applications such as postgraduate courses, which could create a bridge between science and the media [3].

Finally, future research should also take a variety of control variables into account that might have an impact on how laypeople deal with tentative scientific information. Such control variables might include people's personal interest in medical issues in general or in the particular medical topic at hand; whether they have been diagnosed with a relevant disease (here, depression), or in the case of more established therapeutic treatments, their prior knowledge of the medical procedure.

Conclusions

The processes involved in laypeople's active contribution to online medical forums are highly complex and dynamic and are therefore difficult to investigate systematically. The study reported here has made an advance by applying a simulated online forum in a controlled laboratory setting. This allowed for the manipulation of situational aspects as well as the precise measurement of trait factors that may influence laypeople's behavior in such a forum. We have shown that the ability to understand the tentativeness of DBS research in an online forum was not at all universal. Influential factors included people's scientific literacy, epistemological beliefs, and academic self-efficacy. Their understanding of tentativeness was additionally and independently also affected by other users' comments already appearing in the simulated forum.

We have made an observation that calls for awareness in future investigations, particularly in those involving real-life online forums. Users appear to be only as "good" at applying critical thinking as the existing system of the forum itself. In order to recognize the tentativeness of medical research findings, readers of online medical news articles do not only depend on article authors to refer to the fact that research findings may be uncertain, temporary, controversial, or inconsistent [61]. They may also benefit from other Internet users who have already gained this insight and have identified the scientific tentativeness in their own comments.

Targeting the specific trait characteristics that were identified in this study as being influential on the ability to understand the tentativeness of medical research, and which are modifiable to greater or lesser degrees [34,62,63], may be a fruitful approach. Specifically, scientific literacy, epistemological beliefs, and academic self-efficacy could all represent useful targets for modification through formal instruction. Promoting scientific literacy and supporting people in recognizing the nature of scientific knowledge may support the public understanding of science. Such educational programs should include addressing how people deal with scientific topics, how they understand knowledge itself, and how they should deal with individuals' motivations for advancing particular views [64,65]. Programs for intervention that target these factors may well have the potential to promote critical thinking in laypeople who participate in online forums to discuss findings on DBS and potentially other medical research findings [66].

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Conflicts of Interest

None declared.

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Abbreviations

ANCOVA: analysis of covariance
CAEB: Connotative Aspects of Epistemological Beliefs
DBS: deep brain stimulation

NoS: Nature of Science

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Original Paper

Understanding Online Health Groups for Depression: Social Network and Linguistic Perspectives

Ronghua Xu[1,2*], BEng, MS; Qingpeng Zhang[1,2*], BEng, MS, PhD

[1] Department of Systems Engineering and Engineering Management, City University of Hong Kong, Kowloon, China (Hong Kong)

[2] Shenzhen Research Institute of City University of Hong Kong, Shenzhen, China

[*] all authors contributed equally

Corresponding Author:
Qingpeng Zhang, BEng, MS, PhD
Department of Systems Engineering and Engineering Management
City University of Hong Kong
83 Tat Chee Avenue
Kowloon,
China (Hong Kong)
Phone: 852 34424727
Fax: 852 34420173
Email: qingpeng.zhang@cityu.edu.hk

Abstract

Background: Mental health problems have become increasingly prevalent in the past decade. With the advance of Web 2.0 technologies, social media present a novel platform for Web users to form online health groups. Members of online health groups discuss health-related issues and mutually help one another by anonymously revealing their mental conditions, sharing personal experiences, exchanging health information, and providing suggestions and support. The conversations in online health groups contain valuable information to facilitate the understanding of their mutual help behaviors and their mental health problems.

Objective: We aimed to characterize the conversations in a major online health group for major depressive disorder (MDD) patients in a popular Chinese social media platform. In particular, we intended to explain how Web users discuss depression-related issues from the perspective of the social networks and linguistic patterns revealed by the members' conversations.

Methods: Social network analysis and linguistic analysis were employed to characterize the social structure and linguistic patterns, respectively. Furthermore, we integrated both perspectives to exploit the hidden relations between them.

Results: We found an intensive use of self-focus words and negative affect words. In general, group members used a higher proportion of negative affect words than positive affect words. The social network of the MDD group for depression possessed small-world and scale-free properties, with a much higher reciprocity ratio and clustering coefficient value as compared to the networks of other social media platforms and classic network models. We observed a number of interesting relationships, either strong correlations or convergent trends, between the topological properties and linguistic properties of the MDD group members.

Conclusions: (1) The MDD group members have the characteristics of self-preoccupation and negative thought content, according to Beck's cognitive theory of depression; (2) the social structure of the MDD group is much stickier than those of other social media groups, indicating the tendency of mutual communications and efficient spread of information in the MDD group; and (3) the linguistic patterns of MDD members are associated with their topological positions in the social network.

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KEYWORDS

mental health; depression; social media; information science; online health group; social network analysis

Introduction

Mental health problems, such as anxiety, bipolar disorder, and depression, have become increasingly prevalent in recent years. According to a recent report from the World Health Organization [1], one in four people in the world will be affected by mental disorders at some point in their lives. Among the various problems, depression is prevalent and could lead to other mental disorders [2]. More than 350 million people suffer from depression worldwide. Once being depressed, it is common to recur and will often last for many years [3]. However, due to the stigma and discrimination, depression is widely unreported and many symptoms are unrecognized [4]. The situation is even worse in China because of the rapid pace and high pressure of society, and the Chinese *Mianzi* (meaning “face” or a person's own sense of dignity or prestige) culture.

During the past decade, social media has played an increasingly important role in the promotion of mental health. It has been widely utilized by people to deal with health-related issues because of its publicity, broad reach, usability, and immediacy [5]. People use social media to acquire health information and seek social awareness [6]. In addition, they also form online health groups to grant and receive health suggestions and social support [7-9]. With respect to mental disorders, various online groups (either predefined by the platform or created by the users) encourage patients to anonymously share their innermost feelings and talk about their experiences and problems, which may not be possible in real life [10]. Therefore, the wide adoption of social media platforms presents an ideal data source and a testbed for researchers to study mental health problems from a brand new perspective [6,7,10-13].

Many research works have used social media for the detection and monitoring of depression. In Ramirez-Esparza et al [11], the authors performed content analysis of online forums about mental health topics in both English and Spanish. They found that linguistic differences existed between depressed and nondepressed posts, indicating that depression symptoms were revealed by the content in online media. Park et al [12] compared the tweets of people without mental disorders and those of people diagnosed by psychological tests with depression and showed that social media contained useful signals of depression, such as emotion words and language use styles. Similar studies with the Facebook data of college students verified that the symptoms of depression were consistent both online and offline [13,14]. Although the patterns of language use were effective in the detection of depression, there is little understanding of Web users’ conversations, which contain important information on social interactions as well as language use styles [15].

In addition to linguistic patterns, the topological properties of the social networks formed in social media also play an important role in the understanding of depression-related issues [16,17]. Social networks not only represent the communication among social media users, but also implicate the social structure of the whole group [10,18,19]. More importantly, social condition, which is one of the major causes and manifestations of mental health problems, could be derived from the analysis of social networks [20,21]. However, previous research works either focused on the linguistic factors or the social network factors with respect to mental problems; few have focused on both factors. This work attempts to study depression by exploring both the social structure and language use.

In this paper, we investigate online health groups for depression with data from Douban, a popular social media platform in China. Douban allows users to create interest groups so that users with similar interests can get together to discuss related topics, such as a specific disease, a city, a hobby (eg, photography), etc. Among various interest groups, more than 1000 are related to mental health, with more than 1 million members. We named these health-related interest groups as “online health groups” and chose the most popular Douban group related to depression, called the major depressive disorder (MDD) group [22]. We selected this group because it is the largest active Chinese online health group specifically designed for people who have been clinically diagnosed with depression [23]. We use “MDD group” to refer to this online health group in this paper.

In this research, we attempt to answer the following questions:

1. What are the unique language use patterns in the conversations of the MDD group?
2. What are the unique characteristics of the social networks formed by the conversations in the MDD group?
3. What are the relations between the language use patterns and the topological properties of members in the MDD group?

Methods

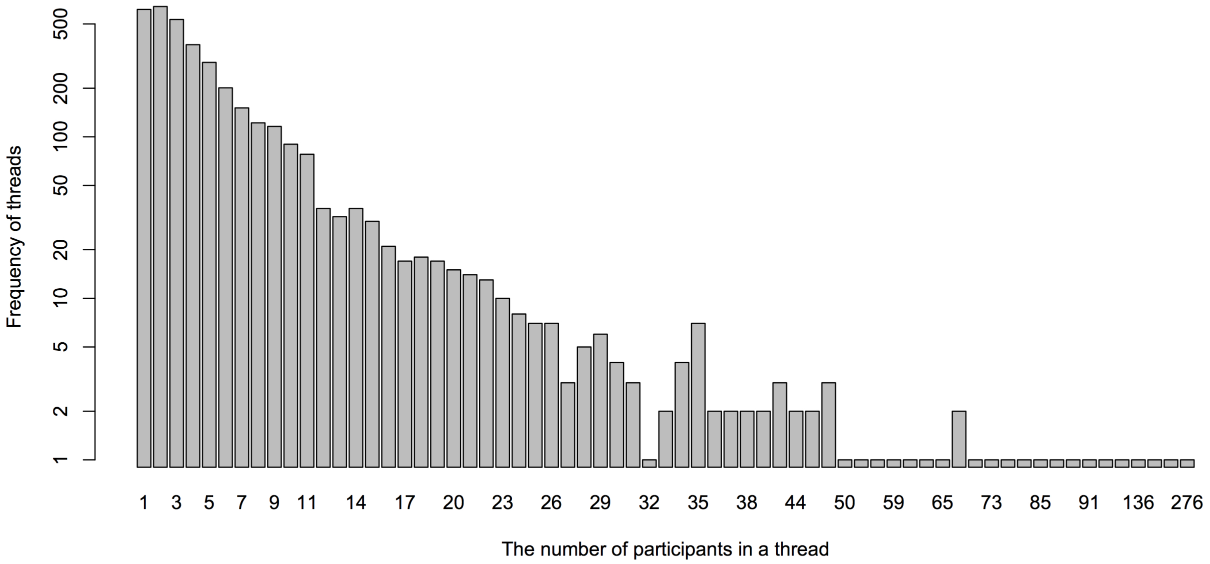
Data Collection

The group we studied was the MDD group on Douban [22] compared to minor and subsyndromal depression. The MDD group is specifically designed for people who have been clinically diagnosed with depression as compared to other online health groups for people with depressive moods. To provide mutual help, the group encourages its members to discuss their problems and exchange possible therapies and suggestions to cope with negative emotions and tough experiences with the disorder. The MDD group was founded on August 26, 2008; 5050 members joined the discussion since then. According to the purpose and scope of the group, all members have self-tested or have been clinically diagnosed with depression. They grouped together to give experience, understanding, support, and help to one another during the course of the illness.

In Douban interest groups, members use an anonymous user ID to communicate with one another. Once the group is created, any Douban user can start a discussion thread in this group. Each thread contains the title, the user ID of the creator (initiator), the created time, and the content of the message posted by the creator. MDD group members can join the discussion by posting messages in a certain thread. A message contains the user ID of the member, the post time, and the content of the message. A member can specify the message is a reply to the original post of the initiator or to an existing message posted by another member, thus forming a reply-to relationship.

We focused on the textual content of messages and the reply-to relationship between members in the MDD group. The messages conveyed valuable information about the linguistic patterns of the members. The reply-to relationship among the members represented their mutual conversations in the MDD group. We collected the full information of 3700 threads, 40,357 messages, and from 5050 members from the founding date on August 26, 2008 to January 6, 2015. Figure 1 shows the distribution of the number of participants in a thread in log-scale. In general, the frequency peaks at two participants and then diminishes along with an increase in the number of participants. The largest number of participants in a thread was 276, indicating that there were 276 unique user IDs participating in the discussion in the corresponding thread.

Figure 1. Distribution of the number of participants in a thread.



Text Processing

To process Chinese content, we employed a popular open-sourced toolkit, jieba, to perform the Chinese segmentation task [24]. Then the segmented words were fed into Linguistic Inquiry Word Count (LIWC), a validated and well-adopted toolkit for psychometric analysis in mental expression research [25,26]. LIWC can reveal the language use associated with a psychological disorder by classifying the input words into linguistic categories (eg, articles, numbers, and pronouns), psychological categories (eg, cognitive, affective, and social), or personal concern categories (eg, death, home, and school). The detailed explanations of the categories can be found on the LIWC website [27]. The resulting categories are standardized to be the occurrence rate of corresponding categorical words in the messages.

To analyze Chinese text, we used the Chinese version dictionary of Linguistic Inquiry Word Count (SC-LIWC) [28]. The dictionary contains 7444 Chinese words from 64 subcategories out of seven higher-level main categories. The seven main categories are function words (eg, 或许 [maybe], 许多 [many], 那些 [those]), social processes (eg, 家人 [husband], 接纳 [accept], 打招呼 [buddy]), affective processes (eg, 气愤 [annoyed], 感恩 [grief], 失望 [sad]), cognitive processes (eg, 理解 [know], 选择 [select], 质疑 [guess]), perceptual processes (eg, 温暖 [feeling], 经验 [heard], 注视 [see]), biological processes (eg, 头晕 [dizzy], 拥抱 [hug], 流汗 [sweat]), and relativity (eg, 以前 [before], 相比 [compare], 达到 [achieve]) [28]. Based on the dictionary, the LIWC toolkit was able to extract 75 dimensions of language uses, including 64 subcategories and seven main categories, and four descriptive properties: the word count, the tag rate, the number of words per sentence, and the number of words longer than six letters. These linguistic properties could be further used as proxies of depressive and suicidal signs relevant to depression and other mental disorders. Because we were investigating the MDD group, we selected a set of properties closely related to depression, including word count, the seven main categories, and the five subcategories related to emotion and pronouns.

Network Construction and Analysis Methods

We constructed the social network formed by the conversations (indicated by the reply-to relationship of messages) of the members. A unique node in the network represented a unique user ID. An edge between two nodes represented the existence of a reply-to relationship between the two corresponding nodes. The direction of an edge is from the user who posted replies to the user who posted the original message. There could be multiple edges between two nodes because there could be multiple replies. The procedure of network construction was as follows:

1. When a Douban user joined the MDD group, either by initiating a new discussion thread or posting a message in an existing discussion thread, a new node representing the new member was generated and a new edge representing his or her behavior was constructed based on the following rules.
2. When a user *A* initiated a new discussion thread, a self-loop of *A* was added to denote the thread initiation.
3. When a user *B* posted a message in a discussion thread in the group, a new directed edge from *B* to the initiator of the thread was constructed.
4. When a user *C* posted a message in a discussion thread and the message was a reply to another message posted by a

> user *D*, a directed edge from *C* to *D* was constructed. If *C* posted a reply to a message posted by *C* (*D* was *C*), a self-loop of *C* was formed.

We named the constructed network the MDD network, which was a directed network with self-loops and multiple edges.

We adopted a set of well-established network metrics to analyze the MDD network, including degree centrality (including both in-degree and out-degree), average shortest path length, betweenness centrality, and clustering coefficient. For detailed explanations of these metrics, please refer to Newman [16]. In the MDD network, the in-degree of a node represents the number of replying messages that the corresponding user received from other users. The out-degree of a node represents the number of messages that the corresponding user posted as a reply to another user. The average shortest path length of a node is the mean of the shortest path lengths to all other nodes that could be reached through a directed path in the network. The betweenness centrality of a node is the proportion of the shortest paths between any pairs of two nodes traversing through this node. It represents the importance of this node for the interactions of other nodes in the network. The clustering coefficient of a node is defined as the proportion of the existing edges among the neighbors of this node over all the possible edges among his or her neighbors. It measures the connectivity, transitivity, and clustering intensity among users in the MDD group. From the view of the whole network, we also analyzed the network density, network diameter, and network reciprocity. The network density is defined by the ratio of the number of existing edges over the number of all possible edges. The network diameter is the largest value of the average shortest path length of all pairs of nodes. The network reciprocity is the tendency of node pairs to form mutual reply-to edges between one another.

In addition, the Bow-Tie model was used to examine the general structure of the MDD network in more detail. In the Bow-Tie model [29,30], the central core of the group is represented by the largest strongly connected component (SCC), within which any user can reach any other users through a directed path. The IN component consists of users who only replied to the members in SCC, and did not receive any response from SCC users. The OUT component consists of the users who only received replies from the users in SCC, but did not post any replies to SSC users. TENDRILS component consists of users who connected to either IN or OUT. TUBES component consists of non-SCC users who connected two users from IN and OUT components. The rest nodes are in DISC, indicating that they are disconnected components.

To have an in-depth understanding of the formation of the MDD group, we compared the network properties of the MDD network with other online health groups, social media communities, and the Web. We also employed the classic Erdös-Rényi random network model [31] and Barabási-Albert preferential attachment model [32] to simulate the MDD network. To generate networks with the same number of nodes and edges as the MDD network, we generated a Barabási-Albert model by starting with a complete network of five nodes and adding a new node and seven edges at each step. In addition, we also abstracted the undirected network, called MDD-friend network, by excluding the direction of edges in the MDD network. We assumed that if two members have exchanged messages, they possessed a weak social relation. In this way, we can also compared the MDD-friend network with undirected networks formed in other online health groups, particularly the network of MedHelp presented in Vydiswaran et al [10]. For the undirected MDD-friend network, we adopted an Erdös-Rényi model (resulting network was called Erdös-Rényi model-friend) and the Watts-Strogatz for simulation purposes [33]. The Watts-Strogatz model starts with a ring-shaped network, in which each node has seven neighbors, and set the rewire probability to 0.45.

Results

Results of the Linguistic Analysis

We collected the full information of the MDD group with 2,281,678 words written by 5013 group members in 3565 threads. There were a total of 5050 users in the MDD group, but 37 users deleted their Douban accounts making the content of their messages inaccessible; therefore, we have the information about their social networking behaviors without the actual text content of their posts. So we analyzed the linguistic patterns of 5013 users instead of 5050 users in this section. In all, 74.82% (1,707,151/2,281,678) of the words in our dataset were tagged into one or more categories defined by the SC-LIWC dictionary. Compared to the tag rate of other studies using LIWC/SC-LIWC [24], this tag rate is reasonably high and representative.

The distributions of the word count and the seven main categories are shown in Figure 2. The occurrence of certain categories (eg, affective processes, cognitive processes) is 100% because of the existence of short messages containing only words from one category. The occurrence of function words and cognitive processes words peaked at approximately 50% and 20%, respectively. Other categories had relatively lower occurrence frequencies. The mean occurrence rates of the seven main categories are labeled in Figure 3a. On average, function words and cognitive processes categories accounted for the largest parts of the words used.

Previous psychological studies observed that style words made up approximately 55% of all the words people speak, hear, and read [25]. The style words include, but are not restricted to, function words and relativity words. In the MDD group, the style words (as represented by function words and relativity) accounted for nearly 60% of the whole corpus (summing the two occurrence rates in Figure 3). This finding is consistent with real-world psychological experiments indicating that the writing styles of depressed people (represented by the members of MDD group) are consistent both online and offline.

According to Beck’s cognitive theory of depression, self-preoccupation and negative thought content are the characteristics of depression [34]. This motivated us to verify whether the members in the MDD group also had these characteristics as revealed by the use of words related to self-preoccupation and negative thoughts. It is worth noting that although using the occurrence rates of positive and negative words gave us a straightforward view of the emotion polarization of the users, it was limited with little concern about the grammar and semantic features. Developing specific methods to quantify the sentiments and semantics is our future work.

We first calculated the frequency of individual words and drew the word clouds for better visualization. Figure 4 shows both the Chinese and translated English versions. We observed the intensive use of self-focus words, such as “I (我)” and “self (自己),” and negative words, such as “no (不)” and “none (没有).” We then examined the subcategories under affective processes (positive and negative) and pronoun (first-person pronoun and second-person pronoun).

The affective processes category has negative and positive subcategories. Negative words can be further divided into anxious, angry, and sad words. In the MDD group, there were 11.87% (595/5013) of users who used negative words but not positive words; 11.03% (553/5013) of users used positive words but not negative words. In all, 58.51% (2933/5013) of users used both positive and negative words in their messages and 18.59% (932/5013) used neither positive nor negative words, as shown in Figure 3b. To gain a more detailed understanding, the box chart of the occurrence rate of affective processes words of the members who used both positive and negative words is shown in Figure 5a. The mean occurrence rate of the positive and negative words was 4.06 (SD 2.67) and 4.48 (SD 2.99), respectively (t_{5499}=5.50, P<.001). Statistically, more negative words were used. This finding indicates that, in general, the users in the MDD group posted more negative content than positive.

The pronoun category had five subcategories, in which “I” and “we” were combined into first-person pronouns, “you” belonged to second-person pronouns, and “she,” “he,” and “they” belonged to third-person pronouns. The first-person pronouns-only or second-person pronouns-only members were not differentiated because both values were small (<5%). Similar to the affective processes category, we analyzed the occurrence rates of pronouns words for members who used all three types of pronouns and the results are shown in Figure 5b. Obviously, the first-person pronoun (especially the first-person singular pronoun) words were used more often than other pronouns. This may imply that a member in the MDD group wanted to talk about “their” versus “others” stuff. This finding is consistent with the psychological observations of depressed college students [34].

To summarize, more intensive use of negative and first-person pronoun words verified the characteristics of self-preoccupation and the negative content focus, which indicated that the users of the MDD group possessed the two characteristics of depression depicted by Beck’s cognitive theory. In addition, the MDD group members also revealed additional linguistic signals of depression (eg, the occurrence rates of the seven main categories), which could be further used in the surveillance and detection of depression in public health. These findings were also verified by aggregating the messages on individual threads (refer to Multimedia Appendix 1 for more details).

Figure 2. Distributions of word count and the seven main categories of words.

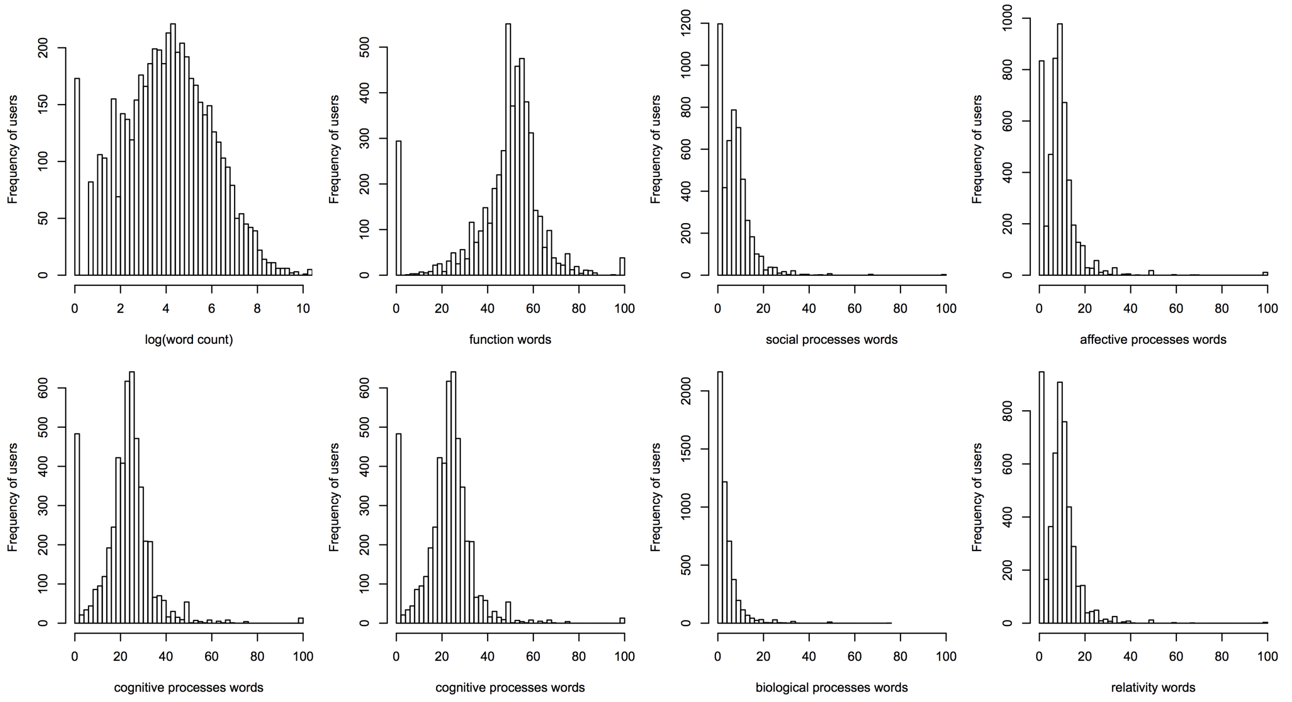


Figure 3. Pie charts of (a) the mean occurrence rates of the seven main word categories and (b) the proportions of members (N=5013) using negative and positive words.

