Journal of Medical Internet Research

Journal Impact Factor (JIF) (2023): 5.8
Volume 18 (2016), Issue 10   ISSN 1438-8871   Editor in Chief: Gunther Eysenbach, MD, MPH

Contents

Original Papers

Corrigenda and Addenda

Original Paper

Overcoming Addictions, a Web-Based Application, and SMART Recovery, an Online and In-Person Mutual Help Group for Problem Drinkers, Part 2: Six-Month Outcomes of a Randomized Controlled Trial and Qualitative Feedback From Participants

William Campbell[1], PhD; Reid K Hester[1], PhD; Kathryn L Lenberg[2], MPH, PhD; Harold D Delaney[3], PhD

[1]Behavior Therapy Associates, LLC, Research Division, Albuquerque, NM, United States
[2]Truman Health Services, University of New Mexico, Albuquerque, NM, United States
[3]Psychology Department, University of New Mexico, Albuquerque, NM, United States

Corresponding Author:
William Campbell, PhD
Behavior Therapy Associates, LLC
Research Division
9426 Indian School NE
Albuquerque, NM,
United States
Phone: 1 505 345 6100
Fax: 1 505 345 4531
Email: william.campbell.iv@gmail.com

Abstract

Background: Despite empirical evidence supporting the use of Web-based interventions for problem drinking, much remains unknown about factors that influence their effectiveness.

Objective: We evaluated the performance of 2 resources for people who want to achieve and maintain abstinence: SMART Recovery (SR) and Overcoming Addictions (OA). OA is a Web application based on SR. We also examined participant and intervention-related factors hypothesized to impact clinical outcomes of Web-based interventions.

Methods: We recruited 189 heavy drinkers through SR's website and in-person meetings throughout the United States. We began by randomly assigning participants to (1) SR meetings alone, (2) OA alone, and (3) OA and SR (OA+SR). Recruitment challenges compelled us to assign participants only to SR (n=86) or OA+SR (n=102). The experimental hypotheses were as follows: (1) Both groups will reduce their drinking and alcohol-related consequences at follow-up compared with their baseline levels, and (2) The OA+SR condition will reduce their drinking and alcohol or drug-related consequences more than the SR only condition. Additionally, we derived 3 groups empirically (SR, OA, and OA+SR) based on the participants' actual use of each intervention and conducted analyses by comparing them. Primary outcome measures included percent days abstinent (PDA), mean drinks per drinking day (DDD), and alcohol or drug-related consequences. Postbaseline assessments were conducted by phone at 3 and 6 months. Secondary analyses explored whether clinical issues (eg, severity of alcohol problems, level of distress, readiness to change) or intervention-related factors (eg, Internet fluency, satisfaction with site) affected outcomes.

Results: Both intent-to-treat analyses and the actual-use analyses showed highly significant improvement from baseline to follow-ups for all 3 groups. Mean within-subject effect sizes were large ($d>0.8$) overall. There was no significant difference between groups in the amount of improvement from baseline to the average of the follow-ups. We found that participants who stopped drinking before joining the clinical trial had significantly better outcomes than participants who were still drinking when they joined the study. Neither Internet fluency nor participants' reported ease of navigating the site had an impact on outcomes.

Conclusions: These results support our first experimental hypothesis but not the second. On average, participants improved on all dependent measures. Both SR and OA helped participants recover from their problem drinking. Web-based interventions can help even those individuals with lengthy histories of heavy drinking to make clinically significant reductions in their consumption and related problems. These interventions work well for individuals in the action stage of change.

Trial Registration: Clinicaltrials.gov NCT01389297; https://clinicaltrials.gov/ct2/show/NCT01389297 (Archived by WebCite at http://www.webcitation.org/6kLNUNDcc)

(J Med Internet Res 2016;18(10):e262) doi:10.2196/jmir.5508

KEYWORDS

alcohol addiction; intervention study; psychological techniques; digital interventions; engagement; online program; self-help

Introduction

Background

Clinicians, researchers, and public health officials working to reduce the prevalence of substance use disorders have sought to develop and implement a range of evidence-based treatments and techniques (EBTs) over the last 20 years. Concomitant with these clinical developments, the emergence and growth of personal computing, media technology, and the Internet afforded new means and contexts for the adaptation and delivery of EBTs. In fact, apps and Web-based interventions for hazardous drinking have proliferated over the last decade [1-3].

With regard to their ability to deliver clinical services, Web-based interventions in general have several proven as well as potential virtues. Accuracy and validity of assessment protocols, probabilistic feedback algorithms, reliable computations, impartial results and objectives, and tailored recommendations are all appropriate functions of computers, making them (theoretically) optimal for the delivery of evidence-based behavioral health interventions [4-9]. The ubiquity of the Internet and mobile technology afford these interventions with a greater accessibility and reach, on both an individual and public level, and theoretically their impact on public health could be significant. However, the nature of the medium and the way people use Web-based interventions present serious challenges to the field. While developers have control over the content and design of the program, the remote context of implementation affords users a great deal of freedom in how they actually engage with the intervention and also precludes close assessment of ostensible therapeutic mechanisms [10,11]. Further, people often exhibit significantly less engagement with Web-based interventions than developers envision when they design them [11-13]. Indeed, there is a substantial proportion of users who drop out of programs after a single visit to a site [14,15].

When subjected to empirical tests of their effectiveness, self-guided Web-based interventions for problematic alcohol and substance use have consistently exhibited effect sizes that range from medium to disappointingly low [1,4,16-19]. Questions persist as to whether there is in fact a dose-response effect of engagement (ie, greater use of a site is associated with better outcomes), and if so, what can be done to enhance engagement with any given Web-based intervention to increase its effectiveness. The evidence on the relationship between engagement and outcomes is equivocal, with some reviewers and researchers finding support for a connection [20-22] and others finding no such evidence [15,23-25]. Nonetheless, much effort has gone into determining what factors (whether related to the users of the program or the programs themselves) influence adherence and engagement with Web-based interventions [2,14,25]. The general consensus among clinicians and researchers in the field is that until and unless the puzzle of engagement is solved, the seeming potential of Web-based interventions will not be fully realized.

Thus, as studies have accumulated over the last 10 years, interest has grown in identifying factors that might influence engagement with, and the effectiveness of, these interventions [2,3,14,26]. Leading investigators agree that more needs to be known about how EBTs are best adapted to Web-based format (intervention-related factors) as well as who is most likely to use and benefit from access to such a format (participant-related factors) [2,10,12,14,21]. There have also been calls for researchers to cleave to a rigorous set of standards in the development and testing of Web-based interventions (ie, to clearly report the study's rationale, methods, and limitations) and do what they can during clinical trials to explore both intervention-related and participant-related factors that are thought to influence outcomes [1,2,10,14,27,28].

The Study

In this randomized controlled trial, we evaluated the performance of 2 resources for heavy drinkers: SMART Recovery (SR) and Overcoming Addictions (OA). OA is an online intervention that we developed based on the principles and practices of SR. There were 2 main goals of this study. First, we sought to determine whether SR and OA helped individuals make clinically significant reductions in their alcohol consumption and related problems. In addition, we were also interested to know if participants with access to OA would experience better outcomes than those assigned to SR. Second, we wanted to know more about who was most likely to engage with and benefit from these online resources and whether there were factors related to the site that influenced engagement and outcomes. Overall, we sought to learn more about translating EBTs into Web-based programs, and in the process to develop a more effective empirically supported intervention for drug and alcohol misuse.

We chose SR [29] as the model for our intervention because of its sound theoretical orientation, its commitment to EBTs, and, pragmatically, because the cognitive-behavioral exercises found in SR are well suited to online dissemination. SR's program uses a common set of cognitive and behavioral strategies to address all addictive behaviors [30]. Their rationale for this is based on the generally accepted theory that common etiological factors underlie the development and maintenance of addictive behaviors (eg, stimulus control, maladaptive reinforcers) as well as the broad applicability of cognitive-behavioral and motivational strategies that are supported by outcome research in the treatment of various addictions. The outcomes of individuals who visit the SR website have never been subjected to empirical analysis before this study, but because SR is explicitly based on the use of cognitive-behavioral EBTs, we hypothesized that people who visited the site would, on average, change their drinking.

OA is designed to be used either as a complement to traditional SR (ie, meetings and workbook) or as a stand-alone, self-guided program. We thought that a structured, self-guided site, providing an enhanced suite of SR exercises and entailing the benefits of Web-based interventions (ie, accessibility, reliability, interactivity), would improve outcomes for individuals seeking SR. Although at the time of this study SR did offer a workbook, OA's comprehensive structure brought SR's exercises and rationale into an organized, integrated program. We assumed that individuals would benefit from being able to access program content at any time and from any place that was most convenient to them, rather than, for example, having to navigate the scheduling constraints of SR meetings. We reasoned that OA's consistent and clinically valid presentation of treatment components (ie, the concepts being taught or the exercises offered) would increase their effectiveness. We also thought that unique features of the site such as the ability to track and get feedback on triggers and urges to drink, guided mindfulness exercises, and the videos provided by highly regarded SR trainers, would enhance engagement with therapeutic mechanisms and likewise lead to better outcomes.

At the same time, we were interested in learning more about who was most likely to benefit from OA and whether the design of the site was impacting outcomes. The issue of matching clients to interventions is as important to Web-based interventions as it is in the context of face-to-face treatment. Research has found that factors related to characteristics such as gender, age, level of education or income, level of alcohol consumption, and readiness to change all contribute to Web-based treatment adherence [31,32], although the influence is complex [15] and evidence is as yet inconclusive regarding their influence on outcomes on various clinical measures [1,33].

Another individual factor that has received some attention in trials of Web-based interventions is "readiness to change." The Transtheoretical Model of Change [34] has long been recognized for its ability to inform behavioral treatments [35,36] and has in fact been used in the development of Web-based interventions as a theoretical basis for the tailoring they provide [5,37]. Like any self-directed program, Web-based interventions are ostensibly well suited for individuals in the action stage of change [11]. Prior research has shown that Web-based interventions can increase readiness to change [37], and one study found that individuals who were high in treatment readiness (ie, approaching the "action" stage of change) were more likely to complete a Web-based program [28]. It has yet to be shown empirically that such individuals do in fact benefit from Web-based interventions and, conversely, whether individuals who are still in the contemplation stage of change can also benefit from them. Evidence to support establishing such a distinction for individuals seeking to change their drinking could inform treatment recommendations as well as implementation strategies for Web-based interventions more broadly.

A person's relative ability to function effectively with computers and on the Internet is another individual factor of interest to Web-based intervention developers. Feasibility studies have consistently found that site visitors are quite conscious of the difficulty they experience navigating Web-based programs [32,38-41] and may disengage from the programs if the process of using them becomes too frustrating [41-43]. As one way of assessing this difficulty, researchers have examined whether users' relative proficiency with "Internet skills" can moderate their ability to benefit from a Web-based intervention [38-40]. While we know people can struggle to effectively navigate websites and so might fail to obtain relevant information in ways that interfere with Web-based interventions, there is as yet no evidence to support the theory that such difficulties moderate clinical outcomes. Nonetheless, it seemed reasonable to assume that participants who typically spent more time on the Internet and who navigated the site with more ease would have more facility with the program, and so derive greater benefit from the treatment it conveys.

Considering the participant factor of Internet proficiency, we were curious whether there were aspects of OA's design that would influence outcomes in ways not associated with the traditional delivery of EBTs (ie, face-to-face). Specifically, we were interested in participants' subjective sense of how difficult the OA site was for them to navigate (ie, to successfully access the information and exercises in the program). With regard to navigating through course content, evidence shows that low prior-knowledge and low metacognitive learners learn better when the program dictates the pacing and structure of the content (ie, utilizing guided information architecture) rather than leaving it to the learner to decide how to proceed [44]. According to e-learning researchers, novice learners don't know enough about a given domain to benefit from "learner control" over the structure and pacing of the content [45].

Furthermore, one common assumption about Web-based interventions is that persuasive features such as site architecture and navigation, the use of video or social media, or the deployment of email or text messaging prompts can positively impact engagement with therapeutic mechanisms [13,26,32,43]. On the other hand, researchers have found that providing too much content can depress engagement with Web-based programs [46]. The principle applies whether content is added to enhance interest [47], to increase depth [48,49], or to expand on key ideas [50,51]. Given the cognitive impairments commonly associated with early recovery from hazardous drinking, we sought to know whether the user's subjectively rated satisfaction with their ability to navigate the website, as well as the amount of content on the site, would account for variance in outcomes.

Finally, with regard to the optimal methods for conducting a clinical trial on line, among those who develop and validate Web-based interventions, there is a well-known trade-off between more ecologically valid and more clinically rich methodologies [10]. There have been several clinical trials conducted entirely online, the method generally regarded as the most ecologically valid, and so most indicative of "real-world" effectiveness [10,11]. However, in addition to the disadvantage of their typically high rates of attrition, such tests are constrained in their ability to gather data regarding factors that might influence outcomes [10,13,14]. Indeed, it is often impossible to know who the participants are, whether their reports are genuine, and how seriously they are treating the intervention.

For our study, we chose to recruit from individuals who were actively seeking information online about SR. We did this intentionally to test SR and OA with a sample drawn from the population that would likely be interested in SR's treatment approach or EBTs more generally. Furthermore, we chose to conduct our intake and follow-up interviews online and over the phone. Although even this limited contact with our research staff represents a significant deviation from the conditions under which self-guided Web-based interventions are encountered at large, online, we considered it a necessary trade-off in order to gather the data we needed for our qualitative analysis. We sought to minimize the impact of our contact with participants on our findings by conducting our baseline assessments at the three-month follow-up.

Methods

Trial Design

Further details regarding study recruitment, inclusion and exclusion criteria, the screening process, randomization, assessments, baseline and follow-up interviews, and institutional review board approval are presented in Part 1 of this study [23].

Treatment Conditions

SMART Recovery

SR is a nonprofit educational organization run by a board of directors that consists primarily of clinicians with backgrounds in cognitive-behavioral practice [28]. The board determines, based on the empirical evidence and the feasibility of translating elements into self-help formats, what components will make up the SR program. While SR content may vary as empirical research evolves, the underlying philosophy of the protocol has remained consistent since its inception. In particular, SR promotes the dissemination of, and instruction in, empirically supported techniques and practices that "empower" [28] individuals to make changes in their own lives.

SMART Recovery's program for change is focused on the following 4 domains: (1) building and maintaining motivation for change; (2) dealing with urges; (3) managing thoughts, feelings and behaviors; and (4) developing a balanced lifestyle. To build motivation, SR offers such exercises as cost-benefit analysis and guidance on how to develop a change plan. With regard to dealing with urges, SR teaches individuals how to identify and think functionally about triggers as well as how to manage urges when they arise. SR prescribes the use of such cognitive interventions as disputing irrational beliefs, and the "ABC" exercise commonly used to understand and improve upon emotional upsets. SR also provides instructions for learning relapse prevention techniques. Finally, to help support lifestyle changes that coincide with changes in drinking, SR offers exercises designed to help individuals identify and plan for meaningful activities, attain a balanced life, and engage in healthier behaviors.

SMART Recovery has been implemented historically in face-to-face and online self-help or mutual aid groups, with meetings that are facilitated only by individuals who have received official SR training [28]. While there is no formal treatment manual for SR, interested individuals obtain a workbook containing various descriptions of SR principles and exercises. The SR website serves as a resource for individuals who are seeking information about, or are actively engaged in, addressing their alcohol or drug use through SR. The site explains the principles of SR in detail, contains resources to support SR exercises, and serves as a portal for an SR community, including contacts for in-person meetings around the country, live online SR meetings, and a blog. While the site contains a wealth of resources pertaining to SR, it does not provide a Web-based SR intervention, nor does it expressly advise site visitors about how to utilize SR's treatment components.

Overcoming Addictions

OA is a self-directed Web-based intervention designed for individuals who want to stop drinking and are in the "action" stage of change [34]. It is intended to faithfully render the EBTs of SR while also enhancing engagement with its therapeutic mechanisms. Once visitors register to use the site, the program creates a new record in the database, personalizes the content, and directs them to the homepage. The content is organized into "modules" around the 4 points of the SR program. The site also contains exercises not found in the SR handbook or website (eg, mindfulness and meditation exercises), but which are empirically supported and that we judged to be consistent with SR's 4-point program.

For example, the first module, *Getting Started*, provides an overview of the program and its theoretical approach, while also explaining Stages of Change, and addressing how an individual's relative stage might influence their approach to the program. The next module, *Building and Maintaining Motivation for Change*, begins with an exercise to help individuals think about how their drinking and their desire to change relates to their values; it then proceeds to a decisional balance exercise that helps users to consider the pros and cons of changing. The third module, *Dealing with Urges and Cravings*, contains information about urges and triggers and provides users the tools to monitor, track, and develop strategies to handle them. The fourth module, *Self-Managing Thoughts, Behaviors, and Feelings* contains common cognitive behavioral therapy exercises such as problem solving, functional analysis of problematic behaviors and situations, and information about the interactions between thoughts and feelings that may influence drinking. The final module, *Lifestyle Balance for Preventing Relapse*, has exercises that support regaining one's health, learning relaxation techniques, goal setting, and relapse prevention strategies. In order to support self-guided use, we included videos recorded by experienced SR facilitators explaining how to think about and use the various exercises presented on the site. We also included a graphic feedback features wherever appropriate (eg, feedback on changes in urges to drink over time) and the ability for users to save their work and track their progress through the site.

Structurally, we sought to create a site that emulates the philosophy of the intervention. In order to reflect SR's emphasis on autonomy and self-direction, we originally designed the site in an open, unguided format so that a user could access any section or module of the program in any order that he or she believed would best suit the needs of their treatment. However, the site also reflects findings that guided "breadcrumb" navigation works best on behavior-change websites [32,42,52]; thus, once the user chooses an exercise, the program guides them through it in "tunnel" fashion, with a link on every page that leads to the next step of the exercise. We felt this "hybrid style" (ie, matrix to tunnel, and back to matrix) offered the best compromise between an unguided "user-centered" approach and the more directive protocols often used in conventional cognitive-behavioral interventions.

We made additional content available throughout the site via pop-up boxes and links that expand the page (eg, read more>>) to reduce the amount of visible content. We wrote the content for an 8th grade reading level and confirmed that level with the Flesch-Kincaid readability test [53] (built into the Corel *WordPerfect* program). Images only appeared in the page headers that also included navigation links to the home page, module headings, and the My Account page where the text and email features are located.

Group Allocation

In the initial design of the trial, we intended to randomly assign participants who were new to SR to one of the 3 conditions: (1) to use the online resources of SR and their meetings (face-to-face and/or online); (2) to the SR resources plus access to the OA Web app; or (3) to use the OA Web application only. However, as reported in Part 1 [23], we discovered that many potential study participants were disinclined to enroll in the study when they learned that they might be randomized to the OA only group. Because the majority of individuals came to the study after seeing the announcement on the SR website or by attending an SR meeting, they were unwilling to risk giving up the option to attend meetings for the sake of joining the study. After months of confronting this challenge, we ceased randomizing participants to the OA only group and decided to conduct separate posthoc analyses on the original 3 groups, derived empirically based on their actual use of SR and OA. We felt that even this nonrandomized analysis of participants' treatment of choice would render useful data. We dubbed our modified original analyses "intent-to-treat" and our posthoc analyses "actual use."

Primary Analysis

Primary analyses of between-group differences were conducted to detect the effect of OA. Consistent with intent-to-treat analyses, we examined changes within the randomly assigned groups, using repeated measures analysis of variance as well as mixed model analyses, which were used for both tests of null hypotheses and tests of non-inferiority. The primary dependent variables were percent days abstinent (PDA), mean standard drinks per drinking day (DDD), and alcohol-related problems measured by the Inventory of Drug Use Consequences (InDUC) [54]. We used one three-level repeated factor (time of assessment: baseline, 3-month, 6-month), and the between-subject factor of treatment condition. For each analysis, 2 contrasts in the within-subject factor of time were conducted.

Our secondary analysis explored whether participant characteristics, including readiness to change and Internet skills, were associated with outcomes. Further, we tracked the extent to which participants used SR and OA, asked them to rate OA's structure and complexity, and examined whether these indicators of engagement with the intervention were associated with outcomes.

Secondary Analysis

The data for the analysis of the participant and intervention factors thought to impact the use of the intervention were collected in a semistructured exit interview at the six-month follow-up. We asked participants to estimate how much time they spent on the Internet each week. We also asked them to report on any steps they had taken to change their drinking over the course of the clinical trial and to attribute the relative benefit of any factors that helped them. In the OA group, participants were asked to rate the website with Likert scales across several dimensions, including how easy or hard the site was for them to navigate, whether the site's structure helped or hindered accessing its treatment content, and whether they were satisfied with the amount of content on the site.

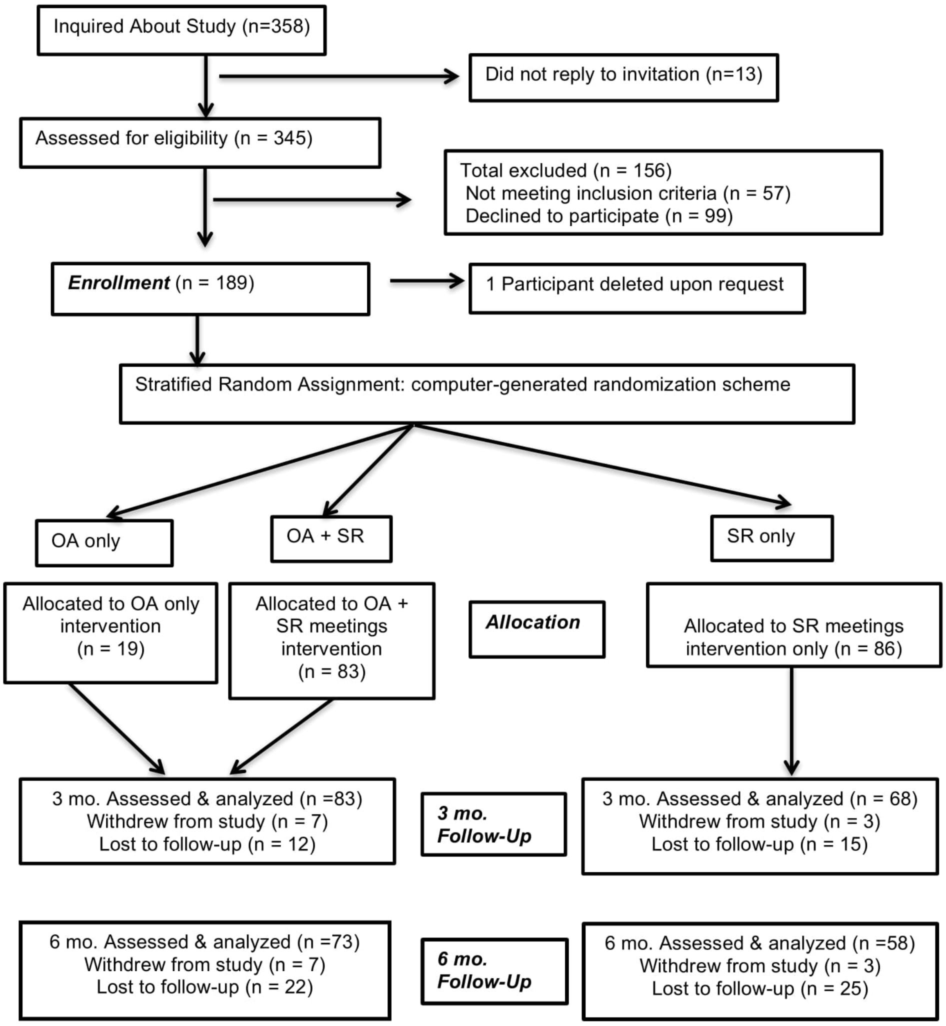
To test for the impact of these factors, separate repeated-measures analyses of variance were conducted on the 3 primary dependent variables (ie, InDuC, PDA, and DDD), with 2 within-subject continuous variables (eg, hours per week spent on the Internet; ease of use) and one within-subject dichotomous variable (amount of information: right or wrong) entered as covariates, and one three-level repeated factor (time of assessment: baseline, 3 month, 6 month). Again, for each analysis, we conducted 2 contrasts of the within-subject factor of time.

Results

Sample

Figure 1 shows the CONSORT flow of participants through the study. A total of 358 people new to SR inquired about the study and of those 345 agreed to be screened. During the initial screening, 19 failed to meet the inclusion criteria and 38 were excluded. After passing the screen, 99 potential participants did not complete the initial consent process, 6 more failed to follow through with the initial assessment, and one asked to be dropped from the study within a day of being randomized. This resulted in 189 individuals who were randomly assigned to one of the 3 groups: SR, OA, and OA+SR. As noted above, due to complications of recruiting through SR's network, the final allocation tallied 102 participants in the OA+SR and OA only groups and 87 in the SR group. Recruitment began from September 12, 2011 (3 pilot participants were recruited in the first 2 weeks of the study) and ended on August 1, 2012. Three-month follow-ups were completed on November 1, 2012. Six-month follow-ups were completed on March 14, 2013.

Figure 1. Consort study participant flow chart. OA: Overcoming Addictions; SR: SMART Recovery.



Participant Characteristics

The general characteristics of the study participants as a whole and by group assignment are presented in Table 1. On average, the sample endorsed clinical levels of psychological and alcohol-related problems. The mean score on the Brief Symptom Inventory (BSI) of 17.4 (SD 12.9) indicates that a majority of participants were experiencing significant depressive, anxious and/or somatic distress at screening. Mean scores on the Alcohol Use Disorders Identification Test (AUDIT)=24.7 (SD 8.1), InDuC Lifetime=31.0 (SD 7.2), and InDuc Recent=41.4 (SD 17.9) indicate that many individuals were at the more severe end of the use disorder spectrum. The majority of the sample was female (61%), which is almost twice the prevalence rate for women in the United States [55], although this level of participation by women is common in eHeath clinical trials for alcohol problems [1,33]. There were no significant differences between groups on any variable. Finally, the sample is remarkably homogeneous with regard to race (90% white).

Table 1. Participant characteristics.

Group	Whole sample	OA[a]+SR[b]	SR only
Participants, n (%)	188	102 (54%)	86 (46%)
Female, n (%)	114 (60.6%)	62 (61%)	52 (61%)
Age in years, mean (SD)	44.3 (10.9)	45.3 (10.7)	43 (10.6)
White, n (%)	170 (90.4%)	94 (92.2%)	76 (88.4%)
Education in years, mean (SD)	16.1 (2.4)	17.7 (2.2)	15.9 (2.5)
BSI[c] total, mean (SD)	17.4 (12.9)	15.7 (13.1)	19.4 (12.5)
AUDIT[d], mean (SD)	24.7 (8.1)	24.6 (8.1)	24.8 (8.1)
InDuC[e] Lifetime, mean (SD)	31.0 (7.2)	30.8 (6.7)	31.3 (7.7)
InDuC Recent, mean (SD)	41.4 (17.9)	40.6 (17.1)	42.2 (19.1)

[a] OA: Overcoming Addictions.

[b] SR: SMART Recovery.

[c] BSI: Brief Symptom Inventory.

[d] AUDIT: Alcohol Use Disorders Identification Test.

[e] InDuC: Inventory of Drug Use Consequences.

Lost to Follow-Up

We compared baseline characteristics between those having complete data and those missing either or both of the 3-month and 6-month follow-ups. No significant differences were found on the following continuous variables at baseline: age, the AUDIT, BSI, InDUC scores, DDD, or PDA. No differences across groups existed on the categorical variables of group assignment, gender, or race. Only education level demonstrated a significant difference—those who provided data at both follow-ups reported having completed more years of education (16.4) than those who did not (15.5), t_{186}= 2.24, P=.03.

Intent-to-Treat Analysis

Of the 73 OA+SR participants assessed at all 3 time points, 53 (72.6%) were classified as actually using the OA program, as defined by 2 or more logins in the first 90 days of the study. In contrast, of the 58 SR only participants assessed at all 3 time points, 51 (87.9%) were classified as having been actually treated, as defined by 2 or more SR meetings attended. This difference in rates of actual use of the treatment options available approached significance, χ^2_1=3.75, P=.053.

We conducted separate repeated-measures analyses of variance on the 3 primary dependent variables to assess the effects of the between-subjects factor of treatment condition (ie, OA+SR or SR) and the within-subjects factor of time. We also had 2 a priori contrasts in the within-subject factor: the improvement from baseline to the average of the 2 follow-ups; and the change from the 3-month follow-up to the 6-month follow-up. As we found in our 3-month data, the improvement over time on PDA was highly significant, $F_{2,128}$=78.26, P<.001. The tests of the preplanned contrasts indicated that, as hypothesized, the improvement from baseline to the average of the post assessments was highly significant, $F_{1,129}$=154.85, P<.001, and the change from 3 months to 6 months was nonsignificant overall, $F_{1,129}$=1.09, P=.30. However, in contrast to our finding with the 3-month data, the test of the treatment x time interaction is now significant, $F_{2,128}$=3.16, P=.046. Tests of interaction contrasts indicated that the improvement from baseline to the average of the follow-up was comparable in the 2 conditions, $F_{1,129}$=0.10, P=.92, but the change from 3 months to 6 months was significantly different in the 2 conditions, $F_{1,129}$=6.32, P=.01. The reason for the latter finding, as seen in Table 2 below, is that while the SR only participants continued improving from 3 months to 6 months, the OA+SR group regressed slightly.