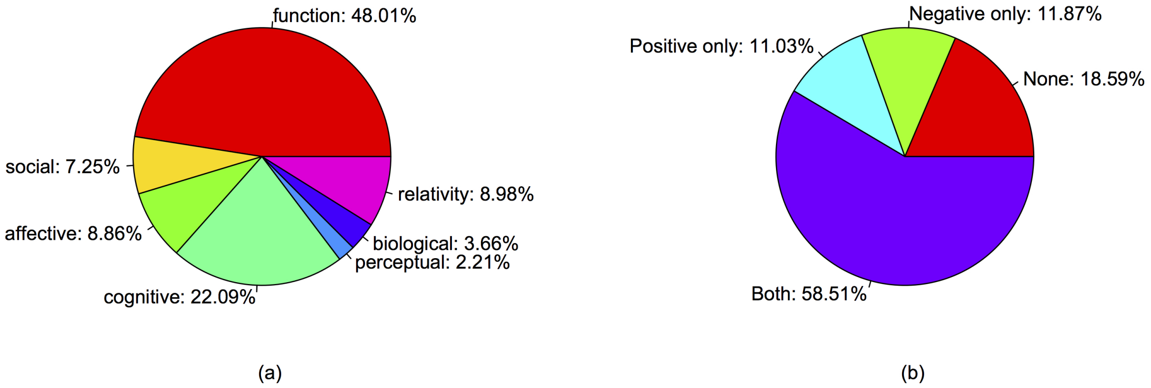


Figure 4. Word clouds of the content of the conversations in the MDD group in (a) translated English and (b) Chinese.

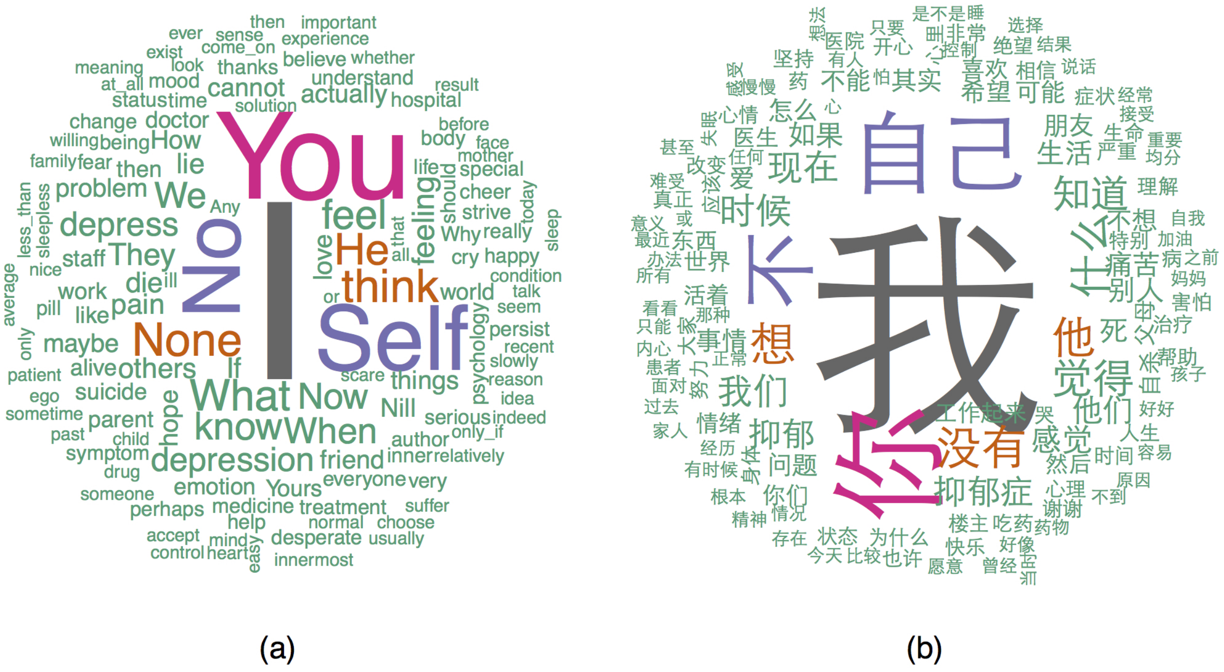
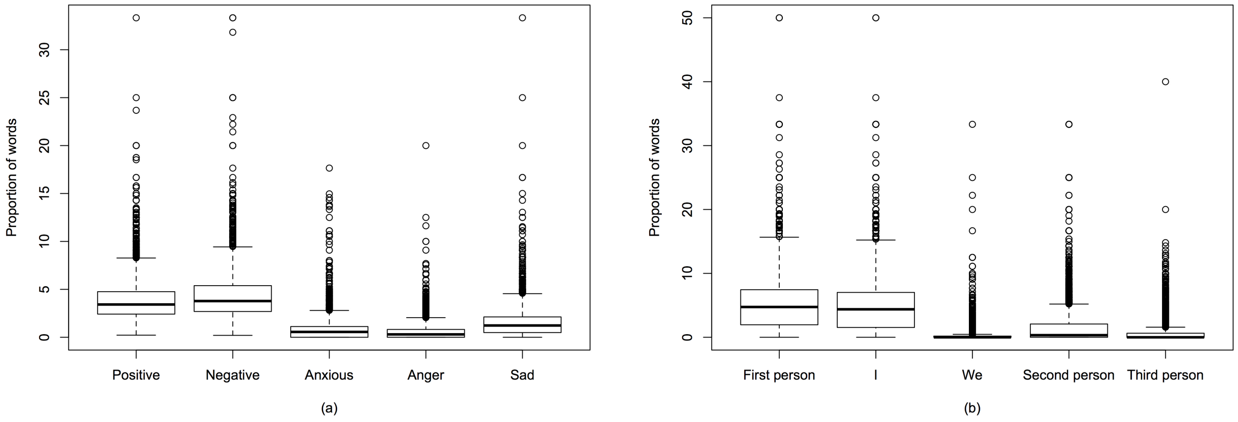


Figure 5. Box plot of the occurrence rate of two categorical words in the MDD group in the (a) affective processes and (b) pronoun categories. The horizontal line within each box represents the median. The top and bottom borders of the box are the 75th and 25th percentiles, respectively. The whiskers above and below the box mark the 90th and 10th percentiles. The points beyond the whiskers are outliers beyond the 90th percentile.



Results of Network Analysis

In the MDD network, there were 5050 nodes (representing individual user IDs) and 36,657 edges (representing the reply-to relations of the messages posted by two corresponding user IDs). It is worth noting that although 37 members deleted their account, we still had access to the information on their conversations with others except for the content of their messages. We excluded self-loops; the network is visualized in Figure 6. This network had 162 weakly connected components. The largest one consisted of 96.69% (4883/5050) of all nodes, indicating that 96.7% of the nodes could reach one another through an undirected path in the same giant component. According to the definition of the edge, 3565 self-loops stood for the threads initialized by group members and the other 135 ones stood for the messages that the initiators left in the thread that was created but did not specify the targeted members. The self-loops would be removed in later analysis of network structure properties because we focused on the conversations among MDD group members.

A node has both in-degree and out-degree. The distributions of in-degree and out-degree are shown in Figure 7. We found that both the in- and out-degree followed the power law distribution, with exponents of 2.13 and 2.20, respectively (shown in Table 1). The difference of the exponents of the in-degree and out-degree revealed the imbalanced tendency of user behaviors in posting messages (self-expression), posting replies (active peer communication), and receiving replies from others (peer response).

Table 1. Comparison of the MDD network, Myspace (in [35]), MedHelp friendship networks (in [10]), and other simulated networks.

Network metric	MDD	Myspace	Erdös-Rényi model	Barabási-Albert model	MDD-friend	MedHelp	Erdös-Rényi - friend model	Watts-Strogatz model
Type	Directed	Directed	Directed	Directed	Undirected	Undirected	Undirected	Undirected
Nodes	5050	36,459	5050	5050	5050	30,915	5050	5050
Edges	36,657	80,675	36,657	36,657	17,401	113,273	17,401	17,401
Connected components	162	1	1	1	162	2	5	2
Nodes in the largest weakly connected component	4881	36,459	5050	5050	4881	30,870	5046	5049
Network density (10^{-5} scale)	143.8	6.07	143.8	138.6	136.5	23.7	136.5	136.5
Network diameter	10	11	8	11	11	—	8	8
Network reciprocity (10^{-2} scale)	34.0	1.45	0.08	0.03	—	—	—	—
Clustering coefficient (10^{-2} scale)	4.47	0.031	0.29	0.64	4.47	3.1	0.13	1.19
Average shortest path length	4.11	5.14	4.53	2.83	3.80	3.81	4.64	4.69
Power law exponent (in/out)	2.13/2.20	2.65/1.99	—	2.15/3.01	2.29	2.12	—	—
Min degree (in/out)	0/0	1/0	5/5	0/4	0	—	0	3
Max degree (in/out)	451/942	558/6077	19/20	6053/7	464	—	19	27

In the MDD network, 36.03% (1820/5050) of nodes had zero in-degree, indicating that there was no other member who replied to their messages in the MDD group. On the other hand, the in-degree could go as large as 541. For the out-degree, 50% of members had a value of either 1 or 2, whereas the largest was 991. We examined the node with the largest in-degree and the node with the largest out-degree. It turned out that it was the same node that had both the largest in-degree and the largest out-degree, indicating that this user was the most active member in the group from both perspectives. This member was also one of the administrators invited by the group initiator. This finding indicates that additional rewarding and ranking mechanisms (eg, coadministrators or facilitators) would be useful to improve the communications in the design of online health groups. In addition, the users with high in-degrees also had high out-degrees, indicating that the users had mixed behaviors. This will be further examined in the next section.

To better understand the unique features of the conversations in the MDD group, we compared the topological properties of the MDD network with the conversation-based network of Myspace [35], the friendship-based MedHelp network [10], and model-generated networks. The results are shown in Table 1. Comparatively, the MDD network and MDD-friend were much denser and more clustered than Myspace and MedHelp as indicated by the large values for network density and clustering coefficient. This indicates that the local neighborhood of a member in MDD tended to have more connections than others. With a small average shortest path length and a large clustering coefficient, the MDD network possessed the small-world property as compared with Erdös-Rényi random graph model.

In addition, the reciprocity of the MDD network was approximately 30 times higher than that in Myspace. That means if a member *A* replied to a message posted by another member *B* in the MDD group, the chance that *B* would also reply to a message posted by *A* was 34%, whereas the chance was 1.45% in Myspace. In addition, 52% of node pairs in the MDD network had at least one directed path from one to the other, whereas the ratio was only 1% in Myspace. These results show that the MDD group was a very sticky community. The majority (more than 50%) of users could be reached by directed paths. This finding is verified by examining the Bow-Tie model in Table 2.

Table 2. Comparison of Bow-Tie model analysis between the MDD network and other networks.

Networks	MDD	Myspace	Java forum	Web	Erdös-Rényi model	Barabási-Albert model
SCC	54.53%	1.17%	12.30%	27.70%	99.91%	0.10%
IN	29.27%	0%	54.90%	21.20%	0.04%	98.10%
OUT	7.80%	81.50%	13.00%	21.20%	0.04%	0%
TENDRILS	4.22%	0.027%	17.50%	21.50%	0%	0.61%
TUBES	0.04%	0%	0.40%	0.40%	0%	0%
DISC	4.22%	17.30%	1.90%	8.00%	0.01%	1.21%

The Bow-Tie model was used to examine the general structure of the network and its reciprocity in more detail. As shown in Table 2, the MDD network was very different from both the networks of Java forum and the Web. Compared with other networks, the MDD network had a much bigger SCC (more than 50%). This indicates that more than 50% of the members in the MDD group could mutually reach one another through a directed path within the SCC. The fraction of SCC in the MDD network was much higher than the fractions of SCC in Myspace (1.17%), Java forum (12.30%), and the Web (27.70%). This finding, together with the high reciprocity and high clustering coefficient values described previously, indicates that the members of MDD formed a sticky social group within which the spread of information was very efficient. These findings generate critical insights about the network structures that facilitate the information diffusion in a social group. Applying the insights to public health research and practice, it can help health providers identify better strategies to promote health-related information in social media and control the spread of negative information.

Note that the definition of the edge direction in the Java forum was the opposite of ours. Therefore, the IN (OUT) component in the Java forum should be OUT (IN) by our definition. Members belonging to the in component behave like members who only answer questions in the Java forum and these members posted messages to others but never got any response. Both the Java forum and the MDD network had a large in component (29.27%) and the proportion of in component was almost four times larger than the out component (7.80%). This also revealed the imbalanced tendency that members in the MDD group would have liked to express their points without getting any responses. To alleviate the heterogeneous behaviors of in and out, some special encouraging functions could be prompted to the users with imbalanced communications when designing/organizing health forums to improve online communications.

Figure 6. Visualization of the MDD network. The size of the node is proportional to the in-degree of the node and the darkness of the edge represents the edge betweenness centrality value.

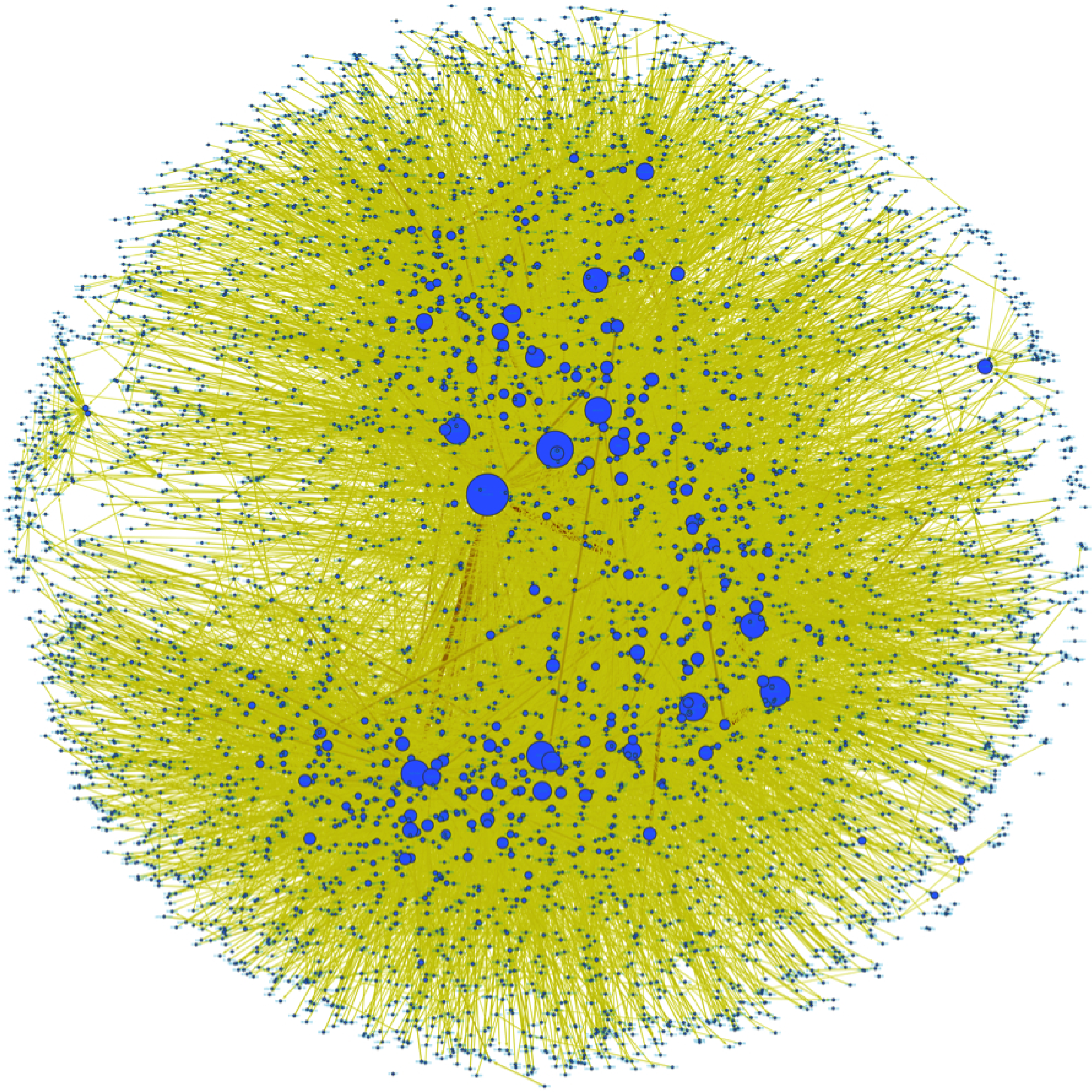
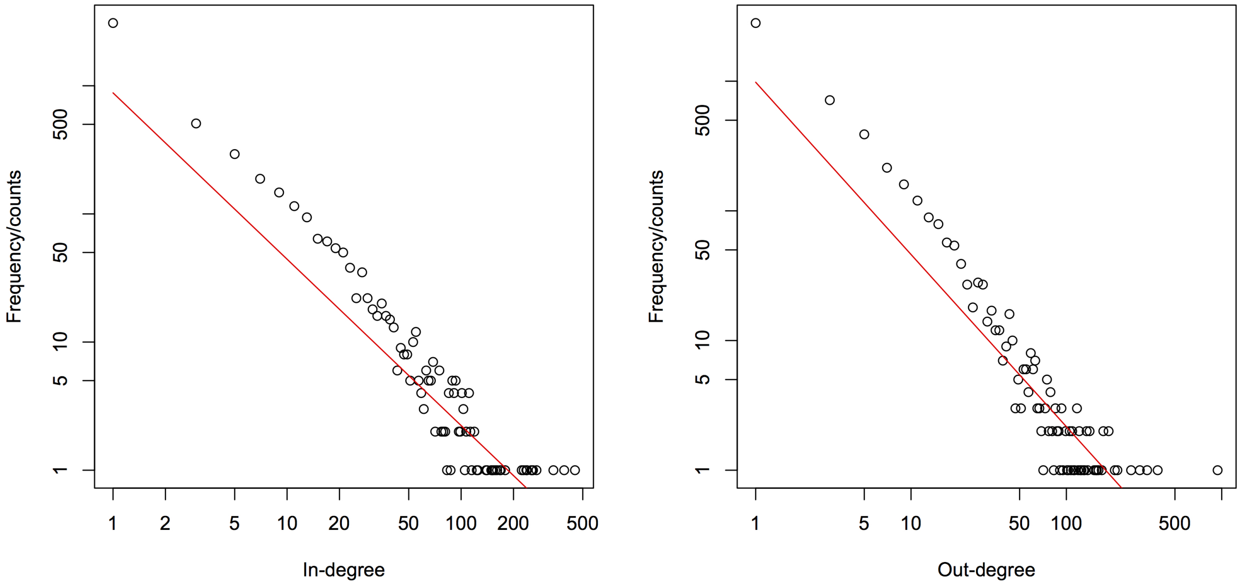


Figure 7. In-degree and out-degree distributions of the MDD network.



Relations Between Linguistic and Topological Properties

The position of a member in a social network represented his or her role in this social group. The roles of members were potentially associated with the language use of the members. A key question that remained unanswered was “What is the relationship between the language use and the topological positions in the network?”

To answer this question, we integrated the linguistic properties and the topological properties observed from the previous two sections. We chose two sets of representative linguistic and topological properties: (1) the word count, the seven categories, and positive, negative, and pronoun words (first-, second-, and third-person); and (2) degree, including in-degree and out-degree, the number of self-loops representing the initiated threads, average shortest path length, betweenness centrality, and clustering coefficient. Spearman correlations were run to assess the relationship between the two sets of properties using the 5013 members in the MDD group; the results are shown in Figure 8.

In terms of the relations between topological and linguistic properties of the same sample size, we found that the correlations were moderately strong (coefficient >.3 or <-.3 [36]) for word count, second-person pronouns, and third-person pronouns, as shown in the left-lower part in Figure 8. The word count had a mild negative association (ρ=-.36) with average shortest path length and moderate positive correlations (ρ>.45) with other topological properties. These findings indicate that, in general, the length of the messages users posted were associated with their topological position/locations in the social network. In addition, there were also moderate positive correlations between both second-person pronouns and third-person pronouns with the in-degree (ρ=.32 and ρ=.42, respectively) and the out-degree (ρ=.43 and ρ=.42). This implies that when a user used the second- or third-person pronouns more intensively, this user had a higher chance of also possessing a higher in-degree and out-degree. The length of the content was still one of the dominating factors, potentially because the longer messages have a higher chance to consist of these linguistic factors.

There was a strong correlation (ρ=.70) between the in-degree and the out-degree of a member. This indicated that if a member posted more messages to other members, this user had a higher chance of receiving more replies from others and vice versa. In addition, there was also a strong correlation between the number of threads a user created and the in-degree and out-degree of the member (ρ=.74 and ρ=.40, respectively), which was expected from the definition of the MDD network.

Figures 9-11 present the scatterplots of the relationships between 19 topological and linguistic properties. Each row and column denotes a particular property. The distributions of individual properties are shown in the diagonals of the scatterplot matrices. The red curve in each subfigure denotes the mean values of the vertical property over the horizontal property. The green curve denotes the best-fitted linear regression of the plots. Note that the distributions of in-degree, out-degree, the number of threads a user created, betweenness centrality, clustering coefficient, and word count followed power law distributions, so we used the log function of these properties to scale down. Average shortest path length and the occurrence rates of categorical words followed multimodal distributions with two or more local peaks. The dotted lines separate the topological and linguistic properties in the scatterplot matrices.

We observed monotonic relations between a set of linguistic properties (word count, second-person pronouns, third-person pronouns) and the topological properties, and also between the topological properties (in-degree, out-degree, the number of threads a user created, average shortest path length, betweenness centrality, and clustering coefficient). Refer to the upper-left parts in Figures 9-11 and the upper-right part in Figure 11. These monotonic relations explained the strong correlations between word count, second-person pronouns, third-person pronouns, and the topological properties (observed in Figure 8).

Conversely, we did not find clear monotonic relations between other pairs of linguistic (including the seven main categories, positive emotion words, negative emotion words, first-person pronouns) and topological properties (except average shortest path length). However, we observed interesting convergent relations. Refer to the upper-right parts in Figures 9 and 10 and the upper-middle part in Figure 11. In general, the nonmonotonic curves could be divided into two phases: monotonically increase (phase 1) and decrease (phase 2). These curves explained the weak correlations between these properties because the Spearman correlation was only feasible to capture the monotonic relations. The convergent patterns indicated that when the values of the topological properties increased, the linguistic properties (the seven main categories, positive emotion words, negative emotion words, first-person pronouns) tended to converge to the mean gradually. These convergent and two-phase relations indicated the self-organizing behaviors of users in the MDD group. The factors lead to these convergent patterns remaining hidden and they will be examined in detail in our future work.

Figure 8. Spearman correlations of the topological (1-6) and linguistic (7-19) properties.

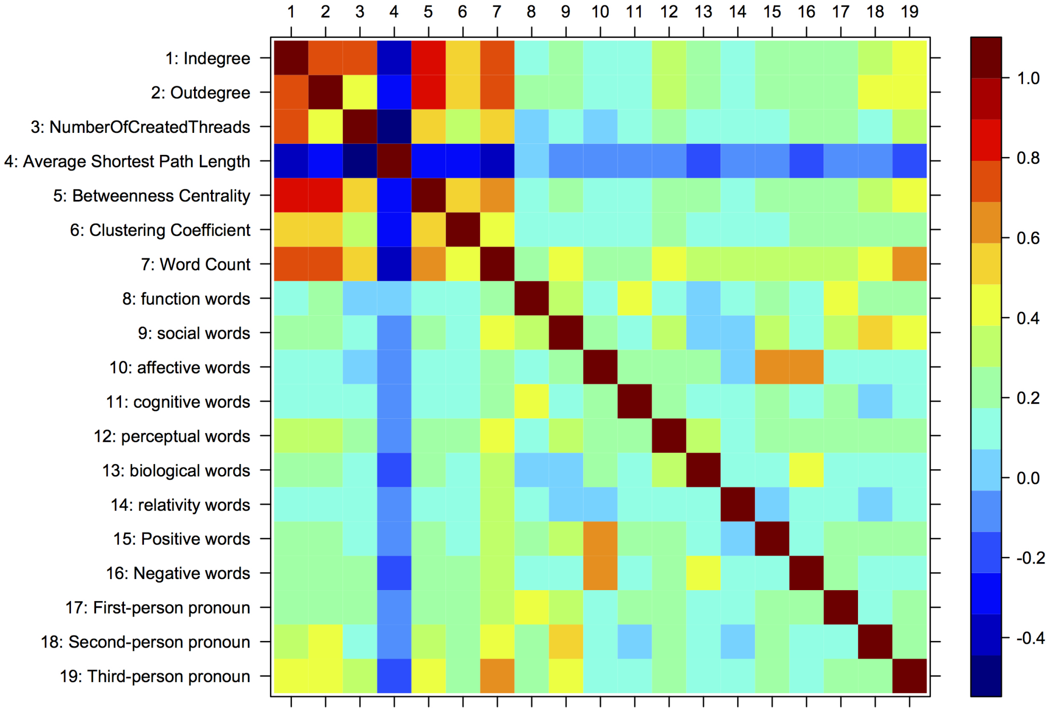


Figure 9. Scatterplot of the relationship between topological (in-degree, out-degree, the number of threads [NumOfThreads]) and linguistic properties (word count [WC] and 7 main categories) (part 1).

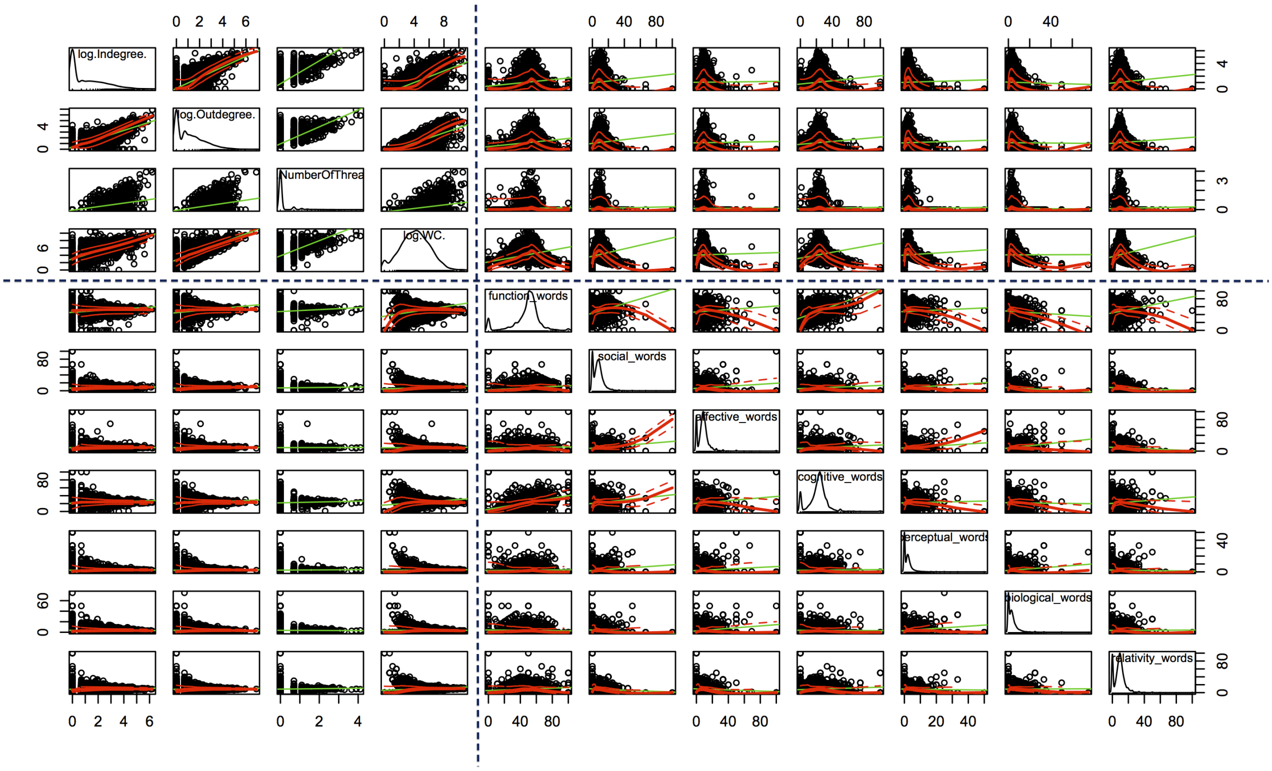


Figure 10. Scatterplot of the relationship between topological (average shortest path length [AsP], betweenness centrality [BwC], clustering coefficient [CuC]) and linguistic properties (word count [WC] and 7 main categories) (part 2).

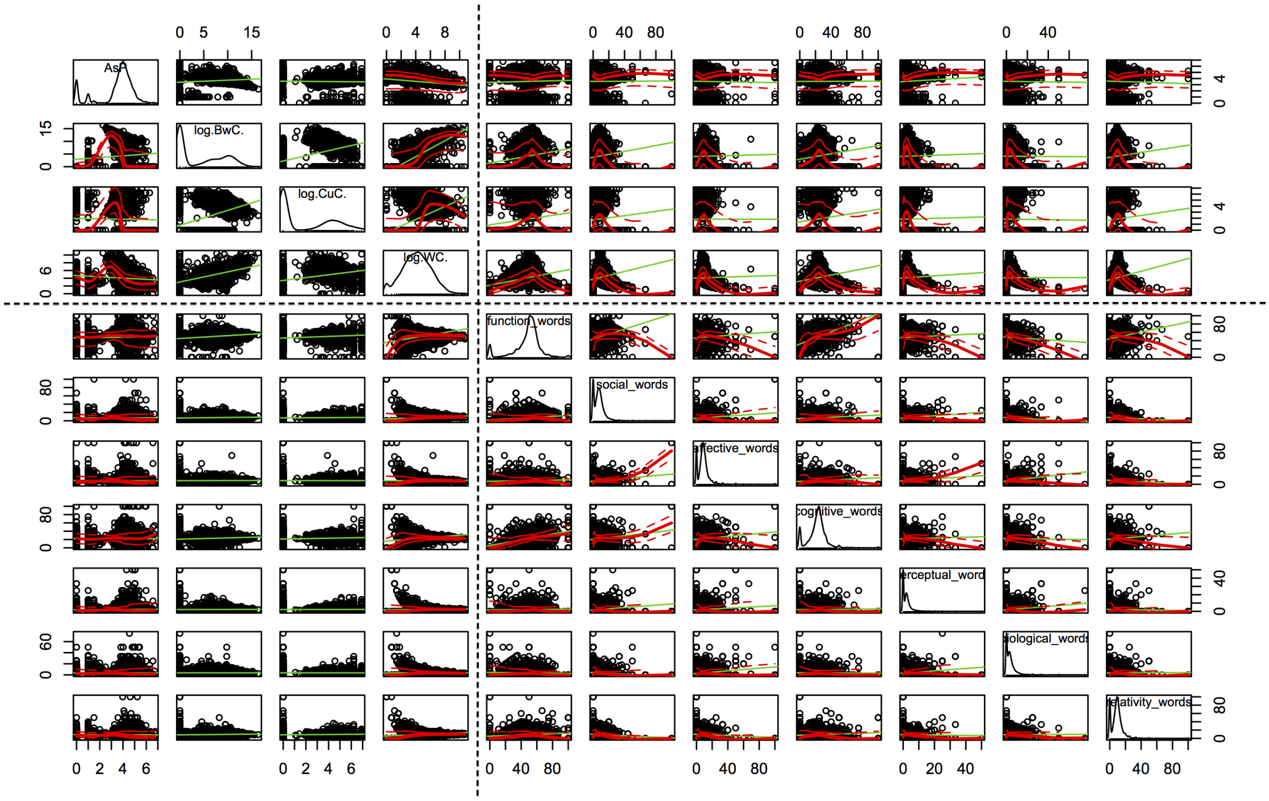
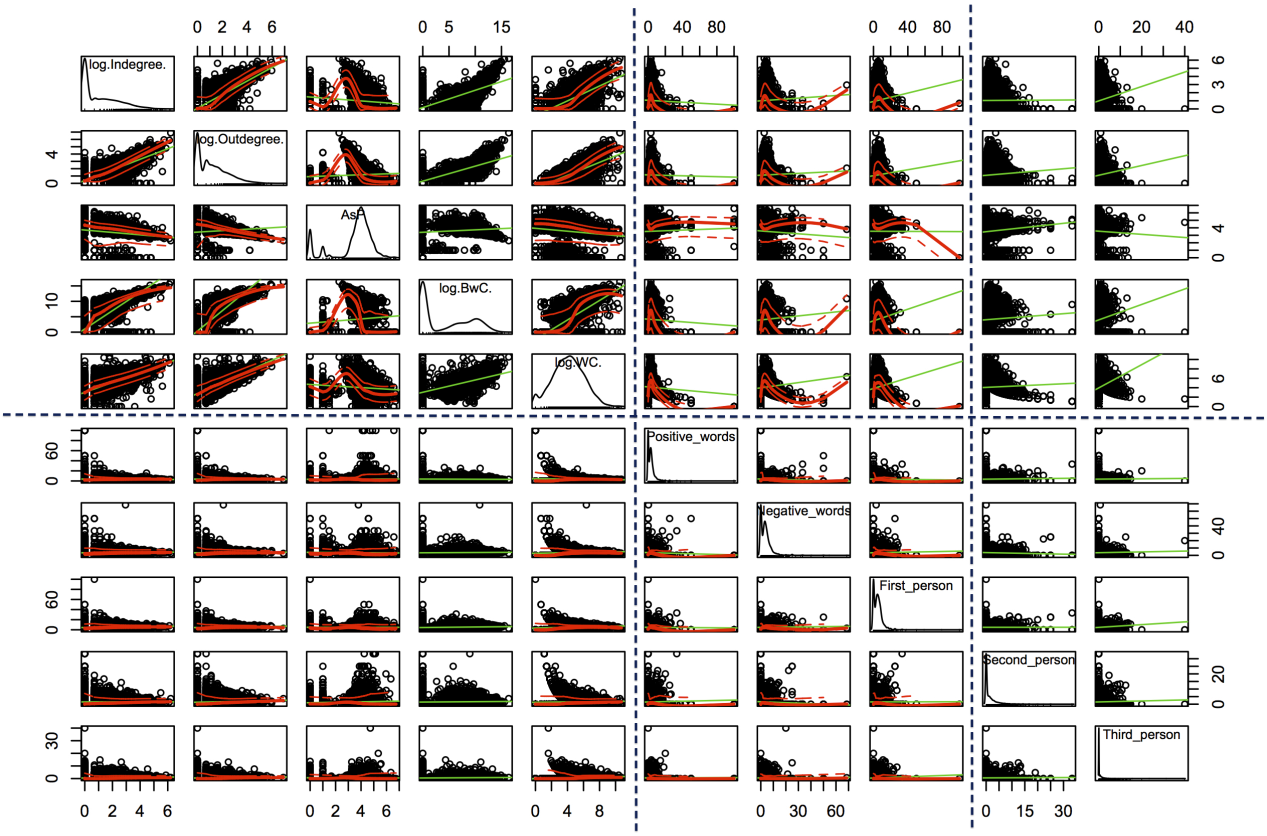


Figure 11. Scatterplot of the relationship between topological (in-degree, out-degree, average shortest path length [AsP], betweenness centrality [BwC]) and linguistic properties (word count [WC], detailed positive and negative affective and pronoun words) (part 3).



Discussion

In this paper, we characterize both the language use and the network properties of a popular online health group for MDD in China. For language use, we aggregate messages on members and verify the characteristics of self-preoccupation and negative focus of depressed individuals revealed in previous psychological studies and in other social media platforms. For network properties, the MDD network differentiates from other social networks with a highly sticky structure, imbalanced in-degree and out-degree, and a high reciprocity. By integrating these two types of properties, we find a set of interesting correlations and interesting convergent relations between the linguistic and the topological properties.

This work sheds light on the in-depth understanding of how Web users communicate with one another in MDD online health groups. The analysis of language use helps understand the expression of depression on a large scale. The results provide important insights for depression surveillance in public health. Our findings help explain the dissemination of depression-related information in a highly mutually connected community devoted to depression (the MDD group). The social network analysis presents novel and efficient information spread patterns of the MDD group that can be further adapted by health care providers to develop better and effective functions to facilitate online communications in the design of Health 2.0 applications.

There are also a number of limitations and questions that need further investigation:

1. How to identify the topics of the discussions in MDD group and other online health communities? We plan to adapt state-of-the-art text-mining methods into the linguistic analysis with LIWC in our future work to address this issue.
2. How to propose new network models to describe and replicate the unique topological properties of the MDD group? We are now developing a new generative network model based on the basic Barabási-Albert model with a focus on being able to control the value of the reciprocity of the network to replicate the higher intendancy of mutual communications in the MDD group. We will also develop models of multiple (interdependent) networks [19,21].
3. Do these unique topological properties only exist in the MDD group or in other online health groups as well? We are collecting data from online health groups for different mental health problems and other types of diseases on different social media platforms. Empirical studies with the new data will be our future work.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

This supplementary file contains content, figures, and tables that support the conclusion of the paper, but are too redundant to be included into the main manuscript. There are two figures in this document (in the text). The high resolution versions of the supplementary figures were uploaded to the system as well.

[PDF File (Adobe PDF File), 413KB - jmir_v18i3e63_app1.pdf]

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Abbreviations

LIWC: Linguistic Inquiry Word Count
MDD: major depressive disorder
SC-LIWC: Simplified Chinese LIWC

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Original Paper

Long-Term Condition Self-Management Support in Online Communities: A Meta-Synthesis of Qualitative Papers

Chris Allen[1], MSc; Ivaylo Vassilev[1], PhD; Anne Kennedy[1], PhD; Anne Rogers[1], PhD

NIHR CLAHRC Wessex, Faculty of Health Sciences, University of Southampton, Southampton, United Kingdom

Corresponding Author:
Chris Allen, MSc
NIHR CLAHRC Wessex
Faculty of Health Sciences
University of Southampton
Building 67
University Road
Southampton, SO171BJ
United Kingdom
Phone: 44 02380597628
Fax: 44 02381204718
Email: ca2v07@soton.ac.uk

Abstract

Background: Recent years have seen an exponential increase in people with long-term conditions using the Internet for information and support. Prior research has examined support for long-term condition self-management through the provision of illness, everyday, and emotional work in the context of traditional offline communities. However, less is known about how communities hosted in digital spaces contribute through the creation of social ties and the mobilization of an online illness "workforce."

Objective: The aim was to understand the negotiation of long-term condition illness work in patient online communities and how such work may assist the self-management of long-term conditions in daily life.

Methods: A systematic search of qualitative papers was undertaken using various online databases for articles published since 2004. A total of 21 papers met the inclusion criteria of using qualitative methods and examined the use of peer-led online communities for those with a long-term condition. A qualitative meta-synthesis was undertaken and the review followed a line of argument synthesis.

Results: The main themes identified in relation to the negotiation of self-management support were (1) redressing offline experiential information and knowledge deficits, (2) the influence of modeling and learning behaviors from others on self-management, (3) engagement that validates illness and negates offline frustrations, (4) tie formation and community building, (5) narrative expression and cathartic release, and (6) dissociative anonymity and invisibility. These translated into a line of argument synthesis in which four network mechanisms for self-management support in patient online communities were identified. These were (1) collective knowledge and identification through lived experience; (2) support, information, and engagement through readily accessible gifting relationships; (3) sociability that extends beyond illness; and (4) online disinhibition as a facilitator in the negotiation of self-management support.

Conclusions: Social ties forged in online spaces provide the basis for performing relevant self-management work that can improve an individual's illness experience, tackling aspects of self-management that are particularly difficult to meet offline. Membership in online groups can provide those living with a long-term condition with ready access to a self-management support illness workforce and illness and emotional support. The substitutability of offline illness work may be particularly important to those whose access to support offline is either limited or absent. Furthermore, such resources require little negotiation online because information and support is seemingly gifted to the community by its members.

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KEYWORDS

social media; patient online communities; long-term conditions; chronic disease; self-management; self-care; illness work; social networks; qualitative meta-synthesis

Introduction

Population aging has resulted in an increased prevalence of long-term conditions, which has resulted in increased expenditure on the provision of care for those affected [1,2]. As a consequence, self-management has become an increasingly important paradigm in health care delivery and the promotion of self-management of long-term conditions is now an enduring feature of health care policy [3-6]. This meta-synthesis of qualitative papers seeks to explore the self-management of long-term conditions in the relatively new context of online communities.

The current economic and philosophical landscape of the National Health Service (NHS) necessitates the need for illness work to be delegated to those with a long-term condition and policy makers hope this will reduce health service utilization [7] and improve health outcomes [2,3,5]. The need for self-management is reinforced by the fact that those living with a long-term condition spend very little time engaged with health care professionals compared to the time spent on activities that are required to manage their condition in daily life [1,8].

Recent research has begun examining the social context of long-term condition self-management and, more specifically, the role of others in shaping and supporting self-management practices [1,7,9,10]. In particular, research conducted by Vassilev et al [9] demonstrate the importance of work in long-term condition self-management, particularly in respect of one’s illness work force, those in one’s network who provide assistance in the self-management of their condition through illness, everyday, and emotional work, which can include a biographical dimension [9,11,12]. Types of illness work suggested by Vassilev et al [9] and Rogers et al [1] include:

- Illness (specific) work: work such as taking medication, taking and interpreting measurements, understanding condition and its symptoms, and making appointments [9]
- Everyday work: tasks such as housekeeping, occupational labor, support, and activities relating to diet and exercise, shopping, and personal care [9]
- Emotional work: work related to comforting when worried/anxious about everyday matters, such as health, well-being, and companionship (including a biographical dimension relating to the reassessment of personal expectations, capabilities, future plans, personal identity, relationships, and biographical events) [9]
- Contingency/improvisation: the work involved in getting things back on track [1]
- Translation/mediation: the work involved in translating abstract knowledge into practical knowledge that can then be implemented [1]
- Coordination: the negotiations and renegotiations in the ways in which work is done, such as what work is done, by whom, when, how, and why [1]
- Advocacy work: work done by others on one’s behalf [1]

Weak social ties also contribute to illness work by affording greater access and transmission of information between network members; the value of these ties lays in their quantity rather than their intensity [8]. Online communities are particularly good at facilitating the creation of weak ties [13-16]. As a result, community membership may afford people a larger, more diverse social network than would otherwise be available because ties mediated online are not restricted by temporal, spatial, or geographical limitations that typically define offline social networks [16,17]. Those with more diverse social networks are said to self-manage their long-term condition better compared to those with fewer social ties [10]; however, this has only been explored in the context of offline social networks and there is a clear need to better understand the role of online contacts in the self-management of long-term conditions.

An existing review by Ziebland and Wyke [18] conceptualizes seven domains through which patient experiences online influence health. These domains were finding information, feeling supported, maintaining relationships, affecting behavior, experiencing health services, learning to tell the story, and visualizing the disease [18]. Although this review was useful in framing the landscape of peer-to-peer support online due to its focus on understanding the exchange of experiential information on health, it did not specifically focus on long-term condition self-management. Moreover, the changing landscape of online communities in relation to the proliferation in the ways in which people access them makes them more relevant to our daily lives because ties mediated online are now more immediately available [19,20].

In this context, its relevant to understand the extent to which social ties created in these online spaces contribute to long-term condition self-management through the negotiation of illness work (illness work is described as the visible and invisible activities of long-term condition self-management) [9]. In recent years, the study of self-management support has introduced a focus on the mechanisms of networks that mediate self-management support for long-term conditions and the influence this has on the mobilization of resources [1,7,9,21]. Although there has been increasing awareness of the significance of the Internet as a forum for support and engagement for self-management support [18], previous studies have not specifically focused on the mechanisms of such networks and how they may mediate long-term condition self-management support. Offline, three mechanisms linking social networks and health-related outcomes exist: sharing knowledge and experience within a community, access and mediation of resources, and an awareness and ability to deal with network relationships [21]. It is clear that in offline networks, those with a long-term condition need to be able to navigate their personal social networks and negotiate and renegotiate existing relationships [21]. Although Vassilev et al’s [21] article successfuly demonstrates the negotiation of self-management support in traditional offline social networks, these specific aspects have not been explored in terms of online communities. Thus, this meta-synthesis aims to generate an elaborated understanding of the negotiation of self-management support and illness work in patient online communities for those with a long-term condition. This is relevant for informing the design of online interventions.

Methods

Qualitative Meta-Synthesis

A meta-synthesis draws on the subjective and interpretive nature of existing qualitative research to construct more complete and plausible understandings of reality than what is currently available from the existing literature. There are several approaches to qualitative synthesis; in this instance, Paterson et al's [22] process of meta-synthesis was used. Like secondary analysis, qualitative synthesis involves reinterpretations, but the analysis is generated from already existing published findings of other authors [23]. Such data exist in the form of first- and second-order constructs [22]. The first-order constructs represent direct feedback from the study participants and the second-order constructs represent the key findings of the researchers [22]. The third-order constructs relate to the interpretation of the findings of the articles based on the synthesized first- and second-order constructs [22]. Paterson et al [22] explains this process by stating that: "The authors of primary research reports have constructed the research findings in accordance with their own understanding and interpretation of the data" [22] (p.6); subsequently, "The meta-synthesists have constructed an aggregated account based on their own interpretations of the primary researchers' constructions. Consequently, the meta-synthesists deals with constructions of constructions" [22] (p. 7). As such, the process moves beyond the findings of the original papers to generate more complete understandings of the phenomena being investigated because it pulls together and makes use of concepts derived from multiple studies, using a wide variety of methods, contexts, and interpretive frameworks [21,22].

By including articles that used different methods, examined different types of online communities, and different conditions, this meta-synthesis is able to add to the existing evidence base, bringing research data from an initially narrow focus (ie, a specific condition and online community) toward a broader interpretation of long-term condition illness work in online settings.

Inclusion/Exclusion Criteria

To guide the systematic search of the literature, the research team (CA, IV, AK, AR) agreed on the following predetermined inclusion and exclusion criteria, taking into account the aims of the meta-synthesis. The predetermined inclusion criteria were (1) studies examining the use of online communities for those with a long-term condition (including communities hosted on social media sites such as Facebook and Twitter), (2) studies that focused on online communities from a naturalistic open setting, (3) research between 2004 (the year the term "Web 2.0" became popularized) and 2015 (when the search took place), and (4) research that used qualitative methods. The predetermined exclusion criteria were (1) studies not written in English, (2) research including interventions, (3) research from the perspective of health care professionals/carers/relatives, (4) research that only used quantitative methods, (5) literature reviews and review papers, letters to the editor and editorials, commentaries and feature articles, dissertation theses, reports, conference papers, and abstracts, (6) studies only on traditional Internet use and without an interactive social component (ie, Web 1.0 and blogs), and (7) studies with a commercial, advertising, or marketing focus, where levels of bias could be seen as high.

Search Strategy

A systematic approach was used to locate the relevant published research studies in the area of online communities and long-term conditions. Because online communities in relation to health have been explored across a multitude of professional and theoretical concepts, health, social care, psychology, and sociology databases were searched. The systematic search of the research literature used the following databases: Allied and Complementary Medicine Database (AMED), Cumulative Index to Nursing and Allied Health Literature (CINAHL), the Cochrane Database of Systematic Reviews, DelphiS, EMBASE, the International Bibliography of Social Sciences (IBSS), MEDLINE, PsycINFO, Scopus, Sociological Abstracts, and Web of Science. The searches were conducted using a predetermined search strategy, using the search terms in (Textbox 1).

The systematic review of the available literature occurred in August 2015. The search strategy using the aforementioned databases located 1944 research articles. Titles and abstracts were reviewed against the inclusion criteria; from this, hard copies of 79 articles were obtained. These were screened against the inclusion/exclusion criteria (by CA, AK and IV), resulting in a total of 14 papers. A further 10 papers were found through submersion in the research literature and through the reference lists of eHealth articles read by the research team. From this, a further seven papers met the criteria for inclusion. All selected papers were discussed by the team in view of the objectives of better understanding the contribution of online social networks in long-term condition self-management. This process can be seen in Figure 1 and a summary of the included articles can be seen in Table 1.

Table 1. Articles included in the meta-synthesis and quality appraisal scores using the Critical Appraisal Skills Programme (CASP) tool.