Table 2. Means (and standard deviations) and within-group effect sizes for each outcome variable for each treatment condition.

Variable and group	Baseline, mean (SD)	3-month follow-up, mean (SD)	6-month follow-up, mean (SD)	Improvement from baseline to average follow-up, mean	Improvement from 3 to 6 months, mean	Within group effect size *d*[a]
Percent days abstinent						
OA[a]+SR[b] (*n*=73)	42.13 (29.01)	74.03 (30.65)	67.28 (33.64)	28.53	−6.75	0.98
SR only (n=58)	43.26 (29.11)	69.92 (32.43)	72.72 (31.57)	28.06	2.80	0.97
Mean standard drinks per drinking day[d]						
OA+SR (n=73)	7.64 (4.45)	4.33 (3.70)	5.08 (5.20)	2.56	−0.75	0.65
SR only (n=59)	8.19 (4.61)	4.82 (4.77)	3.99 (4.84)	4.20	0.83	0.84
Inventory of Drug Use Consequences recent score[e]						
OA+SR (n=73)	39.37 (17.43)	19.01 (17.78)	19.88 (21.52)	19.92	−0.87	1.08
SR only (n=58)	41.25 (19.72)	20.24 (19.50)	19.58 (21.27)	21.01	0.66	1.14

[a]Cohen *d* for change from baseline to average of 3-month and 6-month follow-ups .

[b]OA: Overcoming Addictions.

[b]SR: SMART Recovery.

[d]Standard drink is equal to 12 oz (355 mL) of 5% beer, 5 oz (149 mL) of 12% wine, or 1.5 oz (44 mL) of 80 proof liquor.

[e]Alcohol-related problems.

The DDD variable showed a similar pattern, although the treatment x time interaction did not reach significance. Thus, the improvement over time was highly significant, $F_{2,129}$=36.88, *P*<.001, with again the significant improvement occurring from baseline to the average follow-ups, $F_{1,130}$=72.95, *P*<.001, and the change from 3 months to 6 months being nonsignificant overall, $F_{1,130}$=0.01, *P*=.93. The treatment x time interaction did not quite reach significance, $F_{2,129}$ =2.53, *P*=.08. However, the pattern again was for the improvement from pre to the average of the posts to be comparable across conditions, $F_{1,130}$=1.15, *P*=.29, but between 3 months and 6 months the SR only group continued to improve whereas the OA+SR group regressed slightly, though the test of the interaction contrast assessing differential change across groups did not reach significance, $F_{1,130}$=3.37, *P*=.07.

The alcohol-related problems measure (InDuC) showed the same sharp improvement from pre to post, but in contrast to the other 2 dependent variables, there was no evidence of a treatment x time interaction. The improvement over time was highly significant, $F_{2,129}$=59.96, *P*<.001, with again the significant improvement occurring from baseline to the average follow-ups, $F_{1,130}$=120.86, *P*<.001, and the change from 3 months to 6 months being nonsignificant overall, $F_{1,130}$=0.01, *P*=.95. The treatment x time interaction did not approach significance, $F_{2,129}$=0.20, *P*=.82.

The mean within-group effect size was in the large range (ie, greater than 0.8), with a range 0.65-1.14. The largest effect sizes were in the domain of alcohol-related problems.

In addition to the primary analyses we ran on participants having complete follow-up data, we also analyzed data using maximum-likelihood mixed model methods to allow use of data from all participants, including those having missing data. Results were similar to those reported above. The omnibus test of the main effect of time was again significant for all 3 dependent variables, and the main effect of treatment was again nonsignificant for all 3 dependent variables. The omnibus test of the treatment x time interaction approached significance for PDA and DDD (.05≤ *P* ≤.10). Tests of contrasts agreed with the repeated-measures analyses in indicating that the time main effect was due to the improvement from baseline to the average of the postassessments on all dependent variables (*P*<.001) and that the evidence for a treatment x time interaction was due to the improvement from 3 months to 6 months being greater in the SR only condition than the OA+SR condition, both on PDA (*P*=.02) and on DDD (*P*=.06).

Tests of Noninferiority

Although none of the tests of the null hypothesis of no difference between the OA+SR group and the SR only group in improvement from baseline to the average of the follow-ups approached significance for any of the dependent variables (*P*

> .15), this failure to reject the null hypothesis is different from being able to confidently assert equivalence of the 2 treatments or noninferiority of the OA+SR treatment to the SR only treatment [56]. Thus, explicit tests for noninferiority were conducted where rejection of a null hypothesis that the OA+SR treatment was inferior to the SR only treatment would be a possible outcome [57]. Given a difference between treatments in amount of improvement between baseline and the post average corresponding to a small effect (d=0.2) might have been regarded as clinically significant, we set the margin of equivalence or noninferiority to one half of this amount or 0.1 of a pooled standard deviation. Using the pooled standard deviation on the original dependent variable, this d value of 0.1 was translated into a noninferiority margin for improvement from baseline to the average post score on each of our 3 dependent measures. Computing all differences so that the difference in improvement would be positive if the OA+SR group showed more improvement than the SR only group the mean difference in improvement for PDA was −3.32, 90% CI −11.78 to 5.13 whereas the noninferiority margin was −3.12; for mean drinks per drinking day, the mean difference in improvement was −1.29, 90% CI −2.80 to 0.23 with a noninferiority margin of −0.46; and for the alcohol-related problems measure, the mean difference in improvement was −3.48, 90% CI 10.54-3.59 with a noninferiority margin of −1.81. Noninferiority of OA+SR would have been demonstrated if the lower limit of the confidence interval had been greater than the noninferiority margin. However, in all 3 cases, not only the lower limit of the confidence interval but the mean difference itself was below the noninferiority margin. Thus, noninferiority is *not* established, meaning the result is inconclusive. Although tests of standard null hypotheses indicated we could not claim the predicted significant difference between the 2 conditions, we cannot confidently assert that the OA+SR treatment is not inferior to the SR only treatment.

Actual-Use Analyses

We also conducted post hoc analyses based on participants' actual use of the interventions: the between x within analysis of variance assessing the effects of the treatment condition, ie, OA+SR, OA only, or SR only, and time. As with the initial intent-to-treat analysis, separate analyses were conducted on each of the 3 primary dependent variables, with 2 a priori contrasts in the within-subject factor being of interest, namely, the improvement from baseline to the average of the 2 follow-ups, and the change from the 3-month follow-up to the 6-month follow-up.

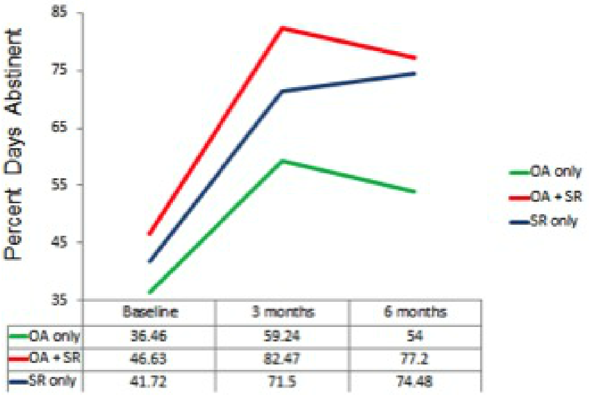
There were 22 participants who reported only using the OA program, some despite having SR available to them subsequent to enrollment; in this sense they were self-selected for this group analysis. These 22 participants in the OA only group did not attend any SR meetings but completed 2 or more of the OA modules. This group was compared with a second group consisting of the 40 participants in the OA+SR condition who completed 2 or more OA modules and who also attended 2 or more SR meetings, as well as with a third group consisting of the 61 participants from the OA+SR condition and the SR only condition who did not complete any OA modules but who attended 2 or more SR meetings. These 3 groups, OA only, OA+SR, and SR only did not differ significantly by gender, ethnicity, age, or education. Although there were no significant differences between these groups in mean baseline values on our 3 primary dependent variables, the trend in each case was for those in the OA+SR group to be less impaired initially than those in the OA only group.

Repeated-measures analyses of variances again indicated highly significant changes over time on all 3 dependent variables (P<.001) with the locus of the effect being the improvement from the baseline to the average of the post measures (P<.001) but there being no significant overall change from 3 months to 6 months. Results for these 3 groups defined by actual use, that is, OA only, OA+SR, and SR only, are shown in Figures 2,3, and 4.

The tests of the group x time interaction were not significant, although there was a trend for an interaction on PDA, $F_{4,208}$=2.06, P=.09 (Figure 1). Tests of interaction contrasts indicated that the locus of evidence for an interaction was that the change from 3 months to 6 months in the SR only group was significantly different from that in the OA+SR and OA only groups, $F_{1,105}$=4.31, P=.04.

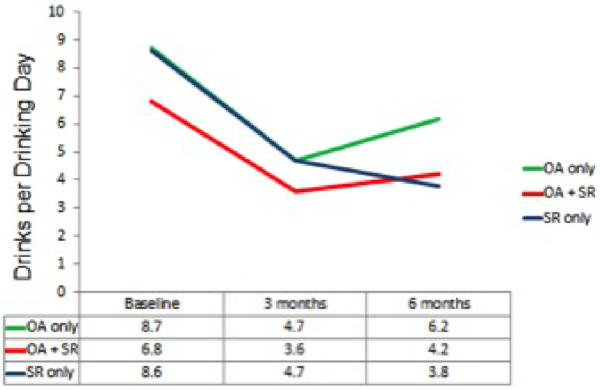
Similarly, for DDD, although the omnibus test of the group x time interaction was nonsignificant, $F_{4,210}$=1.76, P=.14 (Figure 2). The test of the same interaction contrast suggested a trend for the continued improvement in the SR only group to be different from the decline in the OA groups between 3 and 6 months, $F_{1,40}$=3.18, P=.08.

Figure 2. Actual use analysis: percent days abstinent. OA: Overcoming Addictions; SR: SMART Recovery.



	Baseline	3 months	6 months
OA only	36.46	59.24	54
OA + SR	46.63	82.47	77.2
SR only	41.72	71.5	74.48

Figure 3. Actual use analysis: drinks per drinking day. OA: Overcoming Addictions; SR: SMART Recovery.



SMART Recovery Meetings or Other Support

Participation by those in the SR only condition in SR meetings, both face-to-face and online, declined sharply between the first 3 months and second 3 months of the follow-up period. Participants in the SR only condition reported attending 3.17 face-to-face meetings in the 3 months after baseline but only 1.86 in the next 3 months, t_{58}=3.35, P<.001; similarly, online meetings attended declined from 5.85 to 3.02, t_{58}=4.00, P<.001. Because 78% and 66% did not attend, respectively, any face-to-face or online meetings between the 3- and 6-month follow-ups, the frequency of meetings attended in the first 3 months was used to assess evidence for dose-response relationships. Although as we previously reported [23], number of face-to-face meetings attended in the 90 days after baseline had been significantly positively related to improvement from baseline to 3 months on all 3 of our outcome variables, it was found now to be negatively related to improvement from 3 to 6 months on PDA (r=−.082), DDD (r=−.246), and InDUC (r=−.050). The number of days of counselor visits, other meetings, or any support also was negatively nonsignificantly related to improvement from 3 to 6 months. Number of online meetings, in contrast, was at least positively, though nonsignificantly, related to improvement from 3 to 6 months on our dependent measures (0.050, PDA; 0.112, DDD; 0.083, InDUC).

Number of Overcoming Addictions Sessions

In the OA conditions, participation in OA, as measured by number of logins to the website, declined from 7.31 on average in the first 3 months to 1.29 in the next 3 months, t_{72}=10.19, P<.001. Attendance in the SR meetings by OA participants also declined, though the change in participation was not significantly different from that seen in the SR only condition. Interestingly, whereas number of OA logins had been only weakly and nonsignificantly related to improvement from baseline to 3 months on our dependent variables, the use of the OA site during the first 3 months was more strongly predictive of improvement from 3 to 6 months. Specifically, OA logins in the first 90 days after baseline correlated .359 (P=.005) with improvement in PDA from 3 to 6 months and .352 (P=.006) with improvement in InDUC. We also examined the number of OA modules actually completed by participants(mean 6.39, SD 4.28). The OA modules completed also was predictive of improvement from 3 to 6 months on PDA (r=.297, P=.02) and InDUC (r=.332, P=.007). In addition, the number of modules completed was associated with final levels on all three dependent variables: PDA, r=.263, P=.04; DDD, r=−.292, P=.018; and InDUC, r=−.362, P=.003.

Corroboration of Self-Reported Drinking by Significant Others

Data were available at all 3 time points from 97 significant others (SOs) on 2 of our primary dependent variables, PDA and DDD. Examining the effects of time and treatment on these SO reports generally corroborated the clients' self-reports in that the tests of change over time were highly significant, for PDA, $F_{2,94}$=63.49, P<.001, and for DDD, $F_{2,94}$=65.59, P<.001, and the test of the treatment x time interaction were nonsignificant, P>.2. Although the SOs' reports were similar to those of the clients in perceiving by far the greatest change was from baseline to the average of the follow-ups, F>100, P<.001, the reports differed in that the SOs thought there was continued improvement from 3 months to 6 months in both groups whereas the clients reported improvement only in the SR only condition. For example, SOs reported clients continued to improve significantly from 3 months to 6 months in PDA, $F_{1,95}$=6.84, P=.01, and reported PDA increased from 76.4 to 84.6, whereas these corresponding participants reported their PDA declining nonsignificantly from 70.3 to 70.1. The correlations between SO and client reports which ranged from .57 to .69 at baseline and 3 months declined at 6 months to .46 for PDA and to .31 for DDD.

Individual Differences Among Participants: Readiness to Change

In addition to examining treatment effects, we conducted additional analyses of participants' behavioral changes already under way at the time of entry into these programs. A majority (127/188, 67.6%) of the participants enrolling in the study had gone more than one day without drinking immediately before enrolling in the study. The number of days since the last drink in this subgroup ranged from 2 to 84 days before enrolling, with a mean of 15.6 and a median of 10.0. The number of drinks on that last day of drinking before enrollment was much *greater* for those who had been abstinent for more than a day (mean 9.6, SD 6.2) than for those who had been drinking on the day before enrollment (mean 6.0, SD 4.0), $t_{171.5}$=4.76, P<.001.

Similarly, those who had been abstinent for more than a day reported a higher level of mean drinks per drinking day over the previous 3 months, 8.65 versus 6.74, t_{186}=2.87, P=.005. However, those who had taken a break from drinking alcohol reported a much higher PDA for the 90 days before intake than the nonabstinent group, 53.1% versus 25.7%, t_{186}=6.75, P<.001. The 2 groups did not differ in terms of recent alcohol-related problems on InDUC, 41.9 versus 40.1, t<1.