Study	Condition	Platform	Method	Sample	Study details	CASP score[a]
Attard and Coulson [24]	Parkinson disease	Disease-specific discussion board/forum	Qualitative thematic analysis of messages posted to a discussion board	1013 messages posted to the board between 2003-2010	To explore the experiences of members of a Parkinson's disease forum	9
Barker [25]	Fibromyalgia	Disease-specific discussion board/forum	Thematic analysis	249 participants in Fibrospot	Examines the conflicts between lay and expert knowledge in electronic support groups	9
Brown and Altice [26]	Opioid dependence	Disease-specific discussion board/forum	Grounded theory approach	121 threads from 13 discussion boards in a 26-month period	To identify facilitators of self-treatment by online buprenorphine/naloxone users	9
Coulson [17]	Alcohol use disorder	Disease-specific discussion board/forum	Inductive thematic analysis-netnography	738 messages on 3 UK-based discussion boards	To explore in-depth how members of online alcohol use disorder communities engage with peer-to-peer support	9
Coursaris and Liu [27]	HIV/AIDS	Disease-specific discussion board/forum	Content and thematic analysis	5000 postings(not disclosed how many participants contributed to this)	To provide an in-depth understanding of social support exchanges in online HIV/AIDS self-help groups	8
Greene et al [28]	Diabetes	Facebook	Content analysis	233 wall posts and 457 discussion topics	Examine the content of communication in Facebook communities dedicated to diabetes	8
Hadert and Rodham [29]	Arthritis	Disease-specific discussion board/forum	Interpretive phenomenological approach	60 users who posted 87 initial messages + 314 users who posted 981 replies	To discover how and why the online arthritis message board was used	9
Kazmer et al [30]	ALS	Patients Like Me (an online community that connects people with the same condition)	Inductive thematic analysis	1000 randomly selected messages from an available 2500 messages posted between Feb 2006-Nov 2008	How and why knowledge is shared among the distributed participants in the PLM-ALS threaded discussion forum	9
Kirk and Milnes [31]	Cystic fibrosis	Disease-specific discussion board/forum	Online ethnographical approach	279 individuals who participated in forum over a 4-month period	To explore how online peer support is used by young people and parents to support self-care in relation to cystic fibrosis	9
Loanne and D'Alessandro [32]	Motor neuron disease/ALS	Disease-specific discussion board/forum	Content analysis	499 posts made by 133 participants	Explores whether social capital can exist in an online health community for people affected by MND/ALS	8
Matura et al [33]	Pulmonary hypertension	Disease-specific discussion board/forum	Qualitative descriptive methodology	Convenience sample (all posts in 2010)	To determine how patients with pulmonary hypertension use online discussion boards	9
Mazzoni and Cicognani [34]	Systematic lupus erythematosus	Disease-specific discussion board/forum	Content analysis	118 posts corresponding to 118 authors	To explain the demand/supply of social support through the Internet in relation to the description of personal illness experience	9
Merolli et al [35]	Chronic pain	Did not specify; patients recruited through Facebook, Twitter, Daily Strength, and Patients Like Me	Thematic content analysis; online survey	218 people with chronic pain who completed an online survey	To examine what social media therapeutically affords people with chronic pain who are self-managing their condition	9
Mo and Coulson [36]	HIV/AIDS	Disease-specific discussion board/forum	Thematic analysis of completed online surveys	115 participants who completed an online survey	To explore the potential empowering and disempowering outcomes of online support group use by those with HIV/AIDS	9

Study	Condition	Platform	Method	Sample	Study details	CASP score[a]
Rodham et al [37]	Complex regional pain syndrome	Disease-specific discussion board/forum.	Interpretive phenomenological analysis	60 participants who posted or commented on a post on a discussion forum in a 4-month period	To explore how an online message board designed for patients and carers of patients with CRPS was used; specifically, sought to explore the exchanges that took place on the online message board	10
Van Berkel et al [38]	ALS, diabetes, ADHD	Disease-specific discussion board/forum	Deductive thematic analysis	5532 posts from seven message boards	To examine whether empowerment processes occur on message boards discussing medicines used to treat three chronic conditions as well as examining the quality of information that is shared	9
Van Uden-Kraan et al [39]	Fibromyalgia, arthritis, breast cancer	Disease-specific discussion board/forum	Content analysis of postings to a discussion board/forum	Random sample of 1500 postings to discussion board/forum for fibromyalgia, arthritis, breast cancer	To explore who uses online support groups, what topics are discussed, and what self-help mechanisms are used in these groups	8
Van Uden-Kraan et al [40]	Fibromyalgia, breast cancer, arthritis	Disease-specific discussion board/forum	Semi-structured interviews, inductive analysis	32 participants	To explore if, and in which ways, patients feel empowered by participation in patient online communities	9
Wentzer and Bygholm [41]	COPD and fertility problems	Disease-specific discussion board/forum	Qualitative analysis using critical interpretation and narrative analysis	4301 posts to 2 forums	Is communication in online patient support groups a source of individual and/or collective empowerment?	8
Willis [42]	Arthritis	Disease-specific discussion board/forum	Ethnomethodology	20 members across 4 communities	To understand how patient with arthritis use patient online communities to exchange illness related information to better manage their long-term condition	9
Zhang et al [43]	Diabetes	Facebook	Case study	Case study of a Facebook group with 30,000 users	Explores Facebook as a platform for health information and communication, specifically what the characteristics of the Facebook diabetes group and its members	8

[a] Maximum score is 10.

Textbox 1. Predetermined search terms.

“Social media” OR “Social network site*” OR “web 2.0″ OR “Health 2.0″ OR “discussion board*” OR “discussion forum*” OR “forum*” OR “online support group*” OR “electronic support group*” OR “online communit*” OR “patient online communit*” OR “facebook” OR “twitter” OR “tweet*” OR “myspace” OR “patientslikeme” OR “patients like me” OR “second* life”

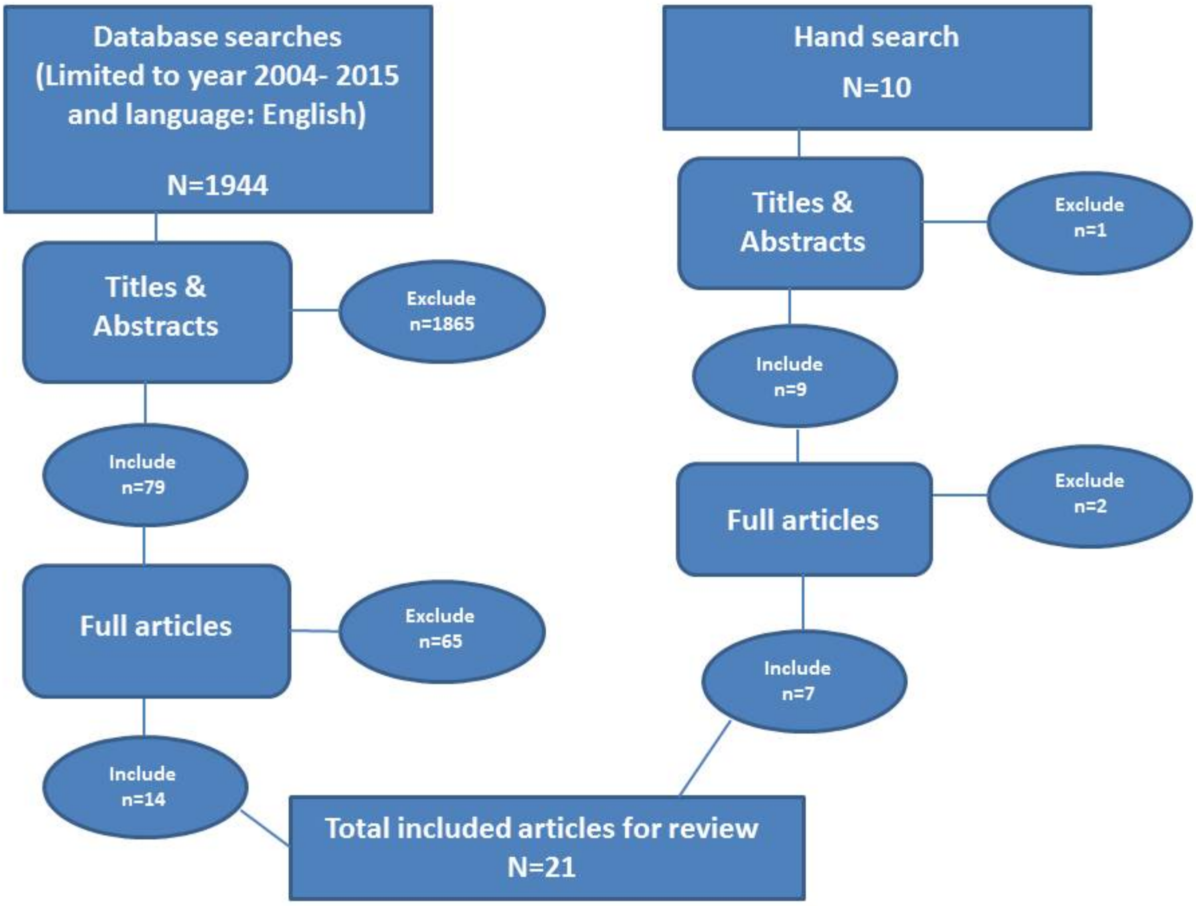
AND

> *Chronic” OR “Chronic disease*” OR “Chronic Illness*” OR “Long term condition*” OR “Long-term condition*” OR “Long term health condition*” OR “LTC*” OR “chronic pain*” OR “pain*” OR “fibromyalgia” OR “chronic obstructive pulmonary disease” OR “COPD” OR “diabet*” OR “irritable bowel syndrome” OR “IBS” OR “heart disease” OR “HIV” OR “AIDS” OR “Stroke”*

AND

> *Self-management” OR “self management” OR “Self-care” OR “Self care”*

Figure 1. Flowchart of systematic search strategy, process and selection of research papers for review.



Quality Appraisal

The included papers were critically appraised according to the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (by CA) [44]. The checklist allows qualitative research evidence to be appraised systematically, guiding the reviewer about the results, their validity, and their transferability [44]. The results can be seen in Table 1 and demonstrate the included articles represented high-quality research; therefore, they were all included in the analysis.

The findings of this synthesis are limited by the methodology of many of the included papers [17,24-34,37-39,41-43], which used either "netnography" (a specific form of ethnography adapted to computer-mediated communities) [45] or other approaches that did not directly engage participants nor did they provide consent toward participation in the study. Although the approach of using the comments of others from public online communities without their specific consent is considered ethical by current British Psychological Society (a representative body for psychology and psychologists in the United Kingdom) guidelines [46], it meant that it was not possible to observe more intimate encounters (eg, direct messaging, email, texting, telephone conversations, or even meeting offline) that may have emerged over time. This meant the behavior of participants was not affected by the presence of a researcher in the community, but it also meant that only what members elected to post could be used as research data.

Only three articles [35,36,40] specifically engaged network members. It is possible that because these papers directly engaged those using these communities that they permitted a greater discussion of how people experienced them. Thus, they were perhaps more likely to discuss the negative and the positive aspects of community membership. It may have been that in the other articles, those with bad experiences were less likely to post negative experiences, such as flaming (a hostile online interaction) caused by toxic disinhibition, which led to people being rude or angry toward others in ways that they would not be offline [47,48]. This kind of behavior had the potential to make people feel personally attacked if they expressed opinions that were different to other members [36]. Additionally, these articles were perhaps more likely to demonstrate concerns about misinformation (eg, people sharing inaccurate or harmful information) and people presenting themselves as experts [35,40]. Therefore, to some extent the positive feel of the other articles may be a result of their methodology; however, there is no shortage of articles that have identified the potential harms [49-57] and ethical issues [57,58] surrounding online communities.

Results

The long-term conditions examined in relation to online communities were diverse and clearly projected different illness experiences. They included heavily stigmatized conditions such as alcohol and substance use disorders [17,26] and human immunodeficiency virus and acquired immune deficiency syndrome (HIV/AIDS) [27,36]; medically contested conditions, such as fibromyalgia [25,35,39,40]; and extremely physically disabling conditions, such as Parkinson disease [24], arthritis [29,39,40], chronic obstructive pulmonary disease (COPD) [41], cystic fibrosis [31], and motor neuron disease [30,32].

Patient Online Communities' Involvement in Long-Term Condition Self-Management: Second-Order Synthesis of Concepts

To synthesize the data, the articles identified were read and logged into extraction forms (by CA). The extraction form used was adapted from a previous meta-synthesis. These were used to ensure the multiple concepts in the included articles were translated into one another. The extraction form included demographics, condition, group type, principal research question/aims, methodology/data collection strategy, principal findings, subthemes, theoretical concepts, conclusions, and study limitations. Within these extraction forms, we also included all verbatim quotes from participants (first-order constructs); this allowed us to see that the quotes from the participants fitted logically into the second-order constructs (the original author's interpretations) of the original articles.

Because the second-order constructs are interpretive, the concepts across the articles are presented in different ways. To synthesize the findings and concepts of the different articles into one another (second-order synthesis), we experimented with different visualizations of the second-order constructs used in the existing articles and examined the different arrangements of the key concepts from these studies. This involved a number of iterations before the final conceptualization of second-order constructs were agreed (by CA, IV, AK, AR). Following the synthesis of the second-order constructs, six second-order constructs were identified that illuminated how the social connections forged online contributed to long-term conditions self-management. From this, the synthesized second-order constructs (taken from translating the key themes in the included articles) were brought together and then reconfigured as a line of argument toward better understanding the negotiation of illness work in patient online communities.

Redressing Offline Experiential Information and Knowledge Deficits

Members were frequently drawn to online groups through an unmet offline need for condition-specific information that was easy to understand [40], could be customized to their specific needs [26,28,40,42], was based on patient experience [30,36,43], and was freely available at their convenience [36]. The need for accessible, accurate, and up-to-date information was often directed by inadequate access to information offline, whereby community members felt let down by information providers in their offline worlds [29,36]. This was often fuelled by time restraints and power relationships experienced in offline consultations, which appeared to inhibit information seeking [29]. Membership to an online community appeared to be a useful way of mitigating this, by affording members with greater access to information [28,29,36,39]. Network members were able to use these online communities to filter and navigate condition-specific information created by peers, in accessible language, at their convenience. This allowed the redressing of information asymmetry by affording individuals information their health care professional (HCP) did not feel they needed, withheld from them, or provided in a format they did not understand [36].

The information available in the groups frequently pertained to lived illness experience [25,28,30]. Members favored this information over the presumed expert knowledge of HCPs, whereby validity was bestowed on embodied illness experience [25,28,30]. Indeed, posts would insinuate that "expert patients" had a higher degree of condition-specific knowledge than HCPs [30]. These expert patients were able, through community action and shared knowledge, to assist others to locate information elsewhere [27,30] (both online and offline). Although some had concerns about the validity of the information posted [40], the information was frequently validated using a process of community vetting [28,43] with members intervening when bad information was posted [40]. This suggests that membership in these communities facilitates improved health literacy and resource navigation by pooling the collective knowledge and lay expertise of its members who have a vested interest in better understanding their condition [27,28].

The Influence of Modeling and Learning Behaviors From Others on Self-Management

The included articles all demonstrated online communities' ability to enable members to reach out to peers for practical illness-specific advice. The peers that they connected with were able to develop expertise about daily treatment practices through trial and error, giving them valuable knowledge and information about the daily practicalities of self-managing a long-term condition that extended beyond the empirical evidence available to HCPs [28,30,42]. This afforded members an enhanced understanding of how to integrate multifaceted treatment regimens to balance the complexities of self-management in daily life [28,30,31,42]. Users learned from the self-management approaches of others by observing their self-management strategies, discovering new and more efficient strategies, and subsequently testing out these new strategies with their peers [42]. From this, they were able to select an approach that best met their needs [42].

The sharing of experiential information in online communities is an important feature in shaping the experience of those living with a long-term condition because the information shared in these communities frequently favored patient-centered goals as opposed to HCP-centered metrics [28,29,31]. This information was easier for members to configure to their specific needs and was less rigid than the information and self-management strategies provided offline [26,28,29,31,42].

Engagement Which Validates Illness and Negates Offline Frustrations

Having access to the online community made members feel less alone and provided a reference for what was a normal illness experience [17,24,25,29,31,36,40]. Members, who often lacked solidarity offline, were able to build a collection of symptoms into a shared identity [24,25,31,33,34]. Offline, members found it difficult to get a real understanding from friends and family and were able to use these online spaces to express these frustrations with a network of people who seemingly understood the challenging nature of self-managing their illness [25,29,34,36,37,40]. This was particularly the case in communities for conditions that lacked visible external cues or for which the somatic nature of the illness was contested [25,29,35]. This disparagement strengthened group solidarity and allowed users to feel validated and believed through engaging and identifying with other network members [25,29].

Meeting people who understood the challenging nature of self-management allowed members the opportunity to be positively appraised for accomplishments that their offline contacts might not recognize as achievements [28,37]. Members were commended for the achievement of smaller self-directed goals as opposed to ones set by HCPs [28,37]. This worked to motivate group members to believe in treatment recommendations, shared beliefs, and practices, thus encouraging treatment compliance [24,41].

The sharing of condition narratives enabled members the opportunity to reevaluate their situation through lateral and downward social comparison. Being able to see how others coped with their condition reassured members that they could manage their condition through education, adjustment, adaptation, and acceptance [17,29,33,35,40,42].

Tie Formation and Community Building

Communities often demonstrated a clear sense of comradery, with the communities inferring strong community structures, cultural norms, and group orthodoxies [24,28,31,32,40,43]. Many of these communities appeared to promote a positive, inclusive culture, bringing people of diverse backgrounds together to meet a shared purpose [24,32,36,43]. This sense of belonging, coupled with a shared lived experience of the condition and frustrations with offline support, facilitated the creation of friendships [24]. This creation of community led to members integrating the community into their everyday lives [32,40]. Members used endearing terms such as “family” and “friends” and would frequently engage in non-condition-related conversations, suggesting that the communities had facilitated strong bonds between members [24,27,36,40] with relationships evolving into offline spaces [36,40], where tangible benefits, such as offers of accommodation, could be realized [36].

In several instances, users connected with these communities to mitigate loneliness and isolation in their offline worlds [32,35,40], which appeared to be particularly important in instances where the disabling nature of the condition had led to an erosion of offline support and a reduced ability to form social ties in offline settings [32,35,40]. Often, network members faced clear social disadvantage in their offline worlds, but online belonged to lively, vivacious communities with resources of information and support offered freely as a public good to community members [32].

Narrative Expression and Cathartic Release

These communities provided a safe environment for the sharing of condition narratives. The process of narrative sharing offered immediate psychological relief because members often felt unable to express negative emotions offline due to the perceived need to maintain a positive social front [29,37]. Some members found sharing experiences easier online, preferring to talk to strangers online about their illness experience than with their offline contacts [35,36,40]. These online spaces provided them with a community of people ready to listen to their concerns and provide them emotional support and refuge [35,36,40]. Because these communities made members feel more able to openly express their need for support, they were possibly more likely to receive it and it is perhaps unsurprising that some users felt more supported online [29].

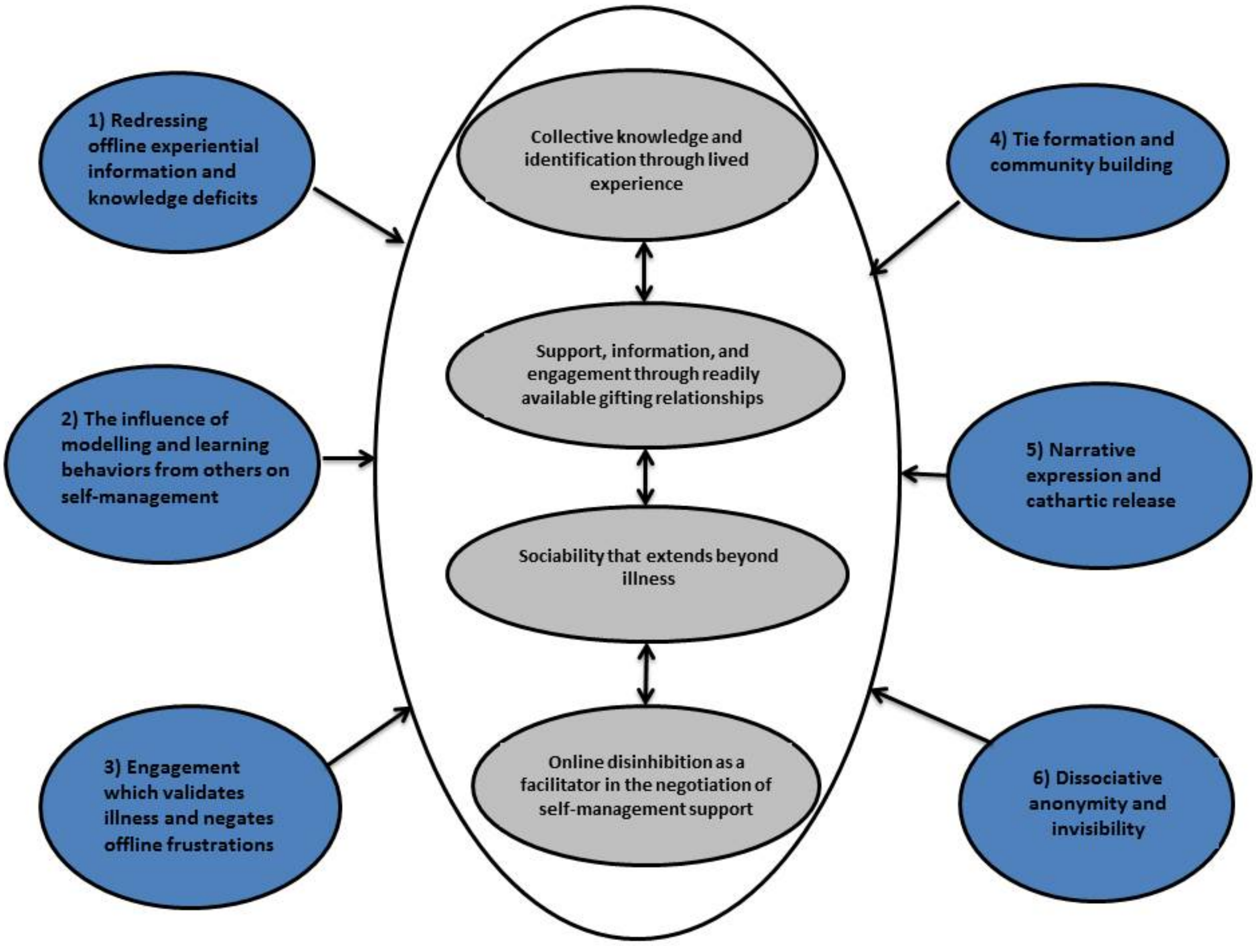
Dissociative Anonymity and Invisibility

Acquiring certain types of sensitive information, that may be important in developing a holistic self-management strategy such as information pertaining to sex and incontinence, appears to be easier to navigate in these online communities due to the presence of benign disinhibition and dissociative anonymity [47]. This appears to have an empowering effect by allowing members to ask questions that they would otherwise be too embarrassed to seek in their physical worlds [24,36].

Understanding the Significance of Negotiating Self-Management Support and Illness Work in Online Communities: Third-Order Synthesis

Following a process of synthesis, the second-order constructs described previously were reconfigured toward understanding what is significant about the negotiation of self-management support and illness work in online communities for those living with a long-term condition. This translated into a line of argument synthesis in which four network mechanisms for self-management support in online communities were identified. A summary of the second- and third-order constructs is shown in Figure 2. In exploring the significance of online support networks compared to traditional offline ones, we drew on previous research examining the social context of long-term condition self-management and the network mechanisms involved in negotiating illness work [1,7,9,21]. This allowed us to examine whether similar mechanisms of self-management support exist and are mobilized online.

Figure 2. Summary of second- (blue) and third-order (gray) constructs in relation to the negotiation of self-management support in patient online communities.



Collective Knowledge and Identification Through Lived Experience

Given that "the Internet has changed people's relationship with information" [59] (p. 1), it is perhaps unsurprising that the ability of these communities to provide information featured highly in the included articles. Information and actionable advice based on lived experience contained highly specialized forms of experiential information that was unobtainable offline. These communities facilitated patient empowerment by affording members the right to explore the self-management of their condition in the context of their daily lives. This patient empowerment perspective, facilitated by membership in these groups, promoted a fundamentally different set of roles for HCPs and patients, whereby the collective knowledge created through lived experience was seen as more useful in the self-management of a long-term condition in daily life than medical knowledge. In line with previous research, these communities appear to foster empowerment and the potential to change the relationship between HCPs and patients, from one of compliance to one of shared ownership [60,61].

In addition to the availability of cocreated experiential knowledge, the presence of distributed health literacy enabled community members to find the information they required. Online social ties can act as health literacy mediators [62] in a process of distributed health literacy between network members, allowing people to benefit from the health literacy of others in their network, who may give them greater access to the information needed to manage their condition.

In offline consultations, a mediator such as close friend or family member is often present to help the person comprehend what is being discussed [7] and individuals can capitalize on the resources and links made with members of their social networks offline [62]. People's knowledge about their condition is often shaped by others with the same condition in their personal networks [7,21]. However, this resource may not be available to everyone, such as in rare conditions or in situations where open discussion is difficult. People appear to be able to substitute offline information deficits with online contacts, whereby community members benefit from the health literacy skills of their peers. Examples included network members assisting in resource navigation [27] and explaining medical terminology [29,36,43].

Additionally distributed knowledge and information in these communities constituted a by-product of the continued engagement of network members [33,34]. Communities generated value through members "cocreating their own service encounter" [34] (p.167). Members were able to select the features that they required and request, receive, or search for information at their convenience [34]. Unlike offline encounters, a permanent record is made, which allows members to benefit from cumulative experiential information generated over time [30,32]. For some, the sheer volume of information available made it difficult to find the specific information they needed [40], which further signposts the need for community members to assist in the navigation of resources in these communities. Essentially, the strength of these communities drives the availability of the information. Many communities have a defined core group of members [63,64], whose informational and experiential knowledge can be disseminated to other members who may be less well informed. As Lester et al [65] hypothesized, although not everyone in the group knows as much as this expert core, they do know how to access expert members, who in turn know how to access information.

The provision of information should be considered an important component of any long-term condition self-management package [66], but information on its own has been found to have very little or no effect on self-management [67] and it is these communities' ability to tie information to real-life parables that is most fascinating. Each individual's needs are highly specific; therefore, self-management support must be tailorable. Members of these communities felt restricted by a lack of flexibility, choice, and control in self-management strategies dictated by HCPs, but could use these communities to observe the practice of others, adapting their self-management strategy to meet a specific problem or a change in their condition [28,35] through navigating the available information and deciding the approach which best met their needs [42]. This is perhaps why the coconstructed authoritative knowledge of community members built around the lived experience of self-managing a long-term condition in daily life was so valuable. Patient online communities appear to deliver a highly individual experience through the cocreation of community content. For example, it is perhaps unlikely that the traditional patient education perspective model of information would be able to disseminate highly experiential information, such as how someone with diabetes can count carbohydrates to enable drinking sessions without risking ketoacidosis [28], but such facets of information are clearly useful to someone with diabetes wanting to self-management their condition.

In addition to information and health literacy mediation, these communities facilitate the negotiation of illness emotional work and its biographical dimension, whereby emotional work relates to the provision of comfort when someone is upset, anxious, or worried about everyday issues, such as their health, well-being, and companionship [1]. Biographical dimensions of emotional work are associated with the revision of expectations, capabilities, plans, identity, relationships, and biographical events [1], and these online communities have a role in the realization of these components, particularly in allowing members the opportunity to reframe their lives [17,29,33,35,40,42].

By engaging in online communities, individuals were able to gain emotional support that they had been unable to access in their offline worlds and by connecting with those with a shared embodied experience were able to feel normal [17,24,25,29,35,36,40]. Through collective identification, these groups facilitated engagement, allowed individuals to make sense of their situation, and allowed them to receive positive appraisal for successful self-management practices [28,37]. Furthermore, through lateral and downward social comparison, these online communities allowed members the opportunity to compare their illness narratives with one another, enabling them to reassess their expectations, capabilities, and plans, while empowering them to realize that successful self-management is achievable [17,29,33,35,40-42]. Thus, through collective identification and engagement, these online communities provided the opportunity for validation, reassessment, and appraisal. But, for some, this was upsetting because it made many negative aspects of the disease visible, some of which they may not have considered [40].

Support, Information, and Engagement Through Readily Available Gifting Relationships

In addition to navigating network contacts, those with a long-term condition need to negotiate and renegotiate existing relationships, roles, and engagement with network members. Negotiating help offline is frequently accompanied by obligations and expectations and may be restricted by time [21]. Such obligations and expectations were not visible in the online communities explored here. Requests for help (resource mobilization) were rarely targeted at a specific network member; often requests for assistance were to the group as a whole, leading to many replying. This information is frequently gifted, with no reciprocal expectation, making help less tangible but potentially easier to obtain online than off.

In much the same way as gifting relationships stock UK blood banks [68], members of these networks gift these communities with information and support freely [29,32,35,36,39,43]. Much like donating blood, the decision to volunteer information cannot "of course, be characterized by complete, disinterested, spontaneous altruism" [68] (p. 89). Information and emotional labor is gifted to these communities by its members, who are potentially motivated to do this through a sense of obligation or through some awareness of need. Like donating blood, there may be "some expectation and assurance that a return gift may be needed and received at some future time" [68] (p. 89). In this sense, these online communities operate much like a gift economy with information and support being freely given, with little expectation of reciprocation, but fuelled by the desire that someone else may find the information useful and the pride of building a community [28,32,34-36].

The process of sharing information appeared to have a useful dual purpose, providing information for those in need, but also affording others with their altruistic need to impart the knowledge that they had accumulated [28,32,34-36]. Being able to offer information that others may find helpful appeared to foster feelings of validation and self-worth, feelings that are often suppressed by illness [35]. The voluntary provision of information was part of these groups' culture and occurred more frequently than in response to direct questioning. Although offline peer mentors have benefited from providing support through finding meaning and social reinforcement of their own self-management behaviors, gift exchange in these online communities is different to that in offline support groups. Offline, the process of sharing has been found to improve the internal capacity of individuals to cope with stress and can be a motivating factor in long-term condition self-management through mediating lifestyle changes and affording new self-management tools [21]. However, these gift exchanges may fail offline because the recipients of the intended gift may not turn up. Because of the asynchronous nature of the Internet, members can post information and support that others may benefit from at a later time. Furthermore, these gifts have the potential to benefit anyone who accesses the group, whereas this kind of gift offered offline can only benefit those physically present because no lasting record is made of the encounter. Because of the giving nature of such communities, there is a wealth of information and support that requires little or no negotiation.

Sociability That Extends Beyond Illness

In these communities, conversations frequently extended beyond illness into everyday matters and interests [29,36,40], which seemed to provide "social hooks" for continued community involvement. Although people appear to migrate into these online communities due to offline information and emotional deficits, it is perhaps these hooks that result in continued engagement. Members spent time relaxing in these online communities [40] and enjoyed being able to socialize [35], which appeared to be particularly appreciated in circumstances where the presence of illness had led to the erosion of offline contacts [35,40]. Members looked forward to their online interactions with one another and enjoyed telling others about their day: "I have just got in from a lovely evening and couldn't wait to get on and see if there was any mail for me...I thought I would share with you the events of the evening" [29] (p.189). For many, engagement with these online communities had become part of their daily routine: "You should really see it as a book. You're in the middle of a story. And when you put the book down at night, you really want to continue reading the next morning." [40] (p.409). These communities accompanied members throughout their day [40] and this may become increasingly important in the future as smartphones continue to integrate these technologies into our daily lives [69].

The presence of a long-term condition may place greater salience on support from family and close friends, reducing the opportunities to build and maintain contacts that extend beyond this. Socializing with people online and being able to build relationships with new people allows individuals to build new networks of influence that extend beyond intimate offline contacts. Consequently, those whose condition may have eroded the ease with which they can build and maintain weak social ties appear to benefit from being able to substitute for this by building new networks of contacts in patient online communities. However, that this support often remained online was a source of frustration for some who wanted to extend their relationship into offline spaces, but were restricted by geography [24]. Despite this, the ability to proactively extend networks that may have been eroded by the presence of a long-term condition is important because research suggests that those with a larger network of contacts consisting of both friends and family typically have the most favorable outcomes [70].

The "Internet paradox" article contains an argument that the Internet, as a social technology, may reduce socialization and psychological well-being [71]. Such concerns were voiced in Mo and Coulson's [36] article: "...I noticed that my real-life relationships were declining due to the time I invested in the online community" [36] (p. 990). However, being able to access these communities enabled those whose social ties had been eroded through illness [35,37] to build new opportunities for sociability: "Through fibromyalgia you lose a lot of personal contact. Because you can't go to birthday celebrations anymore, because you forget things, you're often too tired and so on. And in this way you can rebuild your social contacts" [40] (p. 412). These communities may allow members to reach out to peers when offline socialization is not possible. Thus, being able to access peers online has the potential to mediate feelings of isolation and loneliness. Later research by Kraut et al [72] into the Internet paradox found that although those using the Internet generally experienced positive effects on social involvement, communication, and emotional well-being, the extent to which these benefits were realized was associated with offline support, whereby extroverts with good preexisting offline social networks fared better than introverts with reduced offline support. Additionally, research by Kuss and Griffiths [73] found that extroverts use social media for social enhancement, whereas introverts use them as a means of social compensation [73]. Although these findings were not in the context of patient online communities, it does suggest that introverts managing a long-term condition in these online communities may be distanced from offline social networks able to provide more tangible support in spite of being able to use the Internet to access a more diverse network.

Online Disinhibition as a Facilitator in the Negotiation of Self-Management Support

Being able to act anonymously online highlights the presence of managing moral identity work operating in these communities. Those with a long-term condition may decide that the need to be both independent and autonomous is so important that they choose not to activate offline support despite it being available [21]. As such, these online communities may protect offline relationships and allow those living with a long-term condition to negotiate illness work while remaining both independent and autonomous.

Suler's [47,48] theory of an online disinhibition effect suggests that people behave differently on the Internet due to the presence of:

1. Dissociative anonymity: people may feel that their online actions cannot be attributed to their person. In a process of dissociation, people may feel they do not own their online behaviors.
2. Invisibility: online, people know that others do not know what they look like. This may make people feel more able to do things on the Internet that they would not do offline.
3. Asynchronicity: online interactions often do not occur in real time. Not having to cope with someone's immediate reaction to something that has been said or done may disinhibit people.
4. Solipsistic introjection: the absence of face-to-face cues may alter normal self-boundaries. Because people cannot

see what others look or sound like online, they may introject others into their own psyche.

5. Dissociative imagination: people may feel the online world is not real and that the people they interact with online are not real people.
6. Minimization of status and authority: there is often an absence of authority figures online and people may feel they can act more freely.

Dissociative anonymity, invisibility, and the minimization of status and authority appear to have a positive impact on the negotiation of self-management support online in the included articles. The presence of “benign” disinhibition appears to facilitate the negotiation of self-management support in patient online communities because people may be reluctant to seek certain types of support in their offline worlds due to societal and self-stigmatizations. Although the online disinhibition effect may explain some of the harmful behaviors driven by toxic disinhibition, which was visible in some of these communities [36], the disinhibiting nature of online communication appears to be mostly positive in allowing people to reach out to others for self-management support.

People are able to move around the Internet anonymously [47,48]. In some of these groups, people reveal their identity, but many used pseudonyms. As Suler [47,48] highlights, the Internet gives people the opportunity to separate their offline persona from their online actions. As such, through a process of dissociation, “the online self becomes a compartmentalized self” [47] (p. 322) and, in the context of patient online communities, appears to allow people to reach out to peers for information and emotional support without endangering their offline self. Suler [47,48] suggests that this can facilitate rapid or falsely intimate relationships, which might explain why such strong bonds appear to form in these online communities. Talking about stigmatized conditions is challenging offline. These online communities enable people to talk about their illness while remaining anonymous: “...at the time I wasn’t capable nor [ready] to approach an [AIDS service organization] nor disclose my status. I had so many guilty questions that I needed to talk to someone who would not know anything about my life nor recognize me” [36] (p. 987).

Even when everyone’s identity is known, people can feel invisible online [47,48]. This is protective and facilitates the negotiation of self-management support. Because online communication lacks nonverbal cues, people don’t have to worry about how they look or sound [47]. They can write, examine, and edit posts before sending, allowing complete control over disclosures and expressions. This editorial control is lacking in offline communications. This disclosure scrutiny and editorial freedom can lead to people feeling more comfortable discussing even everyday matters online [74]. Community members felt empowered to disclose due to this increased control: “this is an excellent medium for me to be able to control my interactions” [35]. But because of the lasting record associated with computer-mediated communication, some were skeptical in spite of this increased control: “I do not want to disclose my personal and painful journey via a social network site for it to be highlighted by others and ‘used’ as a way to finish me in my job” [35]. Additionally, online communication lacks nonverbal cues so people do not have to worry about nonverbal responses, such as frowns, shaking of heads, or other nonverbal signs of disapproval [47,48] that may inhibit offline disclosures. Offline, when people discuss emotional matters, they often avoid eye contact. These online communities offer “a built-in opportunity to keep one’s eyes averted” [47] (p. 322), thus avoiding awkward moments in which “the rheumatologist sneers a bit” [40] (p. 410).

The presence of benign disinhibition generates group resources because it facilitates conversations about stigmatized or taboo subjects that others may find useful and validating. It also provides a safe and effective environment for the negotiation of support, allowing people to freely discuss personal and/or embarrassing health narratives, which may be particularly important to those whose condition is heavily stigmatized as well as potentially enabling those with less stigmatized conditions to ask questions about more sensitive aspects of living with a long-term condition [17,47]. For some, these online communities represent the only place where information and support for self-management can be negotiated: “Only they know that I have HIV and my doctor, nobody else. They are my virtual family” [36] (p. 988).

Discussion

This research strengthens our socialized understanding of long-term condition self-management by taking into account the illness work of social ties mediated online and the role such ties may have in the management of a long-term condition in daily life. Effective self-management support utilizes resources and networks that are available in the everyday lives of those with a long-term condition, which operate outside of formal health care, and this meta-synthesis has shown that these are available online and important to people. Those with a long-term condition appeared to reach out to these online communities because of an unmet offline need for information and/or emotional support. This substitutability of illness work has been seen before in offline social networks [7]; in this instance, it clearly signposts the importance of these online communities in negotiating illness work particularly when access to support offline is absent or limited.

It is clear that these communities afforded many benefits that have the potential to positively shape someone’s experience of living with a long-term condition. To some extent, the findings of this meta-synthesis necessarily overlap with the work of Ziebland and Wyke [18]. Certainly, the facility of these online communities to help people find information, feel supported, maintain relationships, experience health services, learn to relate, visualize their disease, and affect behavior [18] were all visible in the included articles and may all help to positively shape self-management. The distinction between this paper and that of Ziebland and Wyke [18] is the specific focus on the contribution of online social networks to long-term condition self-management illness work and the affordances of community membership rather than the impact of online patients’ accounts of experiences with health and health care.

This meta-synthesis has demonstrated that there are several benefits to members of patient online communities over and above those available to people simply searching for the experiential accounts of others. Membership of these online communities affords those living with a long-term condition ready access to a self-management support illness workforce, particularly in relation to illness and emotional work. However, in contrast to offline social ties, these online communities provide social ties that require significantly less maintenance, less reciprocation, and are easier to negotiate. This is potentially due to the presence of benign disinhibition and the gifting economic relationships of these online spaces, whereby information and support is donated freely, as a public good, with no immediate expectation of reciprocation. Unsurprisingly, everyday work appears largely absent in online self-management support perhaps due to the need for physical presence to assist in household tasks, shopping, or personal care. There is some suggestion in the research literature of relationships evolving into more intimate communication channels and offline spaces [36,40]; therefore, it is not unreasonable to suggest that "everyday work" may emerge in these relationships over time.

Importantly, social ties forged in online spaces can perform self-management work that can improve an individual's illness experience and can reach areas that are particularly difficult to navigate offline. Because of this, patient online communities appear to be a promising place for the negotiation of self-management support for long-term conditions that may supplement and support offline information and support and should be included in future studies exploring the social context of long-term condition self-management.

This study had a few limitations from which future directions for research are suggested. The majority of the included articles examined patient online communities that existed on condition-specific discussion forums and boards. In contrast, newer apps, such as Facebook and Twitter, are poorly represented in the existing research literature with no existing research examining long-term condition self-management support in the context of Twitter. There is also a need for future research to conceptualize how best to support those wishing to utilize these resources in their self-management strategy (eg, computer literacy, resource navigation, and training). Additionally, interventions that seek to better engage the lay natural helpers and super users present in these communities could allow us to understand and use this underutilized resource.

The process of group formation in these online worlds appears to be wholly underexplored in the current research literature. It is clear that social characteristics, such as trust and reciprocity, do exist in these online spaces, but far less is known about the process that facilitates them. Additionally, we know little about how the community is created, how issues of brokerage bring new faces into these communities, how people navigate the mass of communities online to pick one that is suitable to them, or what specific features of an online community they see as important (ie, the presence of a moderator, charity run, professional recognition, site architecture). A case study specifically looking at the social processes within these groups could illuminate this and a longitudinal approach would allow us to see how the relationships in these communities evolve over time.

Because many of the papers involved in this review used methods that did not directly engage those using these communities, there is potentially a bias toward the sharing of positive experiences. There is a need for future research to directly engage with members of these communities to find out why people are reluctant to post and illuminate how these communities help people manage their condition in daily life. Such research would also allow us to further develop our understanding of illness work online, while also helping us better understand such work in the context of preexisting offline support.

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Conflicts of Interest

None declared.

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Abbreviations

AMED: Allied and Complementary Medicine Database
CASP: Critical Appraisal Skills Programme
CINAHL: Cumulative Index to Nursing and Allied Health Literature
HCP: health care professional
NHS: National Health Service

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Original Paper

Trusting Social Media as a Source of Health Information: Online Surveys Comparing the United States, Korea, and Hong Kong

Hayeon Song[1], PhD; Kikuko Omori[2], PhD; Jihyun Kim[3], PhD; Kelly E Tenzek[4], PhD; Jennifer Morey Hawkins[5], PhD; Wan-Ying Lin[6], PhD; Yong-Chan Kim[7], PhD; Joo-Young Jung[8], PhD

[1]Gachon University, Seongnam, Gyeonggi Province, Republic Of Korea
[2]St. Cloud State University, St. Cloud, MN, United States
[3]Kent State University, Kent, OH, United States
[4]University of Buffalo, Buffalo, NY, United States
[5]University of Wisconsin-Milwaukee, Milwaukee, WI, United States
[6]City University of Hong Kong, Hong Kong, China (Hong Kong)
[7]Yonsei University, Seoul, Republic Of Korea
[8]International Christian University, Tokyo, Japan

Corresponding Author:
Yong-Chan Kim, PhD
Yonsei University
Shinchon-dong 134, Seodaemoon-gu
Seoul, 120-749
Republic Of Korea
Phone: 82 2 2123 2974
Fax: 82 2 2123 2970
Email: yongckim@yonsei.ac.kr

Abstract

Background: The Internet has increasingly become a popular source of health information by connecting individuals with health content, experts, and support. More and more, individuals turn to social media and Internet sites to share health information and experiences. Although online health information seeking occurs worldwide, limited empirical studies exist examining cross-cultural differences in perceptions about user-generated, experience-based information compared to expertise-based information sources.

Objective: To investigate if cultural variations exist in patterns of online health information seeking, specifically in perceptions of online health information sources. It was hypothesized that Koreans and Hongkongers, compared to Americans, would be more likely to trust and use experience-based knowledge shared in social Internet sites, such as social media and online support groups. Conversely, Americans, compared to Koreans and Hongkongers, would value expertise-based knowledge prepared and approved by doctors or professional health providers more.

Methods: Survey questionnaires were developed in English first and then translated into Korean and Chinese. The back-translation method ensured the standardization of questions. Surveys were administered using a standardized recruitment strategy and data collection methods.

Results: A total of 826 participants living in metropolitan areas from the United States (n=301), Korea (n=179), and Hong Kong (n=337) participated in the study. We found significant cultural differences in information processing preferences for online health information. A planned contrast test revealed that Koreans and Hongkongers showed more trust in experience-based health information sources (blogs: $t_{451.50}$=11.21, P<.001; online support group: $t_{455.71}$=9.30, P<.001; social networking sites [SNS]: $t_{466.75}$=11.36, P<.001) and also reported using blogs ($t_{515.31}$=6.67, P<.001) and SNS ($t_{529.22}$=4.51, P<.001) more frequently than Americans. Americans showed a stronger preference for using expertise-based information sources (eg, WebMD and CDC) compared to Koreans and Hongkongers ($t_{360.02}$=3.01, P=.003). Trust in expertise-based information sources was universal, demonstrating no cultural differences (Brown-Forsythe $F_{2,654}$=1.82, P=.16). Culture also contributed significantly to differences in searching information on behalf of family members ($t_{480.38}$=5.99, P<.001) as well as to the goals of information searching.

Conclusions: This research found significant cultural differences in information processing preferences for online health information. Further discussion is included regarding effective communication strategies in providing quality health information.

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KEYWORDS

social media; medical informatics; trust; culture; consumer behavior; consumer health information; information sharing

Introduction

The Internet has increasingly become a popular source of health information by connecting individuals with health content, experts, and support. According to the Pew Internet & American Life Project [1], the Internet now exists as a popular venue for a number of health-seeking behaviors. For example, 35% of adults in the United States turn to the Internet to find information related to health and medical issues. Doctors and health professionals contribute to online health information, but a growing amount of health information on the Internet originates from individual patients sharing experiences. New digital platforms, such as social media and online support groups, allow a growing number of people to find peers who experience similar medical conditions or concerns, or to follow others' experiences of health. For example, 26% of Internet users read or watched someone else's experience about health or medical issues and 16% of Internet users deliberately tried to find others who experienced the same health concerns [2]. The Internet may serve a crucial role for individuals managing chronic illness, such as high blood pressure and diabetes, because one in four Internet users living with a chronic disease searched the Internet to find others with similar health concerns [2].

Research identifies two types of health information: expertise-based information produced by medical professionals and experience-based information based on laypersons' subjective first-hand experiences of health and illness [3]. With the help of Web 2.0, user-generated, experience-based information emerges from "enormous knowledge assets that reside in collectives and communities" [4]. Further, experience-based information empowered by the Internet's ability "to aggregate individuals' experiences or opinion, pool their information, and identify the expertise of 'nonexperts' based on specific or situated knowledge" [5] currently challenges traditionally credentialed expertise. Some studies empirically investigate how Internet users differentially trust expertise- versus experience-based information sources. Eastin [6] found high-expertise source information tends to be perceived as more credible than low-expertise sources, whereas Hu and Sundar [7] did not find significant differences in the perceived credibility of messages prepared by doctors compared to laypersons.

Limited studies exist explaining such inconsistent findings—a gap remains in research examining possible factors affecting trust in expertise- versus experience-based health information available online. Further, it remains unknown whether clear cultural differences exist in perceptions about experience-based health information compared to expertise-based information sources. Because online health information seeking occurs worldwide [8] and health care is becoming more of a global issue [9], understanding cultural differences in online health information-seeking behavior becomes important. Are certain types of health information sought, trusted, and used more frequently in certain cultures compared to others? Do any cultural differences exist in terms of the effectiveness in communication strategies in providing health information online? Proper answers to these questions would be critical for professionals and community health workers serving multiethnic, multicultural global communities. Accordingly, this study compares data collected from the United States, South Korea, and Hong Kong to investigate if cultural variations exist in patterns of online health information seeking, specifically in perceptions of online health information sources.

Cultural Emphasis on Experience-Based and Expertise-Based Information

Although various factors may affect differences across the United States, Korea, and Hong Kong, cultural theories provide a useful framework for understanding differences in the perception and seeking behaviors of online health information. According to Nisbett [10,11], culture influences information processing strategies and one's general thoughts and beliefs. Nisbett and associates claim Easterners tend to possess a holistic approach, whereas Westerners predominately hold analytical and logical approaches [10-14]. A holistic approach involves an orientation to the context or field as a whole and a preference for explaining and predicting events based on such relationships [10]. Holism resists decontextualization, the separation of form from content, and the reliance on concrete instances and experiences. On the other hand, an analytic approach focuses on the categories to which an object belongs and relies on rules using formal logic. That is, such an approach includes a tendency to analyze the whole to determine key elements using logical understanding.

Several empirical studies have demonstrated Americans and Europeans are more likely to use logical, analytic, and rule-based reasoning, whereas East Asians are more likely to use intuitive, experience-based, and holistic reasoning [14,15]. Norenzayan and colleagues [14] compared the reasoning styles of European Americans and East Asians when participants were provided with a series of tasks (categorization, conceptual structure, and deductive reasoning) activating cognitive conflict. Findings suggest European Americans are more willing to set aside intuition and utilize rule-based reasoning than East Asians. The rationale is that individuals with an analytic approach possess a strong tendency to use abstract rules rather than experience for tasks of categorization and deductive reasoning. Moreover, Buchtel and Norenzayan [15] found Koreans (ie, those from a holistic culture) ranked intuition as more important than logic for success both at work and in relationship building. Further, East Asians rated an employee who made business decisions based on intuition higher than an employee who made decisions based on rule-based logic. Large-scale differences in cognitive preferences may influence various aspects of everyday life, including persuasion [16], trust building [17], and buying decisions [17].

Although not directly studied within a health-related context, extant research has demonstrated how cultural orientation influences people's preferences for online information and trust building on the Internet across cultures. Access to experience-based information through word-of-mouth has been deemed an influential factor affecting consumer behaviors. Many marketing scholars have demonstrated the important role of customer reviews (ie, experience-based information) in e-commerce among various cultures [16,18,19]. For example, Utz et al [19] demonstrated that consumer reviews of stores had stronger effects on consumer behaviors than the overall reputation of the stores in the Netherlands. Lim et al [16] found the use of customer endorsement was more effective in building consumer trust in online shopping stores than the use of portal affiliation with stores in Hong Kong. Further, a study conducted in Taiwan specifically demonstrated that customer recommendations were more effective than expert recommendations on online product choices [18]. Going beyond a study in a single country, Sia and colleagues [17] conducted a comparative study about effects of customer endorsement and portal affiliation between two countries: Australia and Hong Kong. They found the impact of peer-customer endorsement on trust levels was stronger for individuals in Hong Kong than those in Australia. On the other hand, the effect of portal affiliation was more effective in Australia than Hong Kong.

Taken together, the previously mentioned studies imply that experience-based information shared online is becoming important across cultures and that Easterners rely more on it compared to Westerners. Particularly, findings imply that Easterners tend to show stronger trust toward those within their network (a whole), which is relevant to one of the core aspects of holism [12,14]. However, there is little evidence showing that this is also the case for health information seeking. One example is a study that indicates that people in the United States tend to seek information in online medical journals, whereas Japanese people prefer to find online health information in support groups [20].

Based on the previous empirical studies and the theoretical arguments that examine cultural differences in trust of online information, the goal of this study is to investigate cultural differences in trust of online health information. Specifically, we predict that Koreans and Hongkongers, compared to Americans, would be more likely to trust and use experience-based information shared in social Internet sites such as social media and online support groups. Conversely, Americans would be more likely to value health information prepared or approved by doctors or professional health providers (expertise-based information) than Koreans and Hongkongers.

Therefore, hypothesis 1a is Koreans and Hongkongers, compared to Americans, will report higher levels of trust in experience-based online health information sources (eg, social networking sites [SNS], blogs, online support groups). In contrast, hypothesis 1b is Americans, compared to Koreans and Hongkongers, will report higher levels of trust in expertise-based online health information sources (eg, WebMD).

Hypothesis 2a is Koreans and Hongkongers, compared to Americans, will use experienced-based sites more frequently. In contrast, hypothesis 2b is Americans, compared to Koreans and Hongkongers, will use expertise-based sites more frequently.