The importance of differences among participants was assessed in intent-to-treat repeated-measures analyses of variance with 2 between-subjects factors of treatment condition (OA+SR vs SR only) and whether the participant had had his or her last drink more than 1 day before enrollment (break or no break), and the one within-subject factor of time, using number of drinks on the last day of drinking, centered at its grand mean as a covariate. Means are plotted for the 3 outcome variables in Figures 4,5, and 6. For PDA, the break factor did not interact with treatment or time; however, the main effect of this between-subject factor of break was very highly significant, $F_{1,126}$=50.7, P<.001. There was a trend for the advantage of the break group over those still drinking to increase from 25.7 PDA at baseline to 34.1 PDA at the average of the postassessments, but this difference did not reach significance, $F_{1,126}$=2.77, P=.099

With DDD, in addition to the strong between-subject main effect of break, $F_{1,127}$=8.79, P=.004, 2 other effects were significant. The interaction of break with time was clearly significant for DDD, $F_{2,126}$=4.57, P=.01, as was the interaction of time with the covariate of number of drinks on last day of drinking, $F_{2,126}$=20.21, P<.001. As suggested by Figure 6, the reason for the break x time interaction was that although there was little difference at baseline in DDD across groups, the group that had been abstinent for more than one day before enrollment decreased their mean drinking levels much more than those who were drinking on the day before enrollment. For those who taken a break for more than a day, DDD declined from 8.41 at baseline to 4.02 averaging across the 2 postassessments, whereas for the other group the decline was only from 6.87 to 5.63, $F_{1,127}$=9.08, P=.003 (Figure 6).

The reason for the significant time x number of drinks on last day of drinking was that participants who were drinking more just before enrollment decreased their DDD significantly more from baseline to the average of the postassessments, r=.485, P<.001. However, those who were drinking *less* on their last day of drinking improved more from 3 months to 6 months, as the number of drinks on last day of drinking correlated significantly negatively with the improvement (ie, decrease) in DDD from 3 months to 6 months, r=−.274, P=.002.

The pattern on InDUC Recent Total was essentially the same as that for DDD. That is, not only was the between-subject main effect of break highly significant, $F_{1,127}$=14.81, P<.001, but the interaction of break with time was again significant for InDUC, $F_{2,126}$=6.19, P=.003, as was the interaction of time with the covariate of number of drinks on last day of drinking, $F_{2,126}$ (2,126)=4.06, P=.02. Again, as shown in the figure below, those who had taken a break improved more from baseline to the postassessments on InDUC, with the break group declining from 40.7 to 15.2, and those drinking the day before enrollment only declining from 39.2 to 28.2. As before, the reason for the time x covariate interaction was that number of drinks on the last day of drinking correlated significantly positively with improvement from baseline to the average of the postassessments, r=.215, P=.01, but significantly negatively with improvement from 3 months to 6 months, r=−.212, P=.02 (Figure 7).

As might be concluded from the plots above, mean within-group effect sizes differed greatly across these 2 subgroups of participants (see Table 3). Whereas the mean d across the dependent variables was 0.51 (a medium effect size) for participants who had been drinking on the day before enrollment, for those who had not been drinking just before enrollment the mean d was more than twice as large (1.24, or more than 50% greater than Cohen's cutoff for a large effect).

Table 3. Means (and standard deviations) and within-group effect sizes for each outcome variable for subgroups of participants that had or had not stopped drinking for more than one day before enrollment.

Variable and group	Baseline, mean (SD)	3-month follow-up, mean (SD)	6-month follow-up, mean (SD)	Improvement from baseline to average follow-up, mean	Within group effect size d[a]
Percent days abstinent					
Break (n=87)	51.28 (26.57)	84.65 (21.84)	80.15 (25.39)	31.12	1.26
No break (n=44)	25.53 (25.90)	47.63 (33.09)	48.99 (35.90)	22.78	0.71
Standard drinks per drinking day[b]					
Break (n=87)	8.41 (4.81)	3.80 (4.21)	4.25 (5.32)	4.39	0.91
No break (n=45)	6.87 (3.73)	5.99 (3.84)	5.26 (4.47)	1.25	0.31
Inventory of Drug Use Consequences recent score[c]					
Break (n=87)	40.71 (18.73)	14.37 (14.37)	16.07 (18.06)	25.49	1.49
No break (n=45)	39.24 (18.02)	29.60 (21.45)	26.84 (25.27)	11.02	0.51

[a] Cohen *d* for change from baseline to average of 3-month and 6-month follow-ups .

[b] Standard drink is equal to 12 oz (355 mL) of 5% beer, 5 oz (149 mL) of 12% wine, or 1.5 oz (44 mL) of 80 proof liquor.

[c] Alcohol-related problems.

Figure 4. Actual use analysis: alcohol-related problems. OA: Overcoming Addictions; SR: SMART Recovery.

Figure 5. Stage of change analysis: percent days abstinent.

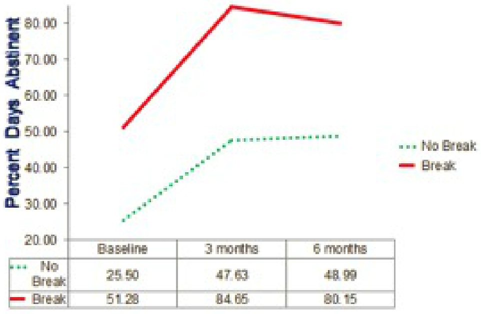


Figure 6. Stage of change analysis: drinks per drinking day.

Figure 7. Stage of change analysis: alcohol-related problems.

Participant and Intervention-Related Variables

In addition to analyzing outcomes according to treatment group and readiness to change, we conducted additional analyses on participants with access to OA in order to explore for the possible influence of factors germane to Web-based interventions. For each variable, separate repeated-measure analyses of variance were conducted on the 3 primary dependent variables (ie, InDuC, PDA, and DDD).

We asked participants to estimate how much time per week they spent on the Internet—at work or school, at home, and elsewhere (café, library, etc). We totaled these estimated hours to create a continuous variable characterizing the participant's relative fluency with the Internet. The continuous moderating variable of average amount of time on the Internet per week was zero-centered. Participants with access to OA reported spending an average of 23.0 (SD 16.8) hours per week on the Internet. Analysis indicated that the impact of participant's fluency with the Internet did not significantly impact treatment outcomes: PDA, $F_{2,63}$=1.004, *P*=.37; DDD, $F_{2,63}$=0.983, *P*=.38; or the InDuC, $F_{2,63}$=0.029, *P*=.97.

To test for the impact of the user's sense of how easy the site was to navigate and use, we examined their responses to the pertinent questions in the exit interview for shared variance and created a new variable —"ease factor"— (that was also z-centered) to test for the impact of this factor. Analysis indicated that participant's subjective rating of how easy it was to navigate the OA site did not significantly impact treatment outcomes: PDA, $F_{2,44}$=0.55, *P*=.58; DDD, $F_{2,44}$=1.21, *P*=.31; or the InDuC, $F_{2,63}$=1.029, *P*=.34. To see whether user's satisfaction with the amount of content on the site had an effect on outcomes, we collapsed the 3 possible responses on the exit interview (ie, too much, too little, just right) into a single, dichotomous variable indicating either a satisfactory or unsatisfactory amount of information. Analysis indicated that participant's satisfaction with the amount of information on the OA site did not significantly impact treatment outcomes: PDA, $F_{2,44}$=0.699, *P*=.50; DDD, $F_{2,44}$=1.06, *P*=.34; or the InDuC, $F_{2,63}$=0.010, *P*=.99.

Finally, we asked all participants in the study to report which treatments, influences, and/or other factors they had used or encountered throughout the duration of the clinical trial with respect to changing their drinking behavior (Tables 4 and 5). Participants were allowed to make as many attributions as they wanted to. Results showed that a majority of the study participants interviewed indicated that both SR and OA were influential in helping them to make changes to their drinking. It is also clear that study participants made use of a variety of therapeutic resources in addition to OA and SR.

Table 4. Participants' attribution to factors that helped them make changes to their drinking.

Treatment or influence	OA[a] SR[b]	Most helpful	Very helpful	Some help	No help	Total positive
SMART face-to-face	OA	7	12	3	43	22
	SR	8	5	2	41	15
SMART online	OA	2	16	8	41	26
	SR	13	17	3	42	33
Overcoming Addictions	OA	14	19	15	20	48
Alcoholics Anonymous	OA	3	5	1	6	9
	SR	1	7	0	1	8
Other treatment program	OA	3	2	2	0	7
	SR	2	3	0	1	5
Personal therapist	OA	4	7	2	1	13
	SR	6	7	3	0	16
Self-determination	OA	20	4	1	0	25
	SR	11	8	0	1	19
Some other factor	OA	12	12	8	1	32
	SR	12	8	3	1	23

[a] OA: Overcoming Addictions.

[b] SR: SMART Recovery.

Table 5. Other factors cited as helpful.

Treatment or influence	OA[a] SR[b]	Number citing
Social support	OA	11
	SR	7
Changed thinking or awareness	OA	9
	SR	5
Joining the randomized controlled trial	OA	7
	SR	3
Medication	OA	3
	SR	5
Just did it	OA	2
	SR	3

[a] OA: Overcoming Addictions.

[b] SR: SMART Recovery.

Discussion

Principle Findings

We compared 2 treatment modalities based on the cognitive behavioral intervention in SR. One modality (SR) is social in nature (ie, entailing meetings either in person or online), while the other (OA) is self-directed. We hypothesized that the structured and personalized design of OA would lead to superior outcomes to SR and that it would enhance outcomes even further when coupled with SR. This was not the case. The experimental hypotheses were: (1) Both groups will reduce their drinking and alcohol or drug-related consequences at follow-up compared with their baseline levels; and (2) The OA+SR condition will reduce their drinking and alcohol or drug-related consequences more than SR only. These results support our first experimental hypothesis but not the second.

On average, all participants improved on outcomes that are important to recovery from problem drinking. They significantly increased the percentage of days they were abstinent over the 6-month follow-up period, significantly reduced the number of drinks they consumed on the days when they did drink, and experienced a marked reduction in alcohol-related problems. The mean effect sizes for reductions in drinking and alcohol-related problems, averaging across the 3 dependent variables, were in the large range (0.8+). These statistically significant results are also clinically significant. We consider it remarkable that participants with this degree of heavy drinking, and reporting a significant level of clinical distress, made and largely maintained these changes over the follow-up period of 6 months. Our decision not to include a no-treatment control in this trial precludes us from making direct causal attributions about the effectiveness of OA. Nonetheless, the results of this trial provide support for the use of both OA and SR, and more generally, the hypothesis that Web-based interventions based on evidence-based treatments can be helpful even for heavy drinkers.

It is clear that participants used the intervention modalities and components available to them according to their own inclinations. Some participants preferred using the Web application alone, some preferred to attend meetings, and many chose to utilize both. Unlike patients provided with “traditional” guided and structured psychotherapy, participants used intervention components as much as they felt they needed to, when they needed to, and reported acquiring the skills and techniques of the SMART model in both the social and self-directed modalities. The heterogeneity in how participants used and benefitted from the intervention presents a stark contrast to the rigidity of structure typically prescribed in evidence-based therapies. Moreover, perhaps the more striking discovery we made during our exit interviews was that participants’ engagement with their recovery was reflected not just in their use of SR or OA alone, but also in the plethora of other means they utilized to support changes in their drinking, concomitant with their use of SR and OA. We feel there are important implications in this finding that bear on the development, implementation, and testing of Web-based interventions.

Similarly, the fact that individuals enrolling in the study were often unwilling to accept assignment to the OA only condition also indicates that they already had a sense of what they wanted to facilitate their recovery. The participants in the study were obviously attracted to SR because of its theoretical approach and the tools it offers, but many of them also wanted a social milieu of some sort through which they could acquire or process these intervention components, regardless of the benefits available through a Web-based intervention. Further, participants who used SR, either alone or in conjunction with OA, exhibited a trend toward slightly better outcomes at the 6-month follow-up than those who used OA exclusively, although this finding was not statistically significant. Given this, our results are consonant with other studies finding that, for some people at least, stand-alone Web-based interventions are more effective when combined with some form of social support or learning. Apart from their advantages, there may be limits to both the appeal and the effectiveness of self-guided Web-based interventions for problematic alcohol use—even those based on EBTs.

While it is good to know that participants in the trial were able to use and benefit from the interventions made available to them in the study, the exit interview results suggest that the conditions required to establish an evidence base for free-standing computer-delivered interventions are inherently equivocal. The remote context of their use and testing make it very difficult, if not impossible, to design an ecologically valid study that could control for sort of treatment foraging exhibited by the participants in this study—even if a no-treatment control group were included in the design. While others have made this observation before [10], in this study, we found strong qualitative data to support this conjecture. It may be the case that not only do people engage in Web-based treatments differently than they do in conventional treatments, but they might also be simultaneously seeking and using other therapeutic resources differently as well. While this state of affairs does present methodological challenges for researchers and intervention developers, it does not obviate the benefits of these treatments. The results of this study support the theory that having different ways to learn about and use the evidence-based tools in the SMART Recovery protocol gives problem drinkers clinically sound options with regard to how they learn to achieve and maintain abstinence. Although researchers typically do not design interventions with evidence-based components to be self-directed, our findings support a therapeutic picture in which having online resources available increase the chances that individuals can find a path to recovery that suits them.

Regardless of which intervention was utilized by study participants, evidence for the added benefit of increased engagement with either OA or SR was limited—as it often is when testing Web-based interventions. The results here contradict the conventional perspective that more treatments, and more structured treatments, facilitate better outcomes. The one notable exception we found to this trend was the “sleeper effect” we detected in the second half of the trial among individuals who made greater use of OA in the first 3 months. While we consider this a positive finding for OA, we can only speculate as to why this was the case. It may be that the cognitive-behavioral tools offered in OA require time and practice to produce gradual but lasting change. It may also be the case that participants in the OA group exhibited assessment reactivity to the 3-month follow-up. The 3-month interview was the first time when participants in the trial were asked to quantify and characterize their drinking, and for individuals who were provided access to OA this may have been the first time they addressed their problem drinking in a social context. The session could have motivated them to renew their attempts to change their drinking behavior. If so, this would corroborate the basis for ongoing questions about the relationship of both social interactions, as well as assessment and feedback protocols, to the effectiveness of Web-based interventions for problematic alcohol use [2,3,14].