Goals of Online Health Information–Seeking Behavior

In addition, we investigated cultural differences in the goals of online health information-seeking behavior to better understand preferences for experience-based and expertise-based information. Studies have suggested that several goals of online health information-seeking behavior differ before and after seeing a physician. Before meeting their doctor, patients go online mainly to (1) assess the need for consultation, (2) decide which physician to see, or (3) prepare for consultation [21,22]. After meeting the doctor, some patients might question the information provided to them by their doctor and decide to go online to get more information [23,24]. Patients may also turn to the Internet to better understand their diagnosis and treatment [21,22] and/or make sure they fully understand their health issues and have enough information [25]. Similarly, Caiata-Zufferey et al [26] categorized the goals related to online health information: (1) health maintenance, (2) preparing for consultation, (3) complementing consultation, and (4) validating/challenging consultation. Given that a significant number of people go online with various goals for health information seeking, it is important for educators, health care professionals, and website developers to further understand if cultural differences exist in types of goals for seeking health information. Thus, the following research question is raised: do cultural differences exist in goals of online health information-seeking behavior?

Searching for Online Health Information on Behalf of Family Members

Individuals seek, find, and share health information online not only for themselves, but also for others, such as friends and family. Surprisingly, approximately half of all online health searches are performed on behalf of someone else [1]. For example, 53% of online health information seekers living with chronic diseases reported their last online health information search was related to the medical situation of someone else.

Although not much is known about the social aspects of online health information-seeking behaviors among Asians, some evidence suggests Asians may seek online health information on behalf of family members more frequently compared to Americans. Studies have found Asian and Latin American adolescents possess greater responsibilities in assisting, respecting, and supporting their families than their European counterparts [27]. Asian cultures often prioritize family along with values of obedience, duty, and in-group harmony [28,29]. We predict that Koreans and Hongkongers, compared to Americans, would possess a higher proclivity to search online health information on behalf of their family members. Therefore, our third hypothesis is cultural differences exist in searching for information for family members, such that Koreans and

Hongkongers, compared to Americans, are more likely to search online health information on behalf of their family members.

Methods

Sample

The survey questionnaire for this study was developed in English first and then translated into Korean and Chinese. The back-translation method ensured the standardization of questions. In 2012, surveys were distributed to college students living in metropolitan areas of three different countries: the United States (Milwaukee, WI), South Korea (Seoul), and Hong Kong. Participants were solicited from large lectures at each university (University of Wisconsin-Milwaukee, Yonsei University, and City University of Hong Kong) using a standardized recruitment procedure and data collection method. Participation was voluntary. Required IRB documents were prepared and approved. An informed consent form was provided at the beginning of the survey.

Measures

Health Information Seeking: Frequency and Trust

The frequency of using particular health information sources—blogs, support groups, SNS (eg, Facebook, Twitter), and professional health information websites (eg, WebMD, Centers for Disease Control and Prevention [CDC])—was measured with a range from 1 (never) to 7 (every day). Health information sources were modified for each country, allowing the list to reflect the most popular and representative sources, and subsequently verified by media statistics and media researchers living in each country. The level of trust in each health information source was also based on a 7-point Likert scale ranging from 1 (not at all) to 7 (completely).

Goals of Online Health Information Seeking

Four major goals of seeking online health information were developed and assessed based on a study by Caiata-Zufferey et al [26]: (1) health maintenance, such as “to maintain a healthy lifestyle” (α=.84); (2) preparation, such as “to determine whether I need to see a doctor” (α=.90); (3) complementing consultation, such as “after seeing my doctor to obtain more information” (α=.89); and (4) validating/challenging consultation, such as “to find different options for treatment” (α=.92). Responses were obtained on a 7-point Likert scale (1=strongly agree, 7=strongly disagree) with five items measuring each variable.

Seeking Health Information on Behalf of Family Members

The extent to which participants sought information on behalf of family members was measured by the level of agreement with the following statement: “Searching information for sick family members is an important family responsibility.” Responses were obtained using a 7-point Likert-type scale (1=strongly agree, 7=strongly disagree).

Statistical Analysis

To test the hypotheses and research question, a series of 1-way ANOVAs were conducted followed by a planned contrast test. Before ANOVA testing, Levene’s test was conducted to check whether or not equal variance could be assumed. When the group variances were statistically equal, ANOVA *F* test was conducted. When equal variance could not be assumed, the Brown-Forsythe test was conducted instead of the ANOVA *F* test to reduce type I error. As a next step, a planned contrast test was conducted to systematically compare cultural differences. For the planned contrast test, the first level was to compare between analytic (ie, United States) and holistic (ie, Korea and Hong Kong) cultures, and then the second level was tested for a subsequent comparison between Korea and Hong Kong. The level of significance was set at .05.

Results

A total of 826 native residents (301 in the United States, 179 in Korea, and 337 in Hong Kong) were included in the analysis (see Table 1). Among the 826 participants, 484 were male and 316 were female. Among US participants, 168 were male and 130 were female, whereas Korean participants consisted of 69 males and 104 females. The Hong Kong sample consisted of 245 males and 82 females. The overall mean participants’ age was 21.11 (SD 3.62) years. The participants from Hong Kong were slightly younger (mean 20.24, SD 2.88 years) than US students (mean 21.56, SD 4.66 years) and Korean students (mean 22.05, SD 2.36 years). Among US participants, a majority (83.2%, 248/298) were white followed by African American (6.4%, 19/298), Asian (3.7%, 11/298), and Hispanic/Latino (2.3%, 7/298). For the Hong Kong and Korean samples, close to 100% identified as Asian.

Table 1. Descriptive statistics of the participants.

Characteristics	United States (n=301)	South Korea (n=179)	Hong Kong (n=337)	Total (N=826)
Gender, n (%)				
Male	168 (56.4)	69 (39.9)	245 (74.9)	482 (60.4)
Female	130 (43.6)	104 (60.1)	82 (24.9)	316 (39.6)
Age (years), mean (SD)	21.56 (4.66)	22.05 (2.36)	20.24 (2.88)	21.11 (3.63)
Internet access, n (%)				
Has Internet access	294 (98.0)	176 (100))	331 (98.2)	801 (98.5)
Internet access through smartphone	177 (58.8)	176 (99.4)	321 (95.3)	674 (82.8)
Internet use				
Daily Internet use, n (%)	296 (98.7)	175 (98.9)	330 (97.9)	801 (98.4)
Hours using Internet/day, mean (SD)	4.44 (0.16)	2.92 (0.31)	4.38 (0.16)	4.23 (2.82)
Health information				
Ever used Internet for health information, n (%)	270 (90.6)	167 (93.3)	261 (80.6)	698 (87.1)
Frequency of online health information seeking, mean (SD)[a]	3.56 (1.11)	3.69 (1.13)	3.20 (0.89)	3.45 (1.06)

[a] Frequency of online seeking measured with 7-point scale (1=never, 2=once a year, 3=couple of times a year, 4=once a month, 5=once a week, 6=2-3 times a week, and 7=every day).

A majority of individuals from each country had Internet access at home or at their primary place of residence, such as a dorm (United States: 98.0%, 294/300; Korea: 100%, 176/176; Hong Kong: 98.2%, 331/337). A majority of participants from Korea (99.4%, 176/177) and Hong Kong (95.3%, 321/336) reported they had mobile phones with an Internet connection, whereas only 58.8% (177/301) of the US sample reported having mobile phones with an Internet connection. Regardless of cultural background, most participants used the Internet daily (United States: 98.7%, 296/300; Korea: 98.9%, 175/177; Hong Kong: 97.9%, 330/337). In terms of the hours spent on the Internet each day, American university students used the Internet most often (mean 4.44, SD 0.16 hours) followed by students from Hong Kong (mean 4.38, SD 0.16 hours) and Korea (mean 2.92, SD 0.31 hours). Most participants reported using the Internet for health information and the frequency of online heath information seeking was from a couple of times a year to once a month.

The first hypothesis tested whether cultural differences exist in trust associated with the types of online health information sources, in particular experience-based online health information and expertise-based sites (see Tables 2-4). Regarding the first hypothesis, significant cultural differences were observed in the level of trust in all the experience-based sources, including blogs (Brown-Forsythe $F_{2,652}$=74.91, $P<.001$), support groups (Brown-Forsythe $F_{2,627}$=210.48, $P<.001$), and SNS (Brown-Forsythe $F_{2,621}$=101.21, $P<.001$). Next, a planned contrast test was conducted to systematically compare the three countries. In the first level of the planned contrast analysis, all three experience-based sources showed significant cultural differences between analytic and holistic cultures such that individuals in the holistic culture compared to individuals in the analytic culture held higher levels of trust in SNS ($t_{466.75}$=11.36, $P<.001$), blog ($t_{451.50}$=11.21, $P<.001$), and online support groups ($t_{455.71}$=9.30, $P<.001$). The additional planned contrast test (level 2) indicated Hongkongers, compared to Koreans, possessed significantly more trust in SNS, online support groups, and professional health sites. No significant cultural differences were detected in the level of trust in expertise-based sources, including online professional health sites (Brown-Forsythe $F_{2,654}$=1.82, $P=.16$). Thus, hypothesis 1a was supported, but hypothesis 1b was not.

Table 2. Cultural differences of the trust level in each source of online health information.

Internet sites	Country, mean (SD)			Brown-Forsythe[a]		Planned contrast			
	United States	Korea	Hong Kong	*F* (*df*)	*P*	Level 1: US vs KOR/HK		Level 2: KOR vs HK	
						t (*df*)	*P*	*t* (*df*)	*P*
SNS	2.30 (1.43)	3.16 (1.18)	3.79 (1.04)	101.21 (2, 621)	001	11.36 (467)	.001	5.76 (316)	.001
Blog	2.86 (1.39)	4.04 (1.04)	3.90 (1.04)	74.91 (2, 652)	.001	11.21 (452)	.001	1.29 (352)	.20
Online support groups	3.34 (1.49)	3.34 (1.18)	5.32 (1.06)	210.48 (2, 627)	.001	9.30 (456)	.001	17.78 (323)	.001
Online professional heath sites[b]	5.54 (1.25)	5.39 (1.10)	5.61 (1.13)	1.82 (2, 654)	.16	.42 (511)	.68	1.98 (355)	.05

[a] For 1-way ANOVA test, we used Brown-Forsythe because equal variances could not be assumed. Thus, *F* value in ANOVA indicates asymptotically *F* distributed.

[b] Expertise-based source.

Table 3. Cultural differences in the frequency of using each source of online health information.

Internet sites	Country, mean (SD)			Brown-Forsythe[a]		Planned contrast			
	United States	Korea	Hong Kong	*F* (*df*)	*P*	Level 1: US vs KOR/HK		Level 2: KOR vs HK	
						t (*df*)	*P*	*t* (*df*)	*P*
SNS	2.16 (1.51)	2.27 (1.21)	3.07 (1.52)	32.25 (2, 697)	.001	4.51 (529)	.001	6.06 (405)	.001
Blog	2.50 (1.47)	3.61 (1.37)	2.85 (1.25)	34.61 (2, 622)	.001	6.67 (515)	.001	5.82 (326)	.001
Online support groups	2.26 (1.54)	2.15 (1.16)	2.74 (1.46)	12.40 (2, 698)	.001	1.64 (497)	.10	4.70 (409)	.001
Online professional heath sites[b]	4.68 (1.62)	2.66 (1.37)	3.08 (1.45)	122.57 (2, 664)	.001	15.02 (508)	.001	360.02 (360)	.003

[a] For 1-way ANOVA test, we used Brown-Forsythe because equal variances could not be assumed. Thus, *F* value in ANOVA indicates asymptotically *F* distributed.

[b] Expertise-based source.

Hypothesis 2a-b investigated a usage pattern of each online health information source, in particular experience-based sites and expertise-based sites (see Tables 3 and 4). Significant cultural differences existed in the frequency of utilizing experience-based information sources (eg, blogs, support groups, SNS) as well as expertise-based sources (ie, online professional health sites). Specifically, results of the 1-way ANOVA test for experience-based knowledge information sources were significant: blogs (Brown-Forsythe $F_{2,622}=34.61$, $P<.001$), support groups (Brown-Forsythe $F_{2,698}=12.40$, $P<.001$), and SNS (Brown-Forsythe $F_{2,697}=32.25$, $P<.001$). The planned contrast test revealed individuals in a holistic culture used blogs ($t_{515.31}=6.67$, $P<.001$) and SNS ($t_{529.22}=4.51$, $P<.001$) significantly more than individuals in an analytic culture. However, no significant cultural differences were found in terms of online support group use ($t_{455.71}=1.64$, $P=.10$). A subsequent planned contrast test (level 2) found significant differences between Koreans and Hongkongers in the use of all four types of information sources. Overall, findings indicate partial support for hypothesis 2a.

Table 4. Cultural differences in the frequency of using each source of online health information.

Source and value label[a]	United States		Korea		Hong Kong	
	n (%)	Cumulative %	n (%)	Cumulative %	n (%)	Cumulative %
SNS						
1	132 (48.5)	48.5	55 (33.1)	33.1	51 (18.6)	18.6
2	64 (23.5)	72.1	53 (31.9)	65.1	59 (21.5)	40.1
3	17 (6.3)	78.3	25 (15.1)	80.1	52 (19.0)	59.1
4	31 (11.4)	89.7	24 (14.5)	94.6	64 (23.4)	82.5
5	19 (7.0)	96.7	9 (5.4)	100.0	33 (12.0)	94.5
6	5 (1.8)	98.5			10 (3.6)	98.2
7	4 (1.5)	100.0			5 (1.8)	100.0
Blog						
1	92 (17.8)	17.8	9 (2.4)	2.4	38 (2.6)	2.6
2	67 (27.5)	45.4	37 (4.8)	7.2	85 (9.2)	11.7
3	39 (22.7)	68.0	27 (18.6)	25.7	60 (13.2)	24.9
4	45 (19.0)	87.0	40 (39.5)	65.3	64 (48.4)	73.3
5	20 (9.7)	96.7	45 (30.5)	95.8	21 (23.8)	97.1
6	7 (2.2)	98.9	9 (4.2)	100.0	5 (2.9)	100.0
7	2 (1.1)	100.0				
Support group						
1	123 (45.7)	45.7	59 (35.3)	35.3	64 (23.5)	23.5
2	57 (21.2)	66.9	59 (35.3)	70.7	76 (27.9)	51.5
3	30 (11.2)	78.1	21 (12.6)	83.2	46 (16.9)	68.4
4	32 (11.9)	90.0	21 (12.6)	95.8	52 (19.1)	87.5
5	12 (4.5)	94.4	7 (4.2)	100.0	24 (8.8)	96.3
6	12 (4.5)	98.9			6 (2.2)	98.5
7	3 (1.1)	100.0			4 (1.5)	100.0
Professional [b]						
1	11 (4.1)	4.1	41 (24.8)	24.8	41 (15.0)	15.0
2	17 (6.3)	10.3	45 (27.3)	52.1	66 (24.1)	39.1
3	35 (12.9)	23.2	29 (17.6)	69.7	62 (22.6)	61.7
4	58 (21.4)	44.6	32 (19.4)	89.1	59 (21.5)	83.2
5	53 (19.6)	64.2	15 (9.1)	98.2	33 (12.0)	95.3
6	59 (21.8)	86.0	3 (1.8)	100.0	8 (2.9)	98.2
7	38 (14.0)	100.0			5 (1.8)	100.0

[a] For value label: 1=never, 2=rarely, 3=sometimes, 4=moderately, 5= fairly often, 6=often, and 7=always.

[b] “Professional” indicates professional online health sites, such as WebMD and CDC. This is also an expertise-based source.

The result of the overall test for expertise-based information was significant (Brown-Forsythe F=233.57, P<.001). The planned contrast test result (level 1) suggested significant cultural differences between analytic and holistic cultures ($t_{508.47}$=15.02, P<.001) indicating Americans searched expertise-based health information (mean 4.68, SD 1.20) significantly more often than participants from Hong Kong (mean 3.08, SD 1.45) and Korea (mean 2.66, SD 1.37). The following level of planned contrast test (level 2) showed the difference between Hongkongers and Koreans was also significant ($t_{360.02}$=3.01, P=.003). Overall, hypothesis 2b was supported. Additional analyses were conducted to determine whether or not offline health information–seeking behavior is similar to that of online health information–seeking behavior. The frequency of using a health care provider as a source of health information showed significant results for both overall

1-way ANOVA test (Brown-Forsythe F=57.23, P<.001) and the planned comparison test ($t_{533.28}$=3.71, P<.001) indicating Americans consulted health care providers to a significantly greater extent than Koreans and Hongkongers.

Regarding the third hypothesis, the result of the 1-way ANOVA test for online health information–seeking behavior on behalf of family was significant (Brown-Forsythe F=27.74, P<.001). The planned contrast test (level 1) revealed significant differences between the United States (mean 4.25, SD 1.57) and Hong Kong (mean 4.61, SD 1.25) and Korea (mean 5.25, SD 1.25; $t_{480.38}$=5.99, P<.001). Thus, participants from holistic cultures were more likely to perceive searching for health information on behalf of a family member was an important family responsibility compared to participants from an analytic culture. At the same time, a significant difference existed between Hong Kong and Korea ($t_{338.08}$=5.16, P<.001). Overall, hypothesis 3 was supported.

Research question 1 asked whether cultural differences existed in the goals of online health information–seeking behaviors. Findings indicated significant cultural differences in the goals of health maintenance (Brown-Forsythe F=8.43, P<.001) with significant differences observed between the United States (mean 3.50, SD 1.33) and Asian countries (Hong Kong: mean 3.22, SD 0.99; Korea: mean 3.06, SD 1.10; $t_{473.54}$=3.75, P<.001). Regarding preparing for consultation, the result of the 1-way ANOVA test was significant ($F_{2,691}$=35.56, P<.001, η^2=0.09). Further, the goal of preparing for consultation was higher among Americans (mean 3.58, SD 0.08) than among Asians (Hong Kong: mean 2.83, SD 0.08; Korea: mean 3.85, SD 0.11; t_{691}=2.30, P=.02). The goal of complementing a consultation also showed significant differences among the three countries ($F_{2,698}$=7.43, P=.001, η^2=0.02). The planned comparison test revealed Asians (Hong Kong: mean 3.49, SD 0.08; Korea: mean 3.40, SD 0.10), compared to Americans (mean 3.09, SD 0.08), tended to engage in health information seeking to a greater extent to complement a health consultation, demonstrating an opposite pattern with the aforementioned two goals. In terms of the goal of health information seeking to challenge a consultation, no significant differences were found among the three countries ($F_{2,689}$=0.87, P=.42).

Discussion

More individuals are turning to social media to share health information and experiences these days. While online, individuals can easily and efficiently find other individuals who have similar health concerns or experiences. This study sheds light on the experience-based health information commonly shared on social sites, such as blogs, SNS, and online health support groups. Specifically, we examined individuals' trust in experience-based health information presented on social sites compared to their trust in expertise-based health information found on professional sites. As expected, peer-to-peer exchange of experience-based health information online was popular: 51.5% of Americans, 76.9% of Koreans, and 81.4% of Hongkongers reported using SNS for health information, whereas 66.2% of Americans, 94.6% of Koreans, and 86.1% of Hongkongers reported using blogs for health information.

Although social Internet sites function as important online health information sources across cultures, we found significant cultural differences in preferences for types of information found and shared on the Internet. Based on theoretical underpinnings of Nisbett's cultural theory, we hypothesized Koreans and Hongkongers, compared to Americans, would be more likely to trust and use social Internet sites, such as blogs, social support groups, and SNS. The hypothesis was supported. In addition, as we expected, the study's findings indicate that expertise-based health information sites are used more frequently by Americans than Koreans and Hongkongers (no country-level differences were detected in terms of trust in expertise-based health information sites). The findings resonate with previous studies demonstrating that Asian cultures, which are predominantly holistic, are more likely to value experience-based information, whereas Western cultures are more likely to value logical expertise- and rule-based information. In addition, we also observed cultural differences in searching for information on behalf of family members. As expected, participants from holistic cultures (Korea and Hong Kong) sought information for family members more than participants from an analytic culture (United States) did.

Regarding information-seeking behaviors in the offline context, Americans generally trusted and used offline sources, including both experience- and expertise-based sources. Further, pairwise comparison revealed that Hongkongers trusted information from laypersons, such as family and friends, more strongly than Americans did, whereas Americans trusted information from health professionals more significantly than Hongkongers. However, no differences were found between Americans and Koreans. When engaging in actual information seeking, Hongkongers consulted both family/friends and health professionals significantly less than did both Americans and Koreans. This finding may suggest the Internet's strengths in tailoring to meet individual needs and cognitive preferences. The Internet is a proficient medium for audience segmentation in that it efficiently finds people who hold similar interests or concerns [30]. When inquiring about health information offline, social networks prove less useful in locating individuals who share the same health concerns or problems. Consulting a wider online social network may produce higher chances of finding someone who shares rare or specific health concerns or questions. With this structural feature, the Internet may better meet needs based on cultural differences.

This study offers several practical implications for the dissemination of health information online. First, our study confirms that experience-based health information is widely used across countries; therefore, professional health information providers should consider actively taking advantage of social media and similar applications when sharing information with patients (eg, providing examples of patients' experiences). Leveraging social media or similar tools as the source of experience-based information can "increase access to, enliven users' experiences with, and enrich the quality of the information available" [4]. Specifically, social media can help disseminate expertise-based health information by enhancing access, relevance, and credibility [4]. Habitual users of social media can access expertise-based information posted to social media sites with greater ease; moreover, the information accessed may be perceived as more relevant due to viewing the first-hand experiences of others in their networks. In addition, experience-based information shared on social media sites can strengthen the credibility of professional health information, which may be particularly true for East Asians.

Second, online health interventions targeting individuals from different cultural orientations should not discount differential cognitive preferences in locating effective communication strategies for providing health information online. Experience-based information can be strategically and differentially incorporated into expertise-based health information to target audiences from diverse cultures. For example, when designing health-related social media forums with expert moderators, stronger focus on rich, experience-based information should be included for Korean and Hong Kong audiences, whereas the expert role should be more pronounced for American audiences. Because perceived credibility is related to intentions to revisit websites [31], tailoring message sources and media environments may be helpful to ensure the success of providing health information across cultures.

Third, the current findings about cultural differences may also inform interactions in the offline context. Previous research with Korean participants illustrates that even though participants indicated a preference for physician interactions, only 10.9% of respondents with a health concern actually went to the physician first, whereas 48.6% indicated they consulted the Internet [32]. Thus, when communicating with Koreans and Hongkongers in medical settings or through health campaign messages, health care professionals and practitioners should maintain an awareness of a strong preference for experience-based knowledge. For example, in discussing treatment options, health care practitioners could ask patients about any experience-based knowledge found online. At the same time, a systematic review of online settings where experience-based knowledge is shared may need to be planned and designed by health professionals to validate the information. Although sharing experiences with similar health problems can be a great information resource for users, such information can be inaccurate or applied to the wrong situations. Professionals using experience-based knowledge strategically would likely produce a synergistic effect.

Lastly, we found, across cultures, Internet users possess different motivations for seeking health information online based on differing goals for the outcome of the search. Koreans and Hongkongers seek online health information primarily to make critical health decisions, such as whether to follow doctor's instructions, whereas the primary goal of health information seeking for Americans is health maintenance and preparation for the medical consultation. In other words, inaccuracy or the incorrect application of information may be more critical among Koreans and Hongkongers than Americans due to goal differences. Incorporating health professionals' comments in health-related blogs, SNS, and support group sites may be imperative for East Asian populations. To address Americans' concerns related to health maintenance and medical consultation, key messages related to preventive health can be beneficial in promoting quality of life and cutting medical costs for Americans [9].

Limitations

Although the study offers several significant contributions, some limitations exist. First, although this study presents data gathered from three different countries, research should focus on extending this work to other countries. Even though both Korea and Hong Kong are considered to be holistic cultures, significant differences still exist. This finding suggests that even though a dichotomous approach to culture bears differences, the cultural separation in beliefs extends beyond two categories. Future studies should include individual-level comparisons in addition to a country-level investigation. Additionally, factors affecting national differences, such as the level of institutional trust [33] or other structural distinctions, need to be further investigated.

Second, the sample consisted of participants who were relatively young, with a mean age of 21 years (SD 3.63); participants in all three countries were university students. Given that young people remain less likely to encounter serious health problems, the patterns observed in online health information-seeking behaviors may not replicate in older age groups. Similarly, because a sample of university students represents a highly educated group, individuals with different education levels or technology efficacy may demonstrate different perceptions and behaviors. For example, previous research indicates that individuals who have lower education levels are not as likely to search for health information online [32]. Health literacy and digital divide concerns are also part of the broader social conversation when it comes to barriers to online health information-seeking behaviors [34,35]. Therefore, future studies should further test the proposed hypotheses of this study on other populations, such as individuals with serious health problems, less education, and those of an older age.