Influence of Participant and Intervention Factors on Outcomes

Our findings indicate that the individuals who had taken steps to stop drinking before joining the study were primarily responsible for the changes over time that we found in both the OA+SR and SR only conditions. SR and OA provided resources for individuals in the action and maintenance stages of change, and those resources both encouraged the nascent steps and supported their durability. A basic tenet of Prochaska and DiClemete's model is that individuals in the action and maintenance stages of change are motivated to use clinical tools (eg, functional analysis, problem-solving exercises) that have been shown to be effective in helping people to confront the challenges they face. Both SR and OA make these resources available and participants in the study who were in the action stage of change made use of them. Based on the evidence, it is also fair to assert that individuals who came into the study without yet having quit drinking were not helped as much with their desire to do so by either OA or SR. The fact that Web-based interventions are associated with positive outcomes among drinkers who are actively seeking resources to support their behavior change, but less so for individuals who are not yet at that stage, should inform their deployment in stepped-care programs, and thus better substantiate their implementation as part of an overall public health strategy.

We found no evidence for the impact of other participant or intervention-related variables thought to influence the effectiveness of Web-based interventions. None of the identified factors related to Web-based interventions (fluency with the Internet, participants' subjective ratings of how easy the site was to navigate, nor satisfaction with the amount of content on the site) exhibited any influence on treatment outcomes. We believe that there are 2 reasons that may account for this negative finding. The first derives from the relatively high level of education reported by participants in this study. Researchers have found that more highly educated individuals are slightly more likely to benefit from Web-based interventions [1,28], in part because more educated individuals tend to solve problem more persistently and effectively when confronted with navigational challenges on websites [40]. Additionally, findings of the Pew Research Center's Internet and American Life Project show that older adults have accessed the Internet at increasing rates over the last 15 years [58]. It is likely the case that as time has passed, the skills required to navigate the Internet have become ever more commonplace, and the structure of websites, whether confused or intuitive, guided or self-directed, have become less and less of a mitigating factor to individuals who seek to access their content.

Finally, one other aspect of this study that we feel deserves mention, and which is consistent with our prior studies of Web-based interventions [24], is the high participation rate (61%) of women. This result is consonant with the ability of Web-based interventions to reach historically underserved populations. Women have greater perceived barriers to treatment than men do. Brady and Ashley [55] reported that women are more likely to report economic barriers and family responsibilities when seeking treatment. Many women realizing the need for treatment are more likely turn to Web applications for help before they seek individual treatment due to gender differences in stigmatization for treatment of alcohol use disorders with shame, embarrassment, and discouragement from family members being more commonly reported by women than by men [59,60]. In addition, women experience the salience of multiple roles (eg, career, mother, spouse, friend) and find they must prioritize their time in the most efficient way possible. OA and online SR meetings are typical of interventions that can provide alternative interventions for alcohol problems that do not impact other roles in the same way as seeking individual treatment.

Analysis of Internet usage and average time spent on the Internet supports our conclusions for the differences in demographics. Slightly more women in North America use the Internet than men and for greater amounts of time [61]. Although Internet usage differs according to the category of activity or personal interest for women and men, health sites are visited more frequently by women (22.8% and 17.4%, respectively). In addition, women across a wide age range (eg, age 15-55+ years) are more apt to turn to community resources available on the Internet at greater rates than men. Even though OA and SR are not tailored to differentially attract women or men, the prevalence of women in our study is consistent with the literature on women turning to the Internet for health and community resources.

Limitations

There are a number of limitations to this study. First, as noted, we did not include a no-intervention control group in our study design. While we found it neither ethically appropriate nor practically feasible to include such a group, the lack of a comparison prevents us from being able to control for individuals whose prior decision to stop drinking was largely responsible for the improvement observed in this study. In addition, we could not separate out the effects of assessment reactivity that, based on participants' anecdotal reports, did sometimes occur as a function of the follow-up evaluation. Third, the relatively small sample size as well as the high level of education (mean 16 years) reported by participants in the study potentially limit the generalizability of the outcomes in populations with lower levels of education. Fourth, the requirement for an SO to corroborate the participant's self-report of drinking may have further limited the generalizability of this sample's results. We considered that requirement necessary though, as we had no other way to confirm participants' self-reports of their drinking. Another limitation is that we were not able to randomize a full complement of participants into the OA only group, which meant that this group was essentially self-selected and that the small sample size of the OA group limited the power of the analyses.

When analyzing variables thought to moderate outcomes (eg, participant characteristics), the ideal method would be to assess them directly before beginning the processes they are thought to influence. Our posthoc assessment, while acceptable given the lack of feasible alternatives, was likely mediated by the participants' recollection of the site. One can't help but wonder whether a follow-up coming closer on the heels of the participant's disengagement from the site might not have yielded more vivid recollections of what it was like for individuals to use it. Further, given the exploratory nature of this study, it was unclear whether the constructs we intended to tap were in fact done so with as great a precision as might be hoped. There may be less intrusive, more ecologically valid methods to probe how participants engaged the site, and how this engagement mediated outcomes on the variables of interest. Indeed, this question lies at the vanishing point where the development of, and research into, the next generation of these interventions converge.

Future Research

The results of this study did influence the subsequent development of OA. Even though navigation was not found to impact outcomes, anecdotal feedback from participants as well as their lower than expected uptake of the intervention motivated us to revise the site. We developed an automated program that sends users an email each week, prompting them to log into the site. The email briefly describes the week's "lesson," and an embedded link takes the users directly to that page in the site, after first allowing them to enter their urge data for the week. We also added linked summary statements in the headers of each module and provided more "tunneling" within the site in response to the feedback of participants who desired more guidance through the site. Finally, we have created new interventions that combine OA with *The Drinker's Check-up* [62,63] hypothesizing that the hybrid design will increase users' motivation for engaging the self-directed exercises in the OA program.

Having said that, our null results with regard to the possible moderating and mediating effects of interface with a Web-based intervention suggest that although low Internet fluency may have at one time presented a significant barrier to accessing these treatments, it may be less of an issue as the revolution in media technology proceeds, at least among more highly educated individuals. Similarly, while it is important that research into website and participant factors continues, and that researchers continue to develop innovative methodologies to test each new generation of interventions [64], we believe that improving their effectiveness will also benefit from an investigation into the novel ways that individuals approach Web-based interventions differently than they do "traditional" treatments. Broader exploration of all the recovery behaviors of individuals who use Web-based treatments for problem drinking may inform current assumptions about both the development and implementation of these interventions, and thus help to solve the riddle that currently links user engagement with clinical outcomes.

Summary

Web-based interventions for heavy drinkers are not as unfamiliar as they once were, but a decade of intensive research and development has left many unanswered questions about their effectiveness. The adaptation of evidence-based techniques and treatments to this relatively new mode of delivery is complicated by the pace and dispersion of technological innovation, human-user adaptation to those innovations, and a lack of evidence to clearly guide the appropriate deployment of Web-based behavioral resources.

This study found evidence of a positive treatment effect for the OA site. The evidence did not detect an added benefit of OA over the preexisting SR intervention upon which it is based, in that it neither surpassed nor enhanced its effectiveness. There was evidence to show that OA can serve as a feasible alternative to SR, and as a Web-based intervention, it entails the advantages of access, reach, and cost-effectiveness. Further, our results suggest that Web-based interventions work particularly well for individuals who are actively making changes to their drinking behavior.

Acknowledgments

This research was supported by a SBIR grant 1R44AA016237 from the National Institute on Alcohol Abuse and Alcoholism (NIAAA). The content is solely the responsibility of the authors and does not necessarily represent the official views of NIAAA or the National Institutes of Health (NIH). We acknowledge the support of SMART Recovery and their efforts in support of the recruitment in our clinical trial and extend our thanks to those who participated in our clinical trial.

Conflicts of Interest

The second author holds the copyright to the Overcoming Addictions Web application. It went "live" to the general public in September, 2013 on a subscription basis with a portion of the proceeds going to SMART Recovery. He is also a member of SMART Recovery's International Board of Advisors, a volunteer position.

References

1. Riper H, Blankers M, Hadiwijaya H, Cunningham J, Clarke J, Wiers R, et al. Effectiveness of guided and unguided low-intensity internet interventions for adult alcohol misuse: A meta-analysis. PLoS ONE 2014;9(6):e99912. [Medline: 24937483]
2. Murray E. Web-based interventions for behavior change and self-management: potential, pitfalls, and progress. Med 2 0 2012;1(2):e3 [FREE Full text] [doi: 10.2196/med20.1741] [Medline: 25075231]
3. Webb T, Joseph J, Yardley L, Michie S. Using the Internet to promote behavior change: A systematic review and meta-analyses of the impact of theoretical basis, use of behavior change techniques and mode of delivery on efficacy. J Med Internet Res 2010;12(1):e4. [Medline: 20164043]
4. Rooke S, Thorsteinsson E, Karpin A, Copeland J, Allsop D. Computer-delivered interventions for alcohol and tobacco use: a meta-analysis. Addiction 2010 Aug;105(8):1381-1390. [doi: 10.1111/j.1360-0443.2010.02975.x] [Medline: 20528806]

5. Portnoy DB, Scott-Sheldon LA, Johnson BT, Carey MP. Computer-delivered interventions for health promotion and behavioral risk reduction: a meta-analysis of 75 randomized controlled trials, 1988-2007. Prev Med 2008 Jul;47(1):3-16 [FREE Full text] [doi: 10.1016/j.ypmed.2008.02.014] [Medline: 18403003]
6. Vernon ML. A review of computer-based alcohol problem services designed for the general public. J Subst Abuse Treat 2010 Apr;38(3):203-211 [FREE Full text] [doi: 10.1016/j.jsat.2009.11.001] [Medline: 20015607]
7. Bewick BM, Trusler K, Barkham M, Hill AJ, Cahill J, Mulhern B. The effectiveness of web-based interventions designed to decrease alcohol consumption--a systematic review. Prev Med 2008 Jul;47(1):17-26. [doi: 10.1016/j.ypmed.2008.01.005] [Medline: 18302970]
8. Copeland J, Martin G. Web-based interventions for substance use disorders: a qualitative review. J Subst Abuse Treat 2004 Mar;26(2):109-116. [doi: 10.1016/S0740-5472(03)00165-X] [Medline: 15050088]
9. Kreuter MW, Wray RJ. Tailored and targeted health communication: strategies for enhancing information relevance. Am J Health Behav 2003;27 Suppl 3:S227-S232. [Medline: 14672383]
10. Cunningham JA, Van Mierlo T. Methodological issues in the evaluation of Internet-based interventions for problem drinking. Drug Alcohol Rev 2009 Jan;28(1):12-17. [doi: 10.1111/j.1465-3362.2008.00001.x] [Medline: 19320670]
11. Riper M, Eapen B, Koo M. Methodological Challenges in Online Trials. J Med Internet Res 2009;11(2):e9. [Medline: 19403465]
12. Eysenbach G. The Law of Attrition. J Med Internet Res 2005;7(1):e11. [Medline: 15829473]
13. Danaher BG, Seeley JR. Methodological issues in research on web-based behavioral interventions. Ann Behav Med 2009 Aug;38(1):28-39 [FREE Full text] [doi: 10.1007/s12160-009-9129-0] [Medline: 19806416]
14. Mohr D, Burns N, Schueller S, Clarke G, Klinkman M. Behavioral intervention technologies: evidence review and recommendations for future research in mental health. Gen Hosp Psychiatry 2013;35(4):332-338 [FREE Full text] [doi: 10.1016/j.genhosppsych.2013.03.008] [Medline: 23664503]
15. Murray E, White IR, Varagunam M, Godfrey C, Khadjesari Z, McCambridge J. Attrition revisited: adherence and retention in a web-based alcohol trial. J Med Internet Res 2013;15(8):e162 [FREE Full text] [doi: 10.2196/jmir.2336] [Medline: 23996958]
16. Khadjesari Z, Murray E, Hewitt C, Hartley S, Godfrey C. Can stand-alone computer-based interventions reduce alcohol consumption? A systematic review. Addiction 2011 Feb;106(2):267-282. [doi: 10.1111/j.1360-0443.2010.03214.x] [Medline: 21083832]
17. Riper H, Spek V, Boon B, Conijn B, Kramer J, Martin-Abello K, et al. Effectiveness of E-self-help interventions for curbing adult problem drinking: a meta-analysis. J Med Internet Res 2011 Jun;13(2):e42 [FREE Full text] [doi: 10.2196/jmir.1691] [Medline: 21719411]
18. White A, Kavanagh D, Stallman H, Klein B, Kay-Lambkin F, Proudfoot J, et al. Online alcohol interventions: a systematic review. J Med Internet Res 2010 Dec;12(5):e62 [FREE Full text] [doi: 10.2196/jmir.1479] [Medline: 21169175]
19. Carey KB, Scott-Sheldon LA, Elliott JC, Bolles JR, Carey MP. Computer-delivered interventions to reduce college student drinking: a meta-analysis. Addiction 2009 Nov;104(11):1807-1819 [FREE Full text] [doi: 10.1111/j.1360-0443.2009.02691.x] [Medline: 19744139]
20. Cugelman B, Thelwall M, Dawes P. Online interventions for social marketing health behavior change campaigns: a meta-analysis of psychological architectures and adherence factors. J Med Internet Res 2011;13(1):e17 [FREE Full text] [doi: 10.2196/jmir.1367] [Medline: 21320854]
21. Richardson A, Graham AL, Cobb N, Xiao H, Mushro A, Abrams D, et al. Engagement promotes abstinence in a web-based cessation intervention: cohort study. J Med Internet Res 2013;15(1):e14 [FREE Full text] [doi: 10.2196/jmir.2277] [Medline: 23353649]
22. Carroll KM, Ball SA, Martino S, Nich C, Babuscio TA, Nuro KF, et al. Computer-assisted delivery of cognitive-behavioral therapy for addiction: a randomized trial of CBT4CBT. Am J Psychiatry 2008 Jul;165(7):881-888 [FREE Full text] [doi: 10.1176/appi.ajp.2008.07111835] [Medline: 18450927]
23. Hester RK, Lenberg KL, Campbell W, Delaney HD. Overcoming Addictions, a Web-based application, and SMART Recovery, an online and in-person mutual help group for problem drinkers, part 1: three-month outcomes of a randomized controlled trial. J Med Internet Res 2013 Jul;15(7):e134 [FREE Full text] [doi: 10.2196/jmir.2565] [Medline: 23846588]
24. Hester RK, Delaney HD, Campbell W. ModerateDrinking.Com and moderation management: outcomes of a randomized clinical trial with non-dependent problem drinkers. J Consult Clin Psychol 2011 Apr;79(2):215-224 [FREE Full text] [doi: 10.1037/a0022487] [Medline: 21319896]
25. Donkin L, Christensen H, Naismith SL, Neal B, Hickie IB, Glozier N. A systematic review of the impact of adherence on the effectiveness of e-therapies. J Med Internet Res 2011 Aug;13(3):e52 [FREE Full text] [doi: 10.2196/jmir.1772] [Medline: 21821503]
26. Kelders SM, Kok RN, Ossebaard HC, Van Gemert-Pijnen JE. Persuasive system design does matter: a systematic review of adherence to web-based interventions. J Med Internet Res 2012;14(6):e152 [FREE Full text] [doi: 10.2196/jmir.2104] [Medline: 23151820]

27. Proudfoot J, Klein B, Barak A, Carlbring P, Cuijpers P, Lange A, et al. Establishing guidelines for executing and reporting Internet intervention research. Cogn Behav Ther 2011;40(2):82-97. [doi: 10.1080/16506073.2011.573807] [Medline: 25155812]
28. Postel MG, de Haan HA, ter Huurne ED, Becker ES, de Jong CA. Effectiveness of a web-based intervention for problem drinkers and reasons for dropout: randomized controlled trial. J Med Internet Res 2010 Dec;12(4):e68 [FREE Full text] [doi: 10.2196/jmir.1642] [Medline: 21163776]
29. Horvath T, Arthur T. Smartrecovery. 2013. SMART Recovery: Self-Management and Recovery Training URL: http://www.smartrecovery.org [accessed 2013-01-28] [WebCite Cache ID 6E14ouBoF]
30. Horvath T, Arthur T. smartrecovery. 2013. SMART Recovery: News and Views URL: http://www.smartrecovery.org/resources/library/Newsletters/Newsletters/fall2010news&views.pdf [accessed 2013-03-12] [WebCite Cache ID 6F4DTv9Fz]
31. Postel MG, de Haan HA, ter Huurne ED, van der Palen J, Becker ES, de Jong CA. Attrition in web-based treatment for problem drinkers. J Med Internet Res 2011;13(4):e117 [FREE Full text] [doi: 10.2196/jmir.1811] [Medline: 22201703]
32. Schneider F, van Osch L, de Vries H. Identifying factors for optimal development of health-related websites: a delphi study among experts and potential future users. J Med Internet Res 2012;14(1):e18 [FREE Full text] [doi: 10.2196/jmir.1863] [Medline: 22357411]
33. Riper H, Kramer J, Keuken M, Smit F, Schippers G, Cuijpers P. Predicting successful treatment outcome of web-based self-help for problem drinkers: secondary analysis from a randomized controlled trial. J Med Internet Res 2008;10(4):e46 [FREE Full text] [doi: 10.2196/jmir.1102] [Medline: 19033150]
34. Prochaska J, DiClemente C, Norcross J. Changing for Good. New York, NY: Avon; 1994.
35. Miller W. Motivational Enhancement Therapy Manual: A Clinical Research Guide for Therapists Treating Individuals With Alcohol Abuse and Dependence. Washington, DC: Diane Pub Co; 1994.
36. Connors G, Donovan D, DiClemente C, Velasquez M. Substance abuse treatment and the stages of change: selecting and planning interventions. New York, NY: Guilford Press; 2001.
37. Hager R, Hardy A, Aldana S, George J. Evaluation of an Internet, Stage-Based Physical Activity Intervention. American Journal of Health Education 2002 Dec;33(6):329-337. [doi: 10.1080/19325037.2002.10604755]
38. van der Vaart R, Drossaert CH, de Heus M, Taal E, van de Laar MA. Measuring actual eHealth literacy among patients with rheumatic diseases: a qualitative analysis of problems encountered using Health 1.0 and Health 2.0 applications. J Med Internet Res 2013 Feb;15(2):e27 [FREE Full text] [doi: 10.2196/jmir.2428] [Medline: 23399720]
39. Feufel MA, Stahl SF. What do web-use skill differences imply for online health information searches? J Med Internet Res 2012;14(3):e87 [FREE Full text] [doi: 10.2196/jmir.2051] [Medline: 22695686]
40. van Deursen AJ, van Dijk JA. Internet skills performance tests: are people ready for eHealth? J Med Internet Res 2011 Apr;13(2):e35 [FREE Full text] [doi: 10.2196/jmir.1581] [Medline: 21531690]
41. Nijland N, van Gemert-Pijnen GJ, Boer H, Steehouder MF, Seydel ER. Evaluation of internet-based technology for supporting self-care: problems encountered by patients and caregivers when using self-care applications. J Med Internet Res 2008;10(2):e13 [FREE Full text] [doi: 10.2196/jmir.957] [Medline: 18487137]
42. Crutzen R, Cyr D, de Vries NK. The role of user control in adherence to and knowledge gained from a website: randomized comparison between a tunneled version and a freedom-of-choice version. J Med Internet Res 2012 Mar;14(2):e45 [FREE Full text] [doi: 10.2196/jmir.1922] [Medline: 22532074]
43. Klein B, White A, Kavanagh D, Shandley K, Kay-Lambkin F, Proudfoot J, et al. Content and functionality of alcohol and other drug websites: results of an online survey. J Med Internet Res 2010;12(5):e51 [FREE Full text] [doi: 10.2196/jmir.1449] [Medline: 21169168]
44. McClure J, Shortreed S, Bogart A, Derry H, Riggs K, St John JJ, et al. The effect of program design on engagement with an internet-based smoking intervention: randomized factorial trial. J Med Internet Res 2013;15(3):e69 [FREE Full text] [doi: 10.2196/jmir.2508] [Medline: 23529377]
45. Clark R, Mayer RE. E-Learning and the Science of Instruction. In: e-Learning and the Science of Instruction: Proven Guidelines for Consumers and Designers of Multimedia Learning. San Francisco, CA: Pfeiffer; 2011.
46. Sanchez C, Wiley J. An examination of the seductive details effect in terms of working memory capacity. Memory & Cognition 2006;34(2):185-199. [Medline: 16752598]
47. Mayer R, Griffith E, Jurkowitz IT, Rothman D. Increased interestingness of extraneous details in a multimedia science presentation leads to decreased learning. J Exp Psychol Appl 2008 Dec;14(4):329-339. [doi: 10.1037/a0013835] [Medline: 19102616]
48. Lehman S, Schraw G, McCrudden M, Hartley K. Processing and recall of seductive details in scientific text. Contemporary Educational Psychology 2007 Oct;32(4):569-587. [doi: 10.1016/j.cedpsych.2006.07.002]
49. Yardley L, Morrison LG, Andreou P, Joseph J, Little P. Understanding reactions to an internet-delivered health-care intervention: accommodating user preferences for information provision. BMC Med Inform Decis Mak 2010;10:52 [FREE Full text] [doi: 10.1186/1472-6947-10-52] [Medline: 20849599]
50. Mayer RE, Jackson J. The case for coherence in scientific explanations: quantitative details can hurt qualitative understanding. J Exp Psychol Appl 2005 Mar;11(1):13-18. [doi: 10.1037/1076-898X.11.1.13] [Medline: 15796671]

51. Mayer R, DeLeeuw K, Ayres P. Creating retroactive and proactive interference in multimedia learning. Appl. Cognit. Psychol 2007 Sep;21(6):795-809. [doi: 10.1002/acp.1350]
52. Danaher BG, McKay HG, Seeley JR. The information architecture of behavior change websites. J Med Internet Res 2005;7(2):e12 [FREE Full text] [doi: 10.2196/jmir.7.2.e12] [Medline: 15914459]
53. Kincaid J, Braby R, Wulfeck WI. Computer aids for editing tests. Educational Technology 1983;23:29-33.
54. Miller WR, Tonigan JS, Longabaugh R. niaaa. 2006 Jul. The Drinker Inventory of Consequences (DrInC): An Instrument for Assessing Adverse Consequences of Alcohol Abuse URL: http://pubs.niaaa.nih.gov/publications/ProjectMatch/match04.pdf [accessed 2016-09-21] [WebCite Cache ID 6kgWowWHW]
55. Whitecrowvillage. Rockville, MD: Department of Health and Human Services; 2005. Women in Substance Abuse Treatment: Results From the Alcohol and Drug Services Study (ADSS) URL: https://www.whitecrowvillage.org/library/getDocument.php?id=111 [accessed 2016-09-21] [WebCite Cache ID 6kgXAIooH]
56. Piaggio G, Elbourne DR, Altman DG, Pocock SJ, Evans SJ. Reporting of noninferiority and equivalence randomized trials: an extension of the CONSORT statement. JAMA 2006 Mar 8;295(10):1152-1160. [doi: 10.1001/jama.295.10.1152] [Medline: 16522836]
57. Walker E, Nowacki AS. Understanding equivalence and noninferiority testing. J Gen Intern Med 2011 Feb;26(2):192-196 [FREE Full text] [doi: 10.1007/s11606-010-1513-8] [Medline: 20857339]
58. Perrin A, Duggan M. Pew Research Center. Americans' Internet Access: 2000-2015: as Internet use nears saturation for some groups, a look at patterns of adoption. Washington, DC: Pew Research Center; 2015 Jun 26. URL: http://www.pewinternet.org/2015/06/26/americans-internet-access-2000-2015/ [accessed 2016-09-30] [WebCite Cache ID 6gNRMiZsm]
59. Thom B. Sex differences in help-seeking for alcohol problems--2. Entry into treatment. Br J Addict 1987 Sep;82(9):989-997. [Medline: 3479184]
60. Beckman LJ, Amaro H. Personal and social difficulties faced by women and men entering alcoholism treatment. J Stud Alcohol 1986 Mar;47(2):135-145. [Medline: 3713175]
61. Digitalads. How women are shaping the Internet URL: http://www.digitalads.org/general%20marketing/comScore_onlinewomen_092010.pdf [accessed 2016-01-04] [WebCite Cache ID 6eGzJuuQk]
62. Hester RK, Squires DD, Delaney HD. The Drinker's Check-up: 12-month outcomes of a controlled clinical trial of a stand-alone software program for problem drinkers. J Subst Abuse Treat 2005 Mar;28(2):159-169. [doi: 10.1016/j.jsat.2004.12.002] [Medline: 15780546]
63. Hester R. Drinkerscheckup. 2013. Welcome to the Drinker's Checkup URL: http://www.drinkerscheckup.com [WebCite Cache ID 6E2g8SqJB]
64. Mohr DC, Schueller SM, Riley WT, Brown CH, Cuijpers P, Duan N, et al. Trials of Intervention Principles: Evaluation Methods for Evolving Behavioral Intervention Technologies. J Med Internet Res 2015;17(7):e166 [FREE Full text] [doi: 10.2196/jmir.4391] [Medline: 26155878]

Abbreviations

AUDIT: Alcohol Use Disorders Identification Test
BSI: Brief Symptom Inventory
DDD: mean standard drinks per drinking day
DWI: driver while intoxicated
InDUC: Inventory of Drug Use Consequences
OA: Overcoming Addictions
PDA: percent days abstinent (in previous 90 days)
SO: significant other
SR: SMART Recovery

Edited by G Eysenbach; submitted 07.01.16; peer-reviewed by M Postel, M Habibovic; comments to author 03.04.16; revised version received 13.07.16; accepted 03.08.16; published 04.10.16.

Please cite as:
Campbell W, Hester RK, Lenberg KL, Delaney HD
Overcoming Addictions, a Web-Based Application, and SMART Recovery, an Online and In-Person Mutual Help Group for Problem Drinkers, Part 2: Six-Month Outcomes of a Randomized Controlled Trial and Qualitative Feedback From Participants
J Med Internet Res 2016;18(10):e262
URL: http://www.jmir.org/2016/10/e262/
doi:10.2196/jmir.5508
PMID:27701064

Original Paper

Effects of the Web Behavior Change Program for Activity and Multimodal Pain Rehabilitation: Randomized Controlled Trial

Catharina A Nordin[1,2], PhD; Peter Michaelson[1], PhD; Gunvor Gard[1], PhD; Margareta K Eriksson[1,3], PhD

[1]Department of Health Science, Division of Health and Rehabilitation, Luleå University of Technology, Luleå, Sweden

[2]Department of Primary Health Care, Norrbotten County Council, Piteå, Sweden

[3]Department of Public Health, Norrbotten County Council, Luleå, Sweden

Corresponding Author:
Catharina A Nordin, PhD
Department of Primary Health Care
Norrbotten County Council
Furunäsets hälsocentral
Modigs gränd
Piteå, SE-94152
Sweden
Phone: 46 702420906
Fax: 46 91192553
Email: Catharina.Nordin@nll.se

Abstract

Background: Web-based interventions with a focus on behavior change have been used for pain management, but studies of Web-based interventions integrated in clinical practice are lacking. To emphasize the development of cognitive skills and behavior, and to increase activity and self-care in rehabilitation, the Web Behavior Change Program for Activity (Web-BCPA) was developed and added to multimodal pain rehabilitation (MMR).

Objective: The objective of our study was to evaluate the effects of MMR in combination with the Web-BCPA compared with MMR among persons with persistent musculoskeletal pain in primary health care on pain intensity, self-efficacy, and copying, as part of a larger collection of data. Web-BCPA adherence and feasibility, as well as treatment satisfaction, were also investigated.

Methods: A total of 109 participants, mean age 43 (SD 11) years, with persistent pain in the back, neck, shoulder, and/or generalized pain were recruited to a randomized controlled trial with two intervention arms: (1) MMR+WEB (n=60) and (2) MMR (n=49). Participants in the MMR+WEB group self-guided through the eight modules of the Web-BCPA: pain, activity, behavior, stress and thoughts, sleep and negative thoughts, communication and self-esteem, solutions, and maintenance and progress. Data were collected with a questionnaire at baseline and at 4 and 12 months. Outcome measures were pain intensity (Visual Analog Scale), self-efficacy to control pain and to control other symptoms (Arthritis Self-Efficacy Scale), general self-efficacy (General Self-Efficacy Scale), and coping (two-item Coping Strategies Questionnaire; CSQ). Web-BCPA adherence was measured as minutes spent in the program. Satisfaction and Web-BCPA feasibility were assessed by a set of items.

Results: Of 109 participants, 99 received the allocated intervention (MMR+WEB: n=55; MMR: n=44); 88 of 99 (82%) completed the baseline and follow-up questionnaires. Intention-to-treat analyses were performed with a sample size of 99. The MMR+WEB intervention was effective over time (time*group) compared to MMR for the two-item CSQ catastrophizing subscale (*P*=.003), with an effect size of 0.61 (Cohen *d*) at 12 months. There were no significant between-group differences over time (time*group) regarding pain intensity, self-efficacy (pain, other symptoms, and general), or regarding six subscales of the two-item CSQ. Improvements over time (time) for the whole study group were found regarding mean (*P*<.001) and maximum (*P*=.002) pain intensity. The mean time spent in the Web-based program was 304 minutes (range 0-1142). Participants rated the items of Web-BCPA feasibility between 68/100 and 90/100. Participants in the MMR+WEB group were more satisfied with their MMR at 4 months (*P*<.001) and at 12 months (*P*=.003).