Lastly, in addition to a theory-based explanation for cultural differences between the East and West, other factors might influence individual's perceptions of online health information credibility and trust across cultures. For example, given the higher degree of ethnic homogeneity of the population in Korea and Hong Kong compared to the United States, it is plausible that individuals in these countries are more likely to be exposed to online health information generated by "people like them." *Homophily*, or the degree of perceived similarity that a receiver ascribes to a message source, has been cited as a factor influencing individuals' perceptions of online health information [36-38]. Wang and colleagues [38] examined how individuals evaluate health information from experts on websites compared to peers in online discussion groups. Their results indicate that when evaluating the health information offered in a discussion group, individuals who perceived stronger homophily reported a more positive evaluation of the information, which consequently led to greater likelihood of acting on the advised information. Similarly, when evaluating information presented on a website, the degree of perceived homophily also directly influenced perceived credibility and positive evaluations of the health information provided [38]. What remains unknown is whether cultural variations exist in the degree homophily is experienced, given the fact that homophily can be motivated by demographic factors (eg, age, ethnicity) and experience/attitudinal factors (eg, sharing emotion, attitude, and experience) [39]. Whether Koreans and Hongkongers, compared to Americans, tend to feel stronger homophily warrants further investigation in the context of online health information seeking.

Conclusions

In conclusion, this study contributes to the literature on online health information–seeking behaviors by demonstrating a tendency for Koreans and Hongkongers to trust and use experience-based knowledge to a greater extent than Americans. Additionally, Koreans and Hongkongers are more likely to search for health information on behalf of family members, resonating with a holistic worldview. Cultural differences also exist in the goals associated with online health information. Asians engage in health information–seeking behavior to make health care decisions, an extremely important finding to consider when evaluating the credibility and trust of health information online. To achieve health and facilitate positive, peer-to-peer communication of health information, clinicians and scholars should continue to be aware of online health information–seeking behaviors before and after medical consultation and provide patients with avenues to navigate online sources. Similarly, health messages should also focus on cultural orientation to provide quality health care.

Conflicts of Interest

None declared.

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Abbreviations

SNS: social networking site

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Viewpoint

Personalized Telehealth in the Future: A Global Research Agenda

Birthe Dinesen[1*], MS, PhD; Brandie Nonnecke[2*], MS, PhD; David Lindeman[2*], MSW, PhD; Egon Toft[3*], DSc, MD; Kristian Kidholm[4*], MS (Econ), PhD; Kamal Jethwani[5*], MD, MPH; Heather M Young[6*], RN, PhD; Helle Spindler[7*], MSc, PhD; Claus Ugilt Oestergaard[1,8*], MS (Econ); Jeffrey A Southard[9*], MD; Mario Gutierrez[10*], MPH; Nick Anderson[11*], PhD; Nancy M Albert[12*], RN, PhD; Jay J Han[13*], MD; Thomas Nesbitt[2,13*], MD, MPH

[1]Laboratory of Assistive Technologies - Telehealth & Telerehabilitation, SMI, Department of Health Science and Technology, Aalborg University, Aalborg, Denmark

[2]Center for Information Technology Research in the Interest of Society (CITRIS), UC Berkeley, Berkeley, CA, United States

[3]Faculty of Medicine, Qatar University, Qatar, Qatar

[4]Center for Innovative Medical Technologies (CIMT), Odense University Hospital, University of Southern Denmark, Odense, Denmark

[5]Connected Health Innovation, Partners HealthCare, Harvard Medical School, Boston, MA, United States

[6]Betty Irene Moore Nursing School, Davis Health System, University of California, Sacramento, CA, United States

[7]Department of Psychology and Behavioral Sciences, Aarhus University, Aarhus, Denmark

[8]Citizens & Labor Market, Esbjerg Municipality, Esbjerg, Denmark

[9]Division of Cardiovascular Medicine, University of California Davis Medical Center, Sacramento, CA, United States

[10]Center for Connected Health Policy, Sacramento, CA, United States

[11]Department of Public Health Sciences, School of Medicine, University of California, Sacramento, CA, United States

[12]Cleveland Clinic Health System, Cleveland, OH, United States

[13]Center for Health and Technology, Davis Health System, UC Berkeley, Sacramento, CA, United States

[*]all authors contributed equally

Corresponding Author:
Birthe Dinesen, MS, PhD
Laboratory of Assistive Technologies - Telehealth & Telerehabilitation, SMI
Department of Health Science and Technology
Aalborg University
Fredrik Bajers vej 7
Aalborg, 9220
Denmark
Phone: 45 20515944
Fax: 45 98 15 40 08
Email: bid@hst.aau.dk

Abstract

As telehealth plays an even greater role in global health care delivery, it will be increasingly important to develop a strong evidence base of successful, innovative telehealth solutions that can lead to scalable and sustainable telehealth programs. This paper has two aims: (1) to describe the challenges of promoting telehealth implementation to advance adoption and (2) to present a global research agenda for personalized telehealth within chronic disease management. Using evidence from the United States and the European Union, this paper provides a global overview of the current state of telehealth services and benefits, presents fundamental principles that must be addressed to advance the status quo, and provides a framework for current and future research initiatives within telehealth for personalized care, treatment, and prevention. A broad, multinational research agenda can provide a uniform framework for identifying and rapidly replicating best practices, while concurrently fostering global collaboration in the development and rigorous testing of new and emerging telehealth technologies. In this paper, the members of the Transatlantic Telehealth Research Network offer a 12-point research agenda for future telehealth applications within chronic disease management.

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KEYWORDS

telehealth; research; individualized medicine; telemonitoring; prevention; mobile phone

Introduction

Telecommunication technologies have been used to bring health care expertise to the point of care since the 19th century. In 1878, *The Lancet* reported on the use of the telephone to reduce unnecessary physician visits and, in 1910, a tele-stethoscope had already been described [1]. During the mid-20th century, NASA used remote monitoring systems to measure astronauts' physiological functions. The Space Technology Applied to Rural Papago Advanced Health Care project further developed this field with the Papago Indians in the southwestern United States [2]. However, the greatest strides in the use of remote monitoring technologies for telehealth have occurred over the last 10 years, with a growing evidence base showing their effectiveness in the management of chronic disease [3-5].

The importance of telehealth as a major vehicle for delivering timely care over distance has become increasingly relevant as the world's health care needs have become overwhelmed by a significant increase in the global level of chronic disease. Chronic disease now exceeds communicable disease as the leading cause of death worldwide. In the United States, more than 70% of deaths are associated with chronic diseases and approximately 75% of annual health care expenses are used on persons with chronic conditions [6,7], a problem that is increasing as the prevalence of chronic diseases grows with aging. In the European Union, it is estimated that chronic illness is a factor in 87% of all deaths [8].

Some telehealth models of care have shown clear benefits for patients with chronic disease that incorporate patients and family members into the care team [9], whereas others have not been able to demonstrate significant improvements [10]. These models of care, which frequently involve remote patient monitoring (RPM), show promise in getting and maintaining patients to achieve their health care goal and, in some cases, lowering the incidence of avoidable hospitalizations and rehospitalizations for patients with chronic conditions [3,10-12]. In the United States and the European Union, telehealth technologies have also been shown to be effective in small-scale studies of patients with chronic diseases; nevertheless, adoption of telehealth solutions remains limited [5,13,14]. There are several obstacles to achieving widespread adoption of telehealth: acceptance of this technology by patients and clinicians, economically sustainable reimbursement systems, interoperability between electronic patient record systems, and technological capacity to accommodate bandwidth-heavy telehealth programs in smaller hospitals, clinics, and in the home.

Purpose

This paper was prepared by an international team of telehealth providers, clinicians, researchers, and policy analysts assembled through the Transatlantic Telehealth Research Network (TTRN). The mission of the TTRN has been to design a future agenda for telehealth innovation and research. The TTRN was established in 2012 to link major institutions in the United States, Denmark, and the European Union. The aim of the TTRN is to develop cutting-edge telehealth research and innovation within telehealth that can be translated into practice and rapidly scaled up. Using an interdisciplinary approach, TTRN members focus on problem-based research and on developing new diagnostic, preventive care, and treatment methods and technologies for patients through telehealth systems.

This paper has two aims:

1. To describe the challenges of promoting telehealth implementation and advancing adoption.
2. To present a global research agenda for personalized telehealth within chronic disease management.

Using evidence from the United States and the European Union, this paper provides a global overview of the current state of telehealth services and benefits, presents fundamental principles that must be addressed to advance the status quo, and provides a framework for current and future research initiatives within telehealth for personalized care and treatment.

Telehealth Today: Benefit and Biases

In 2008, a meta-analysis of home monitoring studies globally found it to be a cost-effective alternative in 21 of 23 studies, the majority of which focused on chronic disease care [15]. The main benefits derived from RPM programs were decreased hospital utilization, improved patient compliance with treatment plans, improved patient satisfaction with health services, and improved quality of life. Multiple studies have found savings associated with the application of telehealth for home monitoring when applied to heart failure patients. A set of recent studies that compared telehealth to traditional outpatient care recorded savings estimates ranging from 17% to 75% [16-22]. Similarly, a recent comprehensive review of telehealth studies among patients with chronic obstructive pulmonary disease (COPD), heart failure, and stroke concluded that there were reductions in hospital admissions/readmissions, length of hospital stay, emergency department visits, and often a decrease in mortality [23].

Although benefits of telehealth were cited in these studies, Wootton [5] identified a publication bias in telehealth studies of chronic disease management, with 108 of 110 articles reporting positive effects. Telehealth studies were characterized by a very short duration, averaging 6 months, and there were few studies of cost-effectiveness. Wootton concluded that the evidence base of telehealth and chronic disease management was both contradictory and weak [5].

A review of the cost-effectiveness of telehealth [24] concludes that economic tools for evaluation are being increasingly used, but better reporting of methodologies and findings is required in future research. The review also concluded that there was no convincing evidence to show that telehealth was more cost-effective than conventional health care [5].

In the United Kingdom, a large telehealth project, the Whole System Demonstrator (WSD) project, was carried out with 3230 patients between 2008 and 2009, including those with heart, lung, and diabetes diseases using a cluster randomized design. During a 12-month observation period, researchers found reductions in mortality and hospital admissions [25]. The effects on health-related quality of life were shown not to be significant

[26]. An economic analysis of the WSD concluded that telehealth was not cost-effective when used as an add-on to standard care and treatment for patients [27]. In addition, a longitudinal case study of the organizational effects of the WSD showed that the randomized research design impeded organizational learning among the trial sites and that the full organizational benefit of WSD was not achieved [28]. In the WSD, qualitative interviews were carried out with those patients who declined to participate in the study. Among this group, 36.7% chose not to participate in the study following a home visit in which they had been informed about the study. Through interviews with this group, their primary concerns were shown to be threats to identity, independence, and self-care; requirements of technical competence and ability to operate equipment; and experiences of disruption of health and social care services [29]. The implication is that there is a bias in telehealth studies and the samples studied tend to consist of people who were already positively disposed to telehealth measures.

In a systematic review focusing on patients’ acceptance of telehealth technologies, the authors concluded that focusing on patient factors alone was not sufficient for understanding the degree of patients’ interest (or lack of interest) in using telehealth technologies [30]. Future research is needed to identify additional factors that promote telehealth acceptance, such as human-technology interaction, organization of the health care system, and social factors. We do not claim that telehealth should be held to a higher evaluation standard than what has been applied to traditional modes of care. However, investigating additional features that affect the success of telehealth utilization will enable more informed development of future telehealth implementations.

Telehealth Challenges

Health care financing models exist in many industrialized nations. In the United States in 2011, a national quality strategy for establishing aims and priorities for quality improvement, known as “the Triple Aims” [31], included improving the overall quality of health care, better population and community health outcomes, and reducing the overall cost of care. In both the United States and the European Union, it is clearly anticipated that technology will play a pivotal role in achieving these goals.

Nevertheless, even with governmental support and a growing evidence base demonstrating the benefit of health care financing models of care that included telehealth, there remain many challenges facing the establishment and sustainability of effective telehealth programs. Financial sustainability of telehealth models of care has been one of the main challenges, particularly in the United States, where—despite the intent of the Affordable Care Act—reimbursement has been and continues to focus more on paying for care processes that occur within health care facilities rather than care processes that affect patient outcomes. Although reimbursement for telehealth increased in the United States, payers such as Medicare do not recognize the home as a reimbursable originating site of care. In settings with capitated reimbursement, such as the US Veterans Administration, the use of telehealth solutions (RPM and home-based chronic disease management) has had remarkable success [3]. Among 17,025 adults, researchers found a 25% reduction in hospital length of stay, a 19% reduction in hospital admissions, and a mean satisfaction score rating of 86%, all at a cost of US $1600 per patient per annum [3].

There are clearly additional challenges beyond reimbursement to bringing telehealth models to scale across different types of health systems and independent practitioners in the United States and the European Union. Most successful telehealth models require an extensive care team, including disease management nurses and other personnel. Independent practitioners may not be able to employ care teams and would potentially need to rely on an intensive service model, such as visiting nurses for home health care. Effective implementation of telehealth often requires receiving and processing data from various devices, which need to be analyzed and translated into actionable clinical information for physicians and other health care providers.

To put it simply, if data from RPM and other telehealth technologies are to be used for clinical decision making, the clinician must be assured that physiological and activity data are accurate. Initiatives such as the Personal Connected Health Alliance are intended to assure that this occurs. As the use of RPM and telehealth becomes more standardized and ubiquitous, and as health data are collected and stored in standard formats, there are considerable opportunities to apply predictive analytics. Ideally, clinicians should have easily interpretable dashboards identifying the daily health statuses for all their chronic disease patients. Some organizations have already begun developing and using chronic disease dashboards for conditions such as diabetes [32]. There are also opportunities to adapt off-the-shelf technologies, such as mobile phones and gaming systems, to serve as tools in remote chronic disease management. Ultimately, in order for technology-enabled chronic disease models to be adopted on a large scale, more research is needed to determine health care professionals’ and patients’ preferences for technologies and care models and methods to assure accurate data.

As new technology solutions, such as sensors, mobile devices, and self-tracking technologies, become more prevalent, organizations will increase use and reimbursement of technology-driven health care services. As technology-driven health care services grow, this will require development of efficient business models and cases for telehealth stakeholders.

Policy Challenges Within Telehealth

Telehealth policies among US states, US federal agencies, and in EU countries are outdated and woefully inadequate to support widespread telehealth adoption and growth. In 2015, the California-based Center for Connected Health Policy (CCHP) undertook a comprehensive analysis of the laws, regulations, and related administrative policies of the 50 states in the United States as well as the federal US policy [33]. Given that each state can define its own policies for its Medicaid Program, a wide range of definitions and reimbursement policies for telehealth care were found, with no two states being alike. Based on the CCHP review, there are several critical policy issues that require attention: (1) defining telehealth care, (2) setting reimbursement policies, (3) licensing and jurisdictional issues, and (4) cost-benefit analysis of telehealth systems. It is hoped that refinements in these state policy initiatives will enable the achievement of the following three goals:

1. Creation of parity for telehealth with other modes of health care delivery;
2. Active promotion of telehealth as a tool to advance stakeholder goals regarding health status, equity of access, greater efficiency in care delivery, and health systems improvements; and
3. Creation of opportunities and flexibility for telehealth to be used in new models of care and systems improvements.

The US federal policy governing the use of telehealth in the Medicare program is also very limited. Reimbursement is limited to certain billing codes and only for live video care. In addition, these services are limited only to beneficiaries who reside in strictly defined rural communities.

An analysis of the eHealth policy initiatives within 27 EU Member States influenced the development of an eHealth roadmap that reflects national, regional, and local conditions that go beyond technical imperatives to include personalized telehealth solutions [34]. Commonalities among US and EU telehealth policies exist at the national and regional levels resulting in generally uniform policy solutions; however, at the local level there tends to be a lack of personalized telehealth solutions.

Definitions and Nomenclature

In a 2014 study [35], 26 US federal agencies were surveyed and seven distinctly unique working definitions of “telehealth” were identified. The study concluded that a common nomenclature for defining telehealth may benefit efforts to advance the use of this technology so that it can address the changing nature of health care and the emerging demands for services as a result of health care reforms [35]. EU telehealth definitions and applications reveal similarly wide variation of terms and restrictions in use [36]. Internationally, there is neither a common understanding of the various forms of technology-enabled health care nor precision in the description of the wide range of health-related activities and services that are covered via telehealth.

Reimbursement

Within the United States and the European Union, reimbursement of telehealth-delivered care and specific reimbursement requirements remain a major challenge. A legal definition of telehealth may relate directly to services that will be reimbursed by public and private payers and the conditions for this reimbursement. It would be beneficial if reimbursement policies, in addition to including live video, were consistent within and between countries and included asynchronous “store-and-forward” and remote monitoring. Policies should also be sufficiently flexible to create parity and should not be restricted by artificial barriers such as geographic limitations (as is the case with Medicare in the United States). Technology-enabled health care should be seen as a virtual modality, not a distinctly separate service requiring unique billing codes. The impact of telehealth-enabled health care will become more of a reality in the United States as health systems shift from fee-for-service to more value-based capitated systems under health care reform. In the European Union and other countries with nationalized health care, opportunities for incorporating telehealth practices in innovative reimbursement schemes are being advanced within different health care systems.

Licensing and Jurisdictional Issues

The scaling of telehealth, particularly in the United States, has been limited by professional licensing issues and competition among professionals. The ability to provide high-quality virtual synchronous and asynchronous health care and patient monitoring has created unprecedented opportunities for dramatically expanding access to quality care for the underserved and simultaneously increasing the efficiency and lowering the costs of care [37]. Services can now be effectively provided across the street and around the planet as long as there is access to high-speed Internet. However, the definition and interpretation of the practice of medicine in the United States is determined at the state level and is defined by each state medical board, thus resulting in significant limitations in geographic and population scaling. Similarly, health care systems vary from country to country. There is no question that the rapid growth of technology-enabled health care will create increased pressure on traditional licensing bodies to reform their laws and policies to allow some form of telehealth practice of medicine and other health care across state lines and borders within the European Union.

Cost-Benefit Analysis of New Legislative Proposals

The US Congressional Budget Office (CBO) produces independent formal cost projections for every bill approved by Congress, including telehealth-related legislation. Although aided by a panel of 22 advisors from a variety of health care fields, the CBO’s current process of formulating cost estimates excludes many of the potential effects of health care and telehealth policy. None of the 21 cost estimate reports on telehealth legislation issued by the CBO in the last decade included an in-depth analysis of cost savings, efficiency, or qualitative impacts. By focusing largely on the short-term financial costs of new legislation, the CBO did not take into account potential cost savings, potential increases in the efficiency of health care resource use, or the value of quality improvements often associated with implementation of telehealth programs. Lack of cost-benefit analysis stymied past efforts to improve telehealth policies at the federal level and hindered the adoption and growth of telehealth programs across the nation. In contrast, European countries, such as the United Kingdom, Denmark, France, Germany, and Sweden, have long-standing Health Technology Assessment (HTA) organizations that advise government bodies on the costs and benefits of potential health technology treatments. These HTA organizations estimate the value of better clinical outcomes using scales such as quality-adjusted life years (QALYs), healthy years equivalent (HYE), and disability-adjusted life years (DALYs), among others, which weigh the potential qualitative effects of health care treatments and technologies against their potential financial costs.

Telehealth Approaches for Cross-Sector Care Integration

In both the United States and the European Union, hospitals and public health care systems tend to be fragmented between hospitals and municipally based health care services. Among fragmented health care systems in the countries within the European Union and in individual states in the United States, the use of telehealth technologies can create jurisdictional conflicts, policy conflicts, and remain tangential to care practices rather than integrated into health care infrastructure. Collectively, barriers to integration may slow the development of a common vision for care, treatment, and rehabilitation of patients and minimize collaborative care among health care professionals across sectors [38].

Health care organizations in the United States, such as Kaiser Permanente or the Veterans Health Administration (VHA), have a single health care system: the hospital, district nursing, health care center, and primary care providers are integrated into a single organization. Such large systems also have a single, unified information technology system, an electronic health record (EHR) to coordinate and plan patients' care processes, tend to have a high degree of adoption of telehealth solutions for patients with chronic diseases, and utilize a more innovative approach to testing new models of care based on patients' preferences for using telehealth technologies within the health care system.

In both the United States and the European Union, telehealth technologies are being tested in many innovative ways to maximize emerging care models, including redesign of chronic disease management and the improvement of cross-sector care management. Examples of new models of care using telehealth technologies are home hospitalization of cardiac patients [39], preventive home monitoring of patients with COPD [40], and telerehabilitation of cardiac patients [41].

Over the last decade in the European Union, information technology solutions and telehealth technologies have been integrated between hospitals and municipalities and have reached a higher degree of data integration and sharing for the benefit of coordination and collaboration between health care professionals across sectors in patient care processes.

Examples of large EU telehealth projects with technologies involving both hospitals and municipalities are Renewing Health [42], United4Health [43], and MasterMind [44]. In the Renewing Health project, 8 countries participated (Denmark, Italy, Sweden, Norway, Spain, Finland, Greece, and Germany). The target group was patients with COPD, diabetes, and heart diseases, and a total of 7000 patients were enrolled in the study. Results from the project showed that the cross-sector telehealth solution led to a shift of tasks between health care professionals across sectors and there was an improvement in communication between professions and between sectors [42]. The health care professionals reported that patients took greater responsibility for their own health when they were able to see their own data. When patients could not see their data, the health care professionals felt that the patients were less responsible for their health care and that the two-way communication was limited [42].

Emerging Issues That Influence Telehealth Delivery

Providing high-quality, accessible, and cost-effective health care remotely for a socially, economically, and financially diverse population presents challenges, whether within a country or between countries. The most substantial challenge is that of providing care for patients with chronic diseases. Fifty percent of patients in the United States have one or more chronic disease(s), accounting for 75% of the financial burden to the health care system [45]. In the European Union, 70% to 80% of health care budgets are spent on chronic diseases [46]. Establishing ways to lessen the burden and provide for these care needs requires systems that offer timely access to care, engage patients to participate, and prevent patients from inappropriate service utilization such as unnecessary emergency room visits. Telehealth is a viable alternative to standard face-to-face health care provider interactions.

A firm commitment to establishing large health care communication networks has existed for many years. As networks have grown, patient-provider communication and smaller handheld devices have been incorporated into the fabric of chronic disease management. Mobile phone apps and Web-based programs allow patients to manage their chronic diseases at home. It has been estimated that 93 million people in the United States have access to mobile phones, a number likely to increase in the future [47].

The telehealth technologies that are emerging are not only smaller and more efficient (eg, offering office-based desktop computer consultation with providers through patient-specific devices), but now include education for patients and may even offer suggestions for change in disease-specific treatment. Key issues driving the future of telehealth include (1) personalization of health care; (2) matching patients with appropriate technologies; (3) optimal use of health care data, including developing a secure interface between patient-generated data and the HER; (4) new education paradigms for patients and providers; (5) new communities of knowledge and practice; (6) new care and business models tailored to sustainability and scalability of telehealth initiatives; (7) transfer of scientific knowledge from research to implementation and practice; and (8) innovative research methodologies within telehealth. Each of these issues will be discussed subsequently.

Personalization of Health Care

There is no "one-size-fits-all" approach to managing patient care with telehealth because chronic diseases management is diverse. For new technologies to succeed, they must accommodate a spectrum of user needs. Technology must engage patients in their care and enhance collaboration with the health care system or they are destined to fail. Patients need skills and tools to proactively apply vital technology information. In addition, patients need their use of new technology to be personally meaningful (ie, in terms of relevant self-care) because these devices can serve as an intrusion into the patient's daily life and must serve to bring their health into focus at a personal level, not define them based on their disease state.

For example, patients with diabetes clearly do not use technology in a uniform manner. Patients with type 1 diabetes engage in accepting their disease and adapt to living with their disease by checking their blood glucose and monitoring what they eat [48,49]. These patients, who are usually younger and more adept at using handheld devices, mobile phone apps, and Web-based programs, tend to be earlier adopters of new technologies that help them log their caloric intake, follow finger-stick blood glucose samples, and monitor daily exercise routines. The key to successful technology-based treatment is getting these patients to participate in using monitoring systems and finding a way to provide ongoing feedback that keeps patients engaged. Providers must offer encouragement and meaningful insight into data throughout their progress or their continued participation may decline.

Patients with type 2 diabetes, who may be older and less familiar with technology, will likely apply technology in a different manner. Some have been dealing with their disease for many years, whereas others are confronted by a diabetes diagnosis only when in their fifties or sixties. Technology might not be as attractive to this group of patients compared to younger patients. Some patients with type 2 diabetes may have lost limbs, suffer from neuropathy, or have visual problems secondary to long-standing uncontrolled blood glucose. These populations, if they are to be successful, may require a different device and a different approach to using technologies. Access, familiarity with technology, ease of use, and size of text fonts are important. A range of devices should be available to meet the diverse needs of this group. Currently, telehealth systems store information from multiple sources: patient-collected physiological data, laboratory data, behavioral information, medication dosages, subjective symptoms of hypoglycemia, event data (eg, emergency room visits), and images (eg, retinal or wound photos) [50]. An all-encompassing approach might benefit patients who are extremely well organized and can handle a large amount of data, but some patients might be overwhelmed and would not participate in telehealth. Ultimately, there must be a match between technology, personalization, and the patients' needs and wishes. Providers must match the proper device and data management approach to the proper patient. Health care providers need to be aware that some patients use telehealth as a means to get in contact with their providers and will also visit a nearby center for a face-to-face follow-up at the same time and for the same health issue.