Conclusions: Adding a self-guided Web-based intervention with a focus on behavioral change for activity to MMR can reduce catastrophizing and increase satisfaction with MMR. Patients in MMR may need more supportive coaching to increase adherence in the Web-BCPA to find it valuable.

ClinicalTrial: Clinicaltrials.gov NCT01475591; https://clinicaltrials.gov/ct2/show/NCT01475591 (Archived by WebCite at http://www.webcitation.org/6kUnt7VQh)

(J Med Internet Res 2016;18(10):e265) doi:10.2196/jmir.5634

KEYWORDS

coping behavior; pain; patient compliance; patient satisfaction; rehabilitation; self-efficacy; Web-based intervention

Introduction

Internet-based medicine or eHealth is under continuous development and considered necessary to provide cost-effective and equal health care [1]. The eHealth definition comprises Internet technology and a commitment to improve the quality of and access to health care by the use of information and communication technology, as well as empowering the individual and increasing participation [2]. Web-based interventions for pain management have been developed and promising treatment effects regarding pain and physical and psychological functioning have been reported [3-5].

Approximately 20% of the adult Swedish and European population suffers from persistent musculoskeletal pain with duration of at least 3 months or recurrent episodes of pain [6,7]. For the individual, persistent musculoskeletal pain is reported to have an impact on the individual’s quality of life [6,8] and imposes high societal costs with large health care consumption, work absenteeism, and sick leave [9,10]. The influence of psychosocial factors [11-13] and reported comorbidity [14] in persistent musculoskeletal pain entail a biopsychosocial and holistic approach to treatment, such as multimodal rehabilitation (MMR) [7,15-17]. The treatment content in MMR can vary, but includes at least a physical (body exercises) and a psychosocial (psychological, social, or occupational) component [15,18], given by health care professionals of different occupations [17,19]. MMR includes a cognitive behavioral approach to help the individual to understand how cognition and behavior can affect the pain experience and to provide tools for self-care [18]. The individual’s active participation in rehabilitation planning and decision making, including setting goals with a focus on participation in daily life and work, have been emphasized [7,16,17,20]. There is evidence for MMR when compared to standard treatment regarding reduced pain intensity and improved functioning [15,19,21], as well as reduced social costs with fewer days of sick leave [22]. However, some reports have demonstrated ambiguous and mixed results [15,23]. The treatment effects of MMR have been associated with the individual’s changes in beliefs and coping [24]. Self-efficacy has been found to mediate a positive treatment outcome [25-27] and to be important in the use of more active coping strategies and self-management [28,29]. In contrast, catastrophizing beliefs have a negative impact on treatment effects [24,26,30]. Although MMR is the recommended treatment for persistent pain, there are reasons for further improvements within treatment content for persistent pain.

In the County Council of Norrbotten, Sweden, the development of eHealth care is a strategy to overcome the regional distance between health care providers and citizens. In order to propose an eHealth solution for a biopsychosocial treatment of persistent musculoskeletal pain, the Web-based Behavior Change Program for Activity (Web-BCPA) was developed. The Web-BCPA is a modified version of an existing Web-based program “To Manage Pain” provided by Livanda (a Swedish supplier of Internet-based medicine) [31]. To Manage Pain is based on behavioral theory literature and face-to-face cognitive behavioral therapy [32-34], and was developed by psychologists of the Livanda company [31]. In cooperation with the founders of Livanda, To Manage Pain was revised into the Web-BCPA program with the aim to target patients in an early stage of persistent pain. The Web-BCPA aimed to increase participants’ physical and cognitive activity in the rehabilitation. The Web-BCPA focuses on increasing cognitive activities, such as learning, problem solving, communication, and making decisions, to help the participants develop new skills and behavior, as well as maintain and generalize behavior changes in life. Further, the Web-BCPA content was designed to encourage activity in everyday life and work, as well as physical activity and self-care.

At the time of this study, there were no interventions combining MMR with a self-guided Web-based intervention for pain management and behavior change. Most studies on Web-based interventions had participants recruited from waiting lists and/or advertising, which indicated that further research needed to focus on integrating Web-based interventions in clinical practice [3,4,35], including evaluations of treatment satisfaction and feasibility [4]. In addition, few studies have evaluated self-guided Web-based interventions with no therapist support [36-39]. We chose to perform our study in the primary health care setting because earlier research on MMR focused on in-patient intervention and there was a lack of studies performed in outpatient rehabilitation of persons with persistent musculoskeletal pain [40].This study is part of a larger collection of data with the main objective to evaluate work ability. Here, we focus on reporting the results of other outcomes in relation to pain to evaluate the Web-BCPA program. The objective of this study was to evaluate the effects of MMR in combination with the Web-BCPA compared to MMR among persons with persistent musculoskeletal pain in primary health care regarding pain intensity, self-efficacy, and coping. The study also aimed to investigate Web-BCPA adherence and feasibility, as well as treatment satisfaction.

Methods

Study Design

The study was a 12-month randomized controlled trial (RCT) with two intervention arms: (1) MMR and the Web-BCPA (MMR+WEB) and (2) MMR with follow-ups at 4 and 12 months. The consecutive recruitment and data collection started in October 2011 and ended in May 2015. The protocol was registered in the clinical trial registry of the US National Institutes of Health (NCT01475591), and approved by the Regional Ethical Review Board of Umeå University, Sweden (Umu dnr 2011-383-31M). This study is part of a larger collection of data and focuses on evaluating Web-BCPA adherence and feasibility, as well as outcomes of self-efficacy, pain intensity, and coping strategies.

Participants

Participants were patients eligible for MMR at health care centers in Norrbotten county, northern Sweden. The inclusion criteria were (1) age between 18 and 63 years; (2) persistent musculoskeletal pain with a duration of at least 3 months in back, neck, shoulder, and/or generalized pain; (3) Örebro Musculoskeletal Pain Screening Questionnaire (ÖMPSQ) score ≥90, screening for psychosocial factors that indicates an estimated risk for long-lasting pain conditions and future disability [12]; (4) work ability of at least 25%; (5) familiar with written and spoken Swedish; and (6) access to a computer and the Internet. Exclusion criteria were reduced cognitive ability (dementia, brain injury), current abuse of alcohol or drugs, in need of other health care (eg, advanced medical investigation, cancer treatment, terminal care), and/or pregnancy.

Procedure

We invited 23 primary health care centers in Norrbotten that were certified for MMR to participate in the study. Management and health care staff were briefed and the rehabilitation coordinator (nurse, occupational therapist, or physiotherapist assigned to support a patient in rehabilitation planning) was trained to assist in the recruitment and data collection as well as introducing the participants to self-guide the Web-BCPA.

In all, 17 health care centers actively participated in the study. The rehabilitation coordinator at each health care center selected the participants according to inclusion and exclusion criteria. When patients were considered eligible for study participation, oral and written information about the study was provided and the patient was asked about participation. Once informed consent was obtained, the participants filled in the baseline questionnaire and were then randomly allocated to either the MMR+WEB group or the MMR group by numbered opaque envelopes. An independent statistician provided the allocation sequences by computer-generated random number sequences for each health care center and stratified by sex before inclusion of participants.

Participants in both intervention groups started MMR treatment according to their rehabilitation plan. Participants allocated to the MMR+WEB group were assisted by the rehabilitation coordinator to form their username and to self-select a password to log in to the Web-BCPA. They were instructed about the general setup of the Web-based intervention and informed that the rehabilitation coordinator was available for support. In addition, participants were informed that the time spent on the Web-BCPA was to be monitored and that participants who did not log in to the program would be contacted by the rehabilitation coordinator.

Participants in both study groups were followed up at 4 and 12 months. On both occasions, the participants met with the rehabilitation coordinator at the health care center and filled in a questionnaire. In addition, the participants were asked for consent to review their patient records for data on number of treatments and sick-leave days.

Interventions

Multimodal Rehabilitation

The MMR was characterized by synchronized treatments based on a biopsychosocial perspective of pain and with the patient in focus. The MMR included treatments from at least three health care professionals from different occupations (eg, nurse, occupational therapist, physician, physiotherapist, psychologist, or psychosocial counselor). The health care professionals worked according to the cognitive behavioral approach for behavior change toward activity and participatory goals. In addition, the participants and the health care professionals were supported by a rehabilitation coordinator in the planning of the rehabilitation and in communication with the Swedish Social Insurance Agency (SSIA). The patient and the health care professionals met at team conference meetings to draw up an individualized rehabilitation plan, which included identification of the patient's resources and restrictions, formulation of goals, planning of treatments, as well as dates for follow-up. The plan was documented by a standard form in the patient record and printed out for the participants. The participants had the opportunity to invite significant others (a relative, an employer, an administrator from the SSIA or the Employment Service) to cooperate in the rehabilitation planning. Mutual decision making and a patient's active participation in MMR treatments and planning were in focus [16,17].

The minimum number of treatments in MMR was specified as two to three times a week for six to eight weeks, including home exercises. The treatments were individual and/or in group sessions. In MMR physical activity (individualized exercise program, warm-water exercise, Basic Body Awareness Therapy), acupuncture, transcutaneous electric nerve stimulation, and manual therapy could be given by physiotherapists. Ergonomics, activity planning, and functional training were provided by occupational therapists. Psychologists and psychosocial counselors were responsible for counseling treatment. Counseling could also be provided by other health care professionals (nurse, occupational therapist, or physiotherapist) trained in cognitive behavioral therapy. The physicians prescribed pharmacological treatment, wrote medical certificates, and made referrals. Patient education, relaxation, mindfulness, and testing disability aids were carried out by health care professionals of various occupations. The MMR treatment period was adjusted according to the patient's needs and progress. The health care centers were responsible for a patient's medical rehabilitation to progress in health, but not principally in charge of the work rehabilitation.

The Web Behavior Change Program for Activity

The Web-BCPA was administrated via the Livanda website, and was exclusive for this study. Only study participants had access to the Web-BCPA, not other Livanda customers. The participants self-guided through the Web-BCPA, without therapist guidance, and had the freedom to choose from the program content. They had access to the Web-based intervention in their own environment 24/7 for 16 weeks. Without participants' active work in the Web-BCPA for 20 minutes, they were automatically logged out. At the first log-in, the Web-BCPA contained an overall introduction to cognitive behavioral therapy principles, information of the content and format of the entire program, as well as general advice on how to work in the Web-BCPA (eg, start with reading the texts and then spend time on the assignments). The Web-BCPA consisted of eight modules: (1) pain, (2) activity, (3) behavior, (4) stress and thoughts, (5) sleep and negative thoughts, (6) communication and self-esteem, (7) solutions, and (8) maintenance and progress. They were delivered to the participant one module per week during the first eight weeks. The modules contained information, assignments, and exercises, assimilated via educational texts, videos, and writing tasks. Each module contained 10 to 15 shorter Web pages of information and 10 to 15 pages of assignments and exercises (Table 1). Further, the assignments were interactive and included self-tests and self-developed action plans aimed at self-analyzing one's resources and restrictions, setting goals and estimating goal achievement, planning activities, and following up results. Help texts with specific how-to instructions, as well as examples of goals and activities, were available to all assignments. Self-developed action plans included assignments on life goals and values, activity scheduling, and planning behavior change. Exercises included relaxation and Basic Body Awareness Therapy exercises, for example, with a duration of 10 to 30 minutes per session. In addition, the participant could choose any physical activity as part of the planning activity assignment. Assignments and exercises were constructed as a progression in cognitive skill building with each module. The participants chose how to use the Web-BCPA freely, except for a well-being test that was mandatory to fill in to get access to modules 2 to 8. The well-being test measured harmony (in contrast to anxiety), energy level, optimism (in contrast to depression), and decisiveness. Data from the well-being test and the assignments were saved as summaries, which the participants could review to monitor progress. All texts and assignments could be printed out. If participants' chose, complementary well-being recommendations were sent to the participant's email box each week. In addition, the program included a CD with relaxation exercises, which was sent to their home address.

Outcome Measures

Web Behavior Change Program for Activity Adherence

Web-BCPA adherence was assessed as minutes spent in each module, which was obtained from the administrative system of Livanda. Total time was calculated.

Web Behavior Change Program for Activity Feasibility and Treatment Satisfaction

Web-BCPA feasibility was measured at 4 months using a set of items constructed for the purpose of this study. The eight items were:

1. It was easy to use the program
2. It was easy to log in to the program
3. Except for the first introduction, I have self-guided in the program
4. It was easy to comprehend the program
5. The graphical design was...
6. The texts have been of good use
7. The exercises have been of good use
8. The videos have been of good use

The ranking was made on a numeric scale from zero (disagree) to 100 (totally agree). The score for item 5 was zero (not at all appealing) to 100 (appealing).

Participants' satisfaction with the Web-BPCA was measured at 4 months with three items: (1) I am satisfied with my own efforts in the Web-based intervention, (2) I am satisfied with the administrative support in the Web-based intervention from the rehabilitation coordinator, and (3) I could recommend the Web-based intervention to others in a similar situation as mine.

In addition, participants' satisfaction with the MMR was assessed at 4 and 12 months using two items: (1) I am satisfied with my multimodal rehabilitation, and (2) I am satisfied with my own efforts in my multimodal rehabilitation. The ratings were on a numeric scale from zero (disagree) to 100 (totally agree).

Patient Records Data

Data on MMR treatment, health care consumption, and sick leave were collected from the participant's patient records.

Pain Intensity

Pain intensity was measured by the 100-mm Visual Analog Scale (VAS) with zero indicating no pain or discomfort and 100 indicating unbearable pain or discomfort [41]. The participants assessed their mean, minimum, and maximum pain for the last seven days [42]. The VAS has good reliability and is well established to assess musculoskeletal pain [43].

Self-Efficacy

Arthritis Self-Efficacy Scale

The certainty to have the capacity to perform a task in relation to pain was measured with two subscales of the Arthritis Self-Efficacy Scale (ASES). The "self-efficacy to control pain" subscale (ASES pain) consisted of five items and the "self-efficacy to control other symptoms" subscale (ASES other symptoms) had six items. The items were scored on a scale from 10 (very uncertain) to 100 (very certain), with a mean score for each subscale computed [39]. Both the original ASES and the Swedish version have been tested for reliability (alpha range .8 to .9) and validity [44-46].

Table 1. Content of the Web Behavior Change Program for Activity (Web-BCPA).