Matching Patients With Appropriate Technologies

As telemedicine and telecommunication have been lauded as a possible solution to the emerging shortage of health care providers, we need to remain cognizant that the use of technology in place of a face-to-face encounter will not be as easy for some patients as others. The US population is increasing and is estimated to grow by 20%—to 363 million—by the year 2030 [51]. The population is aging as well and those aged 65 years and older (12.4% of the population in 2000) will likely make up 19% of the US population by 2030. Accompanying this aging population is an increased incidence of chronic health conditions and expenditures associated with chronic disease management. Novel telehealth platforms require a match based on patient's age, education, interests, physical capabilities, familiarity, access to technology, and support to help with self-care and functional independence. Computer-based desktop apps with large screens and static interaction may be best suited for an aged population of patients who have limited manual dexterity and visual limitations. For the elderly, the user interface often needs to be simple, easy to use, and provide meaningful interaction and feedback. Devices that allow patients to follow a script and alter care based on physiological information need to be efficient and user-friendly. Perceptual, motor, and cognitive abilities need to be considered when matching technology to patients.

A younger population that has been exposed to such technological advances would be more likely to use this type of monitoring device. The ability to follow one's progress, compete with other patients in attaining preset goals, and receive immediate feedback would seem attractive to this younger group. Beyond establishing patient-device symbiosis, researchers have to weigh the intrusive nature of these devices and match patients who appreciate constant oversight with those who would prefer a more discrete means of monitoring. There is a distinct dichotomy between those patients who greatly enjoy having a daily reminder to take their pills, exercise, and eat right versus those who appreciate some early instruction and would then prefer to drop their monitoring altogether. Establishing patient preference in that arena will also take time and effort, and the original protocol for the patient might need to be altered. Either way, we must strive to provide patients with devices that maximize success by applying their strengths and avoiding reliance on functional weaknesses.

Matching patients with a proper device and gathering large amounts of meaningful data will lead to improved insight into a person's disease state and better assessment of the success of care management strategies. The VHA serves as an example in that regard. The VHA established the first large-scale use of telehealth in 1977. In 2013, more than 600,000 veterans accessed VHA health care using a telehealth program. Established in 2003, the VHA Care Coordination/Home Telehealth (CCHT) network provides routine noninstitutional care and targets care management for patients with diabetes, chronic heart failure, hypertension, posttraumatic stress disorder, COPD, and depression. CCHT uses remote monitoring devices placed in the veteran's home to communicate health status and to transmit biometric data that are monitored remotely by care providers [44]. At present, more than 70,000 patients concurrently participate in this program, which is projected to grow to reach more than 92,000 patients within the next few years. Analysis of ongoing data has allowed the VHA to change their approach and management strategies over the years, and serves to make the home the preferred place of care whenever possible and appropriate. Through use of telehealth, the VHA telehealth program reduced admissions by 20% in 2010 [52]. Patients with diabetes had a 20% decrease in resource utilization, those with heart failure had a 30% reduction, and those with depression had a 56% reduction [9]. Patient satisfaction remained above 86% and all but 10% of those approached were willing to participate in the program. Analysis of those patients who utilized the program suggests that the quality of care and patient-specific outcomes have not been compromised by utilizing the CCHT model. As the VHA program continues to grow, it is clear that it will be increasingly successful in gathering and analyzing telehealth data to better serve future patients with chronic diseases.

Optimal Use of Health Care Data and Secure Interface Between Patient-Generated Data and the Electronic Health Record

Large health systems have much to gain by providing increased communication and patient engagement through mobile devices and Web-based interfaces. Beyond chronic disease management, secure methods of data capture working directly with patient communities open up major opportunities for wellness and health maintenance initiatives, as well as dynamic participation in research [53,54]. Yet there remain significant concerns regarding the ownership and obligations inherent in the communication of personal health data by health systems for data collected through patients' mobile devices. Health systems are exploring fundamental issues such as when ownership of patient-provided data begins and what scope it encompasses. Given the need for third-party telecommunications carriers to support the connectivity of personal devices, and often independent developer apps to manage local capture of data, there remains a lack of clarity regarding the conditions under which personal data becomes protected data and the legal obligations this imposes on health policies such as the Health Insurance Portability and Accountability Act (HIPAA) [53]. Adding to this challenge are the many patients and health advocates who are frustrated by lack of accessibility to their own personal health information and associated overprotection of such information by privacy laws and paternalistic health institutions. This is a two-fold challenge: that of determining ownership and, ultimately, indemnity for data that can be collected by and from patients, while also deciding on strategies for data that are further aggregated and integrated with different sources within clinical systems. This dual challenge has influenced the lack of broader dissemination to date. Health care systems are inherently risk-averse. They struggle to keep up with the broad opportunities offered by these emerging technologies.

Two routes for obtaining patient-contributed data presently predominate: active participation, in which patients fill out and upload their own health information or test results, and passive participation, in which patients provide data through monitoring devices or other mechanisms that have limited interaction other than aggregate viewing (eg, personal fitness monitors). Both routes of collecting personal health data and the risk-averse policies of institutions are helping to clarify principles of data management. Health providers are moving toward support of a full and auditable "chain of custody" or data provenance support for patient communications in anticipation that health care communication derived from data may be called into question [55]. It should be noted that data provenance has a secondary benefit in that it improves the ability to define and address measures of quality and communications.

At an organizational level, both means of collecting personal health data are altering the roles of institutional data handlers, such as hospitals, clinicians, and testing companies, and are leading to changes in determining ownership of health data. Among proponents of personal ownership of health data, the removal of intermediaries is seen as a strength because it empowers individuals to control and deploy their information for chosen purposes. Among the critics of personal ownership of health data, however, there remain concerns that personal ownership will negatively impact the quality of data and have a subsequent impact on data quality used for the practice of health care.

Increasingly, patients are tracking their health status and incorporating lifestyle information into their overall health management. For the most part, this area of great innovation is taking place in the social media and has not yet been integrated into clinical care. Likewise, community-level data inform and shape health trajectories and health policies and are not well integrated into clinical care. Achieving individual and community improvements in health depends on building capacity to integrate data across sources into actionable packages so that individuals can act to improve their own health and communities can plan and deploy resources and policies to address barriers and facilitators to health attainment.

The incorporation of technology into health care settings, such as the adoption of EHRs, has grown substantially in the past few years, with nearly 40% of all physicians adopting basic EHR capabilities. Original policies pertaining to EHR technology created incentives and penalties that put an overwhelming emphasis on provider-centric health information technology (HIT) with EHR systems built to give providers better access to information and improved methods of storing and sharing that information between providers. The focus was placed on provider adoption, with minimal incentive for patients to engage and use the system. Notably absent in the legislation and goals of federal HIT is the voice of the patient in creating HIT that meets the needs of patients and can lead to meaningful health outcomes. The lack of focus on patients has come to the attention of numerous groups, including the American Telemedicine Association and Healthcare Information and Management Systems Society, which have joined five additional industry groups in advocating the inclusion of standards that require the EHR to incorporate patient-generated data from remote monitoring devices. Underlying this advocacy is the belief that the value of extending HIT requirements to include patient-generated data and data collected outside of traditional office visits will be realized through increased efficiency of delivery of health care services and systems that support timely exchange of data and information to improve health outcomes. Chronic disease registries and websites could accelerate progress in mobilizing appropriate evidence-based care in a timely fashion, promoting communication among the care team, and helping to design community or population-level interventions to improve health.

Creating New Education Paradigms for Patients

Mobile phone and other emerging handheld applied telehealth-based instruments can be used as electronic (e)-learning tools for patient education, mobile clinical communication, and disease self-management education. When emerging telehealth tools and devices store a great amount of information, they can become the source tool for information sharing and education in examination rooms and at hospital bedsides, and electronically through e-transfer of information. Large wall- and desk-mounted screens are common in health care centers, and home televisions now have monitor functions. When telehealth tools are connected, the education experience may be enhanced.

Data from mobile phones and from internal or external telehealth instruments can be linked to desk-based or free-standing kiosk education devices or centers that will be prevalent in ambulatory centers of the future, and may even be tied into self-service electronic systems used to check-in to appointments, request medication refills, and provide other health care purposes. Patients with in-dwelling or externally applied cardiac (or other) devices that store data or allow for transfer of data to an external storage system will be able to access a kiosk-like education system, retrieve or synchronize data, receive education about the meaning of data, and receive instructions about the plan of care based on e-data findings. Plans for care, as part of the system, would have been previously vetted by health care professionals and be based on individualized algorithms to enhance safety and decrease the risk of harm. The innovative education roles of mobile phones and other technology continue to evolve with new software, hardware, innovative storage solutions, and patient confidentiality solutions.

There are numerous examples of e-learning tools in development and testing. In one report [48], researchers explored an application of Web 2.0 integrated with Internet-protocol television for personalized home-based health information in diabetes education among adults who were not strong computer and Internet users. This intervention provided diabetes educator-delivered, personalized health information directly to patients in their homes through an enhanced home television screen and remote control. The goal was to build health literacy and knowledge about diabetes management. After testing the system, researchers concluded that the system had educational potential [56]. In another study, parents of babies with infantile hemangiomas were trained to assess their children's skin abnormalities for early complications through an e-learning module or by a dermatologist-delivered e-consultation [57]. After e-learning, parents' judgments about diagnosis were found to be in concordance with those of the dermatologist in 96% of the cases. Results of this study indicate that correct diagnosis via e-learning can promote earlier recognition and treatment of infantile hemangioma risk factors and complications.

As new education paradigms emerge that use telehealth and other digital technology, it is important to recognize that there is a digital divide among patients. Those patients especially at risk of negative health outcomes could benefit most from telehealth tools. A qualitative analysis to gain better insight on the digital divide of patients demonstrated that patients' gaps in knowledge of technology are greatest at three points: (1) in the clinical setting, when patients' preexisting personal barriers to care are exacerbated; (2) during screening; and (3) during physician-patient follow-up [58]. Technology knowledge gaps can create confusion and fear, and patients may have low confidence in the quality of the content. Thus, when new education paradigms are created, overcoming the digital divide must be considered.

Creating New Education Paradigms for Health Care Providers

Mobile phones and other emerging handheld devices are powerful and useful professional education tools for health care providers. Professional literature and educational materials can serve as conduits for information that enhance the practice of evidence-based medicine, provide professional education, act as a mobile clinical communication aid (with other health care professionals or office and hospital colleagues), store disease self-management education materials, and allow for remote (live or streamed) patient education. Apps are becoming more sophisticated and include static or motion images, such as in ophthalmological examinations [59], trauma in rural settings [60], and mobile phone and other telehealth tools served for multiple emerging purposes, including health care provider education. Adoption of high technology medical communication—in addition to high-performance computers, fiberoptic equipment, and high-resolution cameras—enables greater capacity for collaboration and learning between health care providers.

Forming Communities of Knowledge and Practice

Given the significant changes in telehealth and telehealth applications brought about by the rapid emergence of health care organizational change, new software apps, new devices, and new forms of data, it is important for providers to form communities of expertise in applying the most recent scientific advances. App developers are rarely health care experts and patients may forget the "buyer beware" motto associated with software purchase or free downloading. One case in point is that of apps for pain, 80% of which are available for iPhones. Researchers found 220 apps, 80% of which were built on the iOS platform and ranged in price from free/nominal cost (generally less than US $5) to as much as US $90. Unfortunately, in 65% of the apps identified, there was no evidence of health care provider involvement in development, even though the primary purposes of these apps was pain education (24.1%), self-management of pain (62.3%), or both (13.6%) [61].

Further, not all telehealth systems successfully meet educational or behavioral outcomes. When telephone-based reminders and Web-based educational tools were used to improve medication adherence for acne treatment, only the Web-based educational tools had a positive effect [62]. When home video telehealth and monthly telephone counseling, respectively, were used to maintain weight in African-American women, there were no differences in outcomes for the two methods; however, valid digital video recorder use during the intervention period was reported as low, ranging from zero to 42% use per participant [63]. In an 18-month longitudinal study of telehealth for diabetes management, patients using telehealth required less support in physical activity, healthy eating, and problem-solving behaviors than control participants, but more support in medication adherence and healthy coping [64]. It might be that telehealth users became dependent on telehealth to promote medication adherence and provide coping advice. Although medication reminders and coping advice are beneficial, patients should become more independent in self-care over time and be able to overcome routine problems that come with managing diabetes. It will be increasingly important to conduct research on a range of telehealth education paradigms and tools to identify attributes of successful training paradigms and ensure that there are no issues related to the digital divide.

As telehealth becomes more prevalent, it will be important to ensure that communities of experts with knowledge of and experience with specific patient populations can develop systems and processes that ensure excellence in educational message content and can match the proper telehealth system with the intended education and clinical outcomes. It is important to use communities of experts to reassess the effectiveness of education content at frequent, regular intervals to ensure that best practice and evidence-based information are used, further ensuring that education (and self-management based on education) will promote optimal clinical and behavioral outcomes. Finally, as e-learning tools become more prevalent in private homes, there will be a greater need for communities of knowledge and practice related to privacy and information security. In a study of home rehabilitation programs for chronic pulmonary disease and diabetes, an assessment was made of e-diaries used to communicate with health care professionals, focusing on privacy, security, and risks to information security. Threats identified regarding data included those related to confidentiality, integrity, availability, and quality. From the perspective of a technical platform, the issue of confidentiality was identified as the most serious, in one case reaching an unacceptable “high-risk” level. Telehealth in the home offers additional threats to privacy and confidentiality compared to hospitals and health care centers that have controlled environments. Consequently, telehealth will require the development of commensurate levels of information security to support the rapid adoption of emerging telehealth tools.

New Care and Business Models Tailored to Sustainability and Scalability of Telehealth Initiatives

In order to reduce risks and costs when starting up a new telehealth service, it is useful to develop new care and business models to increase the probability of success of the service.

To understand the dynamic and workflow of telehealth among health care professionals and within health care systems, a new theoretical framework for understanding cross-sector care integration needs to be developed. One way to develop such a framework is to employ an interorganizational approach, such as that used in the eHealth-enhanced Chronic Care Model [65]. A new framework should address specific approaches for cross-sector care integration, redesign of chronic disease care management, and redesign of multiple care practices through telehealth.

Most of today’s telehealth solutions are designed to provide monitoring functionality for a single chronic disease, even though most elderly adults have multiple chronic medical conditions. In the future, chronic disease management through telehealth technologies needs to be versatile in functionality and to be able to support patients with multiple diseases. Systems need to provide more options or become more patient-specific and personalized. Stratification tools are needed for matching patient preferences and health care providers’ recommendations to specific technology. Guidelines that assist patients in understanding how to use the technology, how the data are analyzed, and how to self-monitor their care need to be developed to help patients obtain a higher degree of self-management.

There exists no common conceptualization of business models and cases for telehealth in the literature [66]. However, it is important to break down the business model and business cases into components to understand and then construct sustainable and scalable telehealth initiatives. Sustainable business models must be developed to meet the demands of the many stakeholders in telehealth programs and to create value for a company as well as for the health care sector and patient. There is limited research on the use of business models and cases in telehealth. However, the identification of innovative telehealth business models is now of interest globally. The question is whether it is possible to develop a general model that can be used across countries and still be sensitive to different legal and operational structures of reimbursement and varied socioeconomic contexts between developed and developing countries. For example, the lack of transportation in developing countries will place a higher emphasis on critical access to basic health care, whereas the value proposition in a developed country would more likely emphasize convenience of location [64].

The self-tracking technologies are expected to change the role of the consumer in the future because we can expect that the consumer will be able to deal directly with the companies selling medical devices or devices for tracking pulse, sleep, etc.

Innovative Research Methodologies Within Telehealth

Evaluation of the efficacy of telehealth has been carried out within the traditional research paradigm using randomized controlled trials (RCTs). RCTs are considered the highest level of evidence because of their high level of internal validity, but they are both expensive and time-consuming. With technologies being rapidly developed, the RCT evaluation paradigm may become too cumbersome and time-consuming for stakeholders and managers within the health care system, and policy makers often do not have time to await a scientific assessment of a given technology before they have to decide on budgets for the coming financial year. Alternatively, managers prefer evidence-based decision making and may request information about clinical impact, cost-effectiveness, patient perception, and organizational aspects of telehealth.

This has been demonstrated recently by Kidholm et al [67] in a study of European health care managers. Globally, there has been discussion about developing a new framework for assessing telehealth technologies at different levels of development. Within the European Union, a new multimodal telehealth assessment tool has been developed, called the Model for Assessment of Telemedicine Applications (MAST). MAST provides a multidisciplinary assessment of telehealth technologies [68]. The assessment process has three steps. First, the preliminary assessment in which the maturity of the technology and the organization using it must be assessed (eg, in the form of a feasibility study). Second, a multidisciplinary assessment of the outcomes of the telehealth application is conducted within seven domains: (1) health problem and characteristics of the application, (2) safety, (3) clinical effectiveness, (4) patient perspectives, (5) economic aspects, (6) organizational aspects, and (7) sociocultural, ethical, and legal aspects. Finally, the third assessment step is a transferability assessment, in which the transferability of the evidence to the local setting is considered. The MAST model is currently the most widely used framework for evaluating telemedicine in the European Union and is used in a number of EU projects. Examples of MAST are available in studies by Minet et al [69] and Rasmussen et al [70].

Transfer of Scientific Knowledge: From Research to Implementation and Practice

Telehealth offers the opportunity to deliver care that is accessible, convenient, and patient-centered, overcoming many of the barriers inherent in traditional health care delivery systems [71]. However, widespread implementation will require attention to systems engineering approaches to health care design so that it can address incentives, technical and human requirements, work processes, and payment issues [72]. To demonstrate and realize added value to health outcomes, telehealth implementation is not simply a feature to be added to existing health care delivery. It must be integrated into innovation at the system level. Integration involves examining the current flow of care for targeted subpopulations and revising the overall approach to care, integrating telehealth, and changing traditional elements. For example, using telehealth to manage chronic disease might incorporate interprofessional involvement, with nurses, pharmacists, or dietitians coaching the patient through telehealth between visits for primary care. Integration may require challenging adjustments in the current delivery of care. For example, the number of planned primary care visits may be reduced as telehealth is used to augment care.

For telehealth to be fully integrated into global health systems, a number of items that support system transformation will be needed. Given that telehealth often includes patient-generated data, significant changes will be needed to insure accurate, efficient, and timely monitoring of health parameters that are useful for guiding clinical decision making. Integration and interpretation of these data are essential to optimizing telehealth, yet many EHR systems do not have the capacity to incorporate patient-generated data nor are they not able to make it available in a time-sensitive fashion. Similarly, new competencies will be required for health care professionals in telehealth and systems engineering to improve health [72]. Finally, telehealth research needs to promote approaches to care that are amenable for adoption in practice. The age-old challenge is to translate research findings into practice to facilitate adoption of new knowledge to telehealth. The challenges are to reinforce the urgency with which evidence is needed to drive policy and provide greater incentive for researchers and practitioners to collaborate.

American and European Visions for Personalized Telehealth

In the United States, the Health Resources and Services Administration works to increase and improve the use of telehealth to meet the needs of underserved people, including those living in rural and remote areas, with low income, uninsured, or those enrolled in Medicaid. The Affordable Care Act is driving changes in health care delivery that bring greater value and access, particularly to populations who require complex care. As reimbursement moves from fee-for-service to value-based and outcome-driven payment, incentives for providing telehealth should improve. Through the Federal Office of Rural Health Policy and the Office for the Advancement of Telehealth (OAT), resources are provided in the United States to support regional telehealth technical assistance centers, a national telehealth policy center, and a national telehealth technology assistance center. In addition, OAT provides grants for the creation of evidence-based tele-emergency networks and for demonstration projects to test the use of telehealth networks in improving health care services for medically underserved populations in urban, rural, and frontier areas of the country.

The World Health Organization (WHO) has developed a European policy framework and strategy for the 21st century called “Health 2020.” The vision of this initiative is to achieve the highest level of health among European countries and to improve health for all citizens, and reduce health inequalities, empower citizens to take care of their own health, and strengthen people-centered health system and public health capacity [73]. In 2011, WHO launched a policy on health technology assessment of medical devices with a focus on this area because new technologies are evolving rapidly [74].

Similarly, the EU Commission launched an eHealth Action Plan for 2012-2020 entitled “Innovative Healthcare for the 21st Century in the EU” [75]. This plan seeks to improve chronic conditions, multiple morbidity management, and strengthen prevention; increase patient-/citizen-centric care via citizen empowerment and organizational sustainability; stimulate cross-border health care, security, and equity; and improve legal and market conditions for developing eHealth products and services [75].

Finally, Denmark has a national strategy for digitalization of the Danish public sector by 2020.0 [76]. Focus is on implementing telehealth at scale, improving personalized telehealth, quality of life for patients and citizens within the health care and social sectors, and to increase the efficiency and effectiveness of workflows within the public sector.

Within the European Union, the “Horizon 2020” research program offers funding possibilities to facilitate more telehealth projects at scale, with an implementation focus, and for international (US and EU) partners. The TTRN advocates more transatlantic telehealth studies to develop synergy in research and gain generalizable results at a more rapid pace.

Personalized Telehealth in the Future: A Global Research Agenda

As telehealth plays an even greater role in global health care delivery, it will be increasingly important to develop a strong evidence base of successful, innovative telehealth solutions that lead to scalable and sustainable telehealth programs. A broad, multinational research agenda can provide a uniform framework for identifying and rapidly replicating best practices, while concurrently fostering global collaboration in the development and rigorous testing of new and emerging telehealth technologies. As an initial effort toward a global research agenda, the members of the TTRN offer a 12-point research agenda that incorporates health care parameters across mediated and traditional modes of care for the benefit of providers, companies, policy makers, and the international research community (see Textbox 1).

Textbox 1. Focus areas for personalized telehealth research.

1. *Patient*

- Assessment of personal engagement in own health through the use of telehealth technologies (quantified self)
- Self-determination and motivation with regard to the use of new telehealth technologies
- Health literacy, eHealth literacy, technology literacy, contributions to design features of technology, and interaction with telehealth technologies
- Patient-to-patient interventions

2. *Home*

- Integration of smart home telehealth technologies (wellness and health devices and software, Internet of Things)

3. *Health care professionals*

- Communication for and between providers and patients (telehealth through mobile, wearable, and remote monitoring)
- Telehealth training and education, including designing communities of knowledge and practice

4. *Health system design, organization, and practice*

- Cross-sector integration using telehealth technologies (Accountable Care Organizations, bundled care, medical homes)
- Telehealth in redesign of chronic disease management
- Adoption of telehealth programs in clinical practice

5. *Technologies*

- Use of self-tracking technologies
- Design of user-friendly technologies
- Development of sensor technologies for detection of fluid in the body, sleep patterns, etc

6. *Data systems and infrastructure*

- Integration of telehealth devices with electronic health records and cloud databases
- Integration of personal health records data and telehealth devices and systems

7. *Data analytics*

- Algorithms for multimodel data platforms, devices, and sources
- Innovative data analytic approaches for integrating data for precision medicine, including predictive, personalized, and customized analytics

8.*Development of new telehealth technologies*

- Assessing mobile, intelligent, and individualized telehealth technologies
- Enhancing the matching of patient preferences and telehealth use
- Anticipation of telehealth innovations still to be invented
- International telehealth technology standards

9.*Research methods*

- Multidisciplinary assessment of the effectiveness of new telehealth services
- Advances in tracking, data transmission, and storage of telehealth data (real-time analytics vs store-and-forward)
- Rapid cycle design evaluation vs traditional randomized controlled trials

10. *Financing*

- Assessing innovative payment and reimbursement systems, especially in the emerging value-based health care environment
- Global variations in financing and paying for telehealth

11.*Privacy and security policy*

- Addressing different cultures of privacy (ethical issues) for patients
- Enhancing telehealth data security (given advances in mobile, wearable, and cloud-based system configurations)

- Local, regional, and international regulatory requirements (licensing, guidelines, standards)

12.*Public policy*

- Telehealth across state and international borders
- Professional licensing and standards
- Variation in intergovernmental and international telehealth policies and financing

The research goals are designed to facilitate comparative evaluations of telehealth solutions at multiple levels, from individual to system level, using a variety of devices and technologies, and in multiple settings and contexts. Although this research agenda requires specific refinements to address country and health system variations, it can provide a comprehensive orientation for pursuing global research in personalized telehealth.

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Conflicts of Interest

None declared.

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Abbreviations

CBO: Congressional Budget Office
CCHP: Center for Connected Health Policy
CCHT: Care Coordination/Home Telehealth
COPD: chronic obstructive pulmonary disease
DALY: disability-adjusted life years
EHR: electronic health record
HIT: health information technology
HTA: Health Technology Assessment
HYE: healthy years equivalent
IT: information technology

MAST:	Model for Assessment of Telemedicine
OAT:	Office for the Advancement of Telehealth
QALY:	quality-adjusted life years
RCT:	randomized controlled trials
RPM:	remote patient monitoring
TTRN:	Transatlantic Telehealth Research Network
VHA:	Veterans Health Administration
WHO:	World Health Organization
WSD:	Whole System Demonstrator

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