Module	Educational texts	Assignments and exercises
1. Pain	Pain mechanism—anatomy and physiology	Life goals and values—health
	Persistent pain	Activity scheduling
	Pain in the neck, back, and shoulder	
2. Activity	Pain mechanism—thoughts, interpretation, behavior	Well-being test
	Pain and physical activity	Life goals and values—work and leisure
	Life balance	Daily exercise level test
	Ergonomics in everyday life	Short exercise program
	Resting positions	Relaxation—breathing exercises
		Basic Body Awareness Therapy exercises
3. Behavior	Pain and learning behavior	Well-being test
	Pacing	Life goals and values—close relationships, family, social relationships, and personal development
	An active sick-leave	Planning activity
		Planning behavior change
		Body scan-applied relaxation
		Basic Body Awareness Therapy exercises
4. Stress and thoughts	Accepting thoughts	Well-being test
	Stress and stress management	Planning behavior change
		Stress test
		Body scan—conditioned relaxation
		Basic Body Awareness Therapy exercises
5. Sleep and negative thoughts	Negative and automatic thoughts	Well-being test
	Sleep, sleep hygiene, and sleep disorders	Challenging negative automatic thinking styles
		Sleep test
		Body scan—conditioned relaxation
		Basic Body Awareness Therapy exercises
6. Communication and self-esteem	Communication skills	Well-being test
	Conflict resolution methods	Effective communication training
	Self-esteem and self-confidence	Setting limits
	Participation in health care	Dealing with difficult emotions
		Planning behavior change
		Basic Body Awareness Therapy exercises
7.Solutions	Problem-solving methods in relationships	Well-being test
	Problem-solving traps	Problem-solving practices
		Planning behavior change
		Basic Body Awareness Therapy exercises
8. Maintenance and progress	Setbacks and relapses prevention	Well-being test
	Maintenance	Planning behavior change
		Maintenance plan and strategies
		Basic Body Awareness Therapy exercises

General Self-Efficacy Scale

A more general aspect of self-efficacy was assessed by the General Self-Efficacy Scale (GSE), which measures an individual's beliefs in one's ability to respond to novel or difficult situations and to deal with associated obstacles or setbacks. The GSE contained 10 items, which were rated on a four-point Likert scale: 1 (not at all true/strongly disagree), 2 (hardly true/partly disagree), 3 (moderately true/partly agree), and 4 (exactly true/strongly agree). The ratings were summarized and divided by 10, resulting in a total score ranging from 1 to 4 [47-49]. The GSE was found consistent (alpha range .7 to .9) in several populations in European countries [50], and the Swedish version has been validated [49].

Coping

Coping strategies were assessed using the two-item Coping Strategies Questionnaire (CSQ), a shorter version of the original CSQ. The two-item CSQ consists of seven subscales, each represented by two items [51]. The subscales represent a coping strategy: diverting attention, reinterpreting pain sensations, catastrophizing, ignoring sensations, praying or hoping, coping self-statements, and increased behavioral activities. The items were scored on a Likert scale from zero (never do that) to 6 (always do that), and a mean score of the two items for each subscale was calculated. A higher score is related to improvement of coping strategies, except for the catastrophizing subscale in which a lower score indicates improvement. Each of the CSQ two-item subscales has shown strong association to the parent subscale [51]. A Swedish version of the two-item CSQ was constructed for this study using the translation of items from the Swedish version of the original CSQ by Jensen and Linton [52].

Statistical Analysis

Data in this study were part of a larger collection of data and the power calculation to detect a medium effect size difference of the MMR+WEB and MMR group was performed on the work ability index [53] because it was the primary outcome variable for the entire research project. A 5% significance level and 80% power indicated that 64 participants in each intervention group were needed. Considering the possibility of a 20% dropout rate, a sample size of 84 participants in each group was determined to be sufficient.

There were some missing values and cases in the data collection. Isolated missing values in specific questionnaires were imputed according to guidelines for ASES [54] and for GSE [48]. Missing values in CSQ were not imputed. Participants lost to follow-up were handled with intention-to-treat (ITT) analysis, with last observation carried forward (LOCF). Data analysis per protocol were performed and showed nonsignificant differences compared to the analysis of imputed data. The analysis of patient records data was performed with valuable data except for two participants that did not give their consent to follow-up patient records data at 12 months.

Internal consistency for ASES, GSE, and CSQ was tested within our dataset. Excellent internal consistency was found regarding ASES pain (alpha=.9), ASES other symptoms (alpha=.9), and GSE (alpha=.9). Internal consistency for the CSQ subscales were diverting attention (alpha=.6), reinterpreting pain sensations (alpha=.7), catastrophizing (alpha=.7), ignoring sensations (alpha=.6), praying or hoping (alpha=.5), coping self-statements (alpha=.6), and increased behavioral activities (alpha=.3).

Differences in baseline characteristics were tested with independent-samples *t* test, Mann-Whitney *U* test, and chi-square test (Pearson). Repeated measures ANOVA statistics were used to analyze treatment effects between groups over time (time*group), and the whole study population over time (time). Differences between groups in mean changes (delta values) in outcome variables at 4 and 12 months were analyzed with independent-samples *t* test. Because the analysis included several repeated statistical analyses, we choose a more conservative approach of $P<.01$ to be considered as statistically significant instead of $P<.05$.

Effect size was assessed between the MMR+WEB group and the MMR group at the time points 4 and 12 months by calculating Cohen *d* (the mean difference between the groups divided by the pooled standard deviation at baseline). A difference in effect size of 0.2 to 0.5 is regarded as small, between 0.5 and 0.8 as medium, and greater than 0.8 as large [55]. An online calculator was used for this purpose [56].

Data analyses were performed using IBM SPSS version 23 (IBM Corporation).

Results

Study Participation

The flow of participants through the study is presented in Figure 1. Of the 196 persons assessed for eligibility according to the inclusion and exclusion criteria, 16 (women: n=12, men: n=4; age: mean 46, SD 13 years) declined participation in MMR, with reference to fatigue, time pressure, preferring unimodal treatment, and fear of being stigmatized. In all, 71 persons (49 women and 22 men; mean age 44, SD 12 years) started MMR, but renounced participation in the study due to fatigue, lack of energy, dyslexia, time pressure, wrong timing, or MMR treatment being enough. Other reasons were having no interest or skill with computer work, not being able to work at the computer due to pain, as well as not being interested and motivated to participate in a study.

A total of 109 participants were randomized to MMR+WEB (n=60) or MMR (n=49). However, five participants in each group did not receive MMR and were excluded from the study. At 4 months, 83 of 99 (84%) participants were followed up. Those lost to follow-up were 12 women and four men, aged between 27 and 58 (mean 42, SD 11) years. The follow-up rate at 12 months was 81% (80/99); 13 women and six men, aged between 31 and 63 (mean 44, SD 11) years, were lost to follow-up. Reasons for not being followed up were either participant's voluntary discontinuation or organizational failure, such as the changing of rehabilitation coordinator or not being able to make contact with the participant. There were no significant differences of baseline characteristics between participants attending follow-up at 12 months and those lost to follow-up.

Participants' Characteristics

Participants' characteristics at baseline are shown in Table 2. Overall, the mean age was 43 (SD 11) years and the majority (84/99) were women. Most participants (81/99) lived with a spouse and approximately 50% (51/99) had children in the household. The education level was higher in the MMR+WEB group with 31% (17/55) of the participants having a university degree compared to 20% (9/44) in the MMR group. More than half (56/99) of the participants in both study groups were working at least 25% at baseline and approximately 75% (76/99) had employment. In the MMR+WEB group, 27% (15/55) of the participants had less than one hour of physical activity per week; in the MMR group, this number was 21% (9/44). The mean body mass index (BMI) was 29 (SD 7) in the MMR+WEB group and 28 (SD 6) in the MMR group, and 20% (20/99) of participants smoked (Table 2).

Overall, participants had pain duration for a mean 78.5 (SD 97.4) months with a mean pain intensity for last 7 days of 65.5 (SD 16.5). The MMR+WEB group showed a significantly higher ÖMPSQ score (mean 136, SD 20) than the MMR group (mean 125, SD 24, *P*=.01). Both study groups showed a mean self-rated overall health state of 46/100 (SD 18) on EuroQol VAS; approximately one-quarter had previous hospital in-patient MMR (Table 2).

Figure 1. Participant flow diagram. MMR: multimodal rehabilitation; MMR+WEB: multimodal rehabilitation and Web Behavior Change Program for Activity.

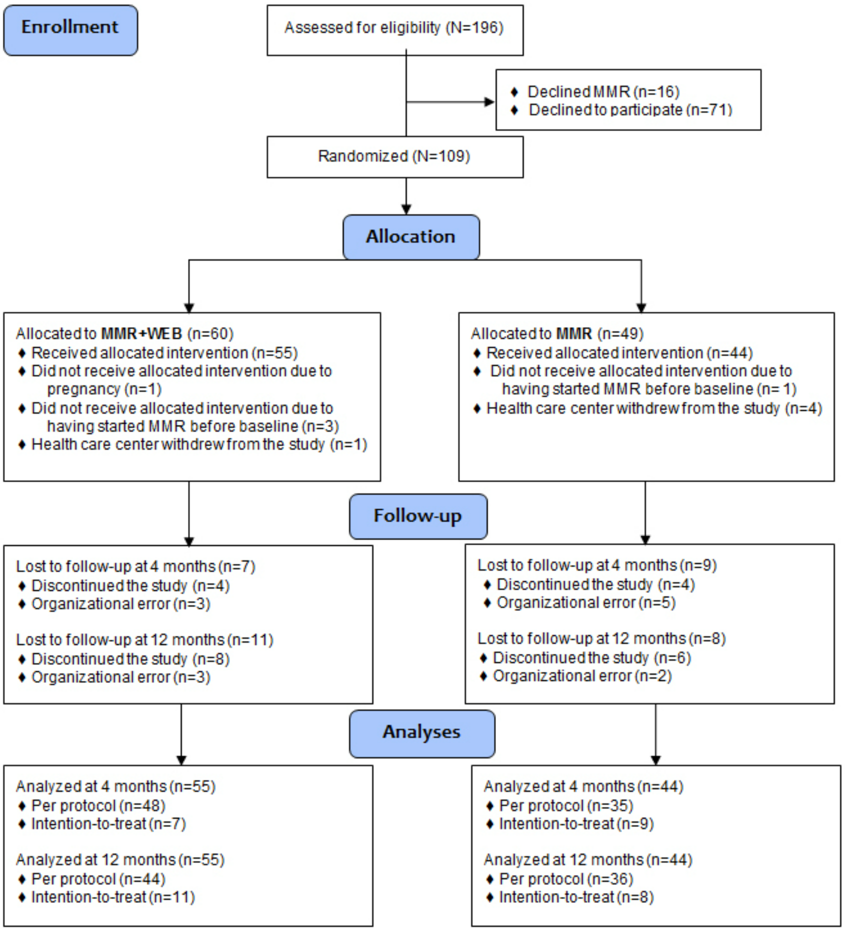


Table 2. Participants' characteristics at baseline (N=99) in the multimodal rehabilitation (MMR) and multimodal rehabilitation and Web Behavior Change Program for Activity (MMR+WEB) groups.

Participants' characteristics	MMR+WEB (n=55)	MMR (n=44)	*P* value
Age (years), mean (SD)	44 (10)	42 (11)	.30
Gender (female), n (%)	47 (86)	37 (84)	.85
Married or cohabitating, n (%)	45 (82)	36 (82)	>.99
Have children in the household, n (%)	28 (51)	23 (52)	.89
Education level, n (%)			.17
Elementary (1-9 years)	8 (14)	10 (23)	
Secondary education (10-12 years)	30 (55)	25 (57)	
University (≥13 years)	17 (31)	9 (20)	
Working condition, n (%)			
Permanent or self-employed	40 (73)	28 (64)	
Temporary employment	5 (9)	3 (7)	
Unemployed	6 (11)	9 (20)	
Student	1 (2)	1 (2)	
Parental leave	0 (0)	0 (0)	
Outside the labor market	3 (5)	3 (7)	
Working ≥25% of time at baseline	31 (56)	25 (57)	.96
Physical activity, n (%)			.47
<1 hour per week	15 (27)	9 (21)	
1-3 hours per week	14 (26)	11 (26)	
>3 hours per week	26 (47)	23 (53)	
Body mass index in kg/m^2, mean (SD)	29 (7)	28 (6)	.20
Smoking, n (%)	11 (20)	9 (20)	.96
Pain duration in months, mean (SD)	79 (97)	78 (99)	.96
Pain intensity last 7 days (VAS),[a] mean (SD)	66 (17)	65 (16)	.67
ÖMPSQ,[b] mean (SD)	136 (20)	125 (24)	.01
EuroQol VAS,[c] mean (SD)	45 (18)	47[d] (18)	.54
Previous MMR,[e] n (%)	14 (26)	10 (23)	.82

[a] VAS: Visual Analog Scale. Score between zero (no pain) and 100 (worst imaginable pain).

[b] ÖMPSQ: Örebro Musculoskeletal Pain Screening Questionnaire. Maximum score=210. A score ≥90 indicates a moderate estimated risk for persistent pain and future disability; ≥105 indicates a higher estimated risk.

[c] Score between zero (worst imaginable health state) and 100 (best imaginable health state).

[d] n=41.

[e] History of hospital in-patient multimodal pain rehabilitation.

Table 3. Adherence to the Web Behavior Change Program for Activity.

Module	Time spent in module (min)		Users per module,[a] n (%)
	Mean (SD)	Range	
1	79 (67)	0-345	54 (98)
2	52 (62)	0-259	43 (78)
3	50 (66)	0-377	41 (74)
4	44 (55)	0-179	37 (67)
5	29 (36)	0-158	32 (58)
6	22 (37)	0-167	27 (49)
7	14 (23)	0-79	25 (46)
8	14 (37)	0-215	20 (36)
Total time	304 (267)	0-1142	

[a] The number of participants that opened the module at some point.

Table 4. Feasibility and treatment satisfaction of the Web Behavior Change Program for Activity (Web-BCPA) for the multimodal rehabilitation and BCPA (BCPA+WEB) group (n=55).

Item	Mean (SD)	n
It was easy to use the program	82 (22)	44
It was easy to log in to the program[a]	90 (23)	44
Except for the first introduction, I have self-guided the program[a]	86 (29)	44
It was easy to comprehend the program[a]	90 (17)	44
The graphical design was...[b]	84 (21)	44
The texts have been of good use[a]	84 (24)	44
The assignments have been of good use[a]	73 (27)	42
The videos have been of good use[a]	68 (27)	41
Satisfied with my own efforts in the Web-based program[a]	62 (32)	43
Satisfied with the administrative support in the Web-based program[a,c]	93 (18)	42
I could recommend the Web-based program to others in similar situations to mine[a]	88 (24)	43

[a] Score ranging from zero (disagree) to 100 (totally agree).

[b] Score ranging from zero (not at all appealing) to 100 (appealing).

[c] Support given by the rehabilitation coordinator.

Table 5. Satisfaction with multimodal rehabilitation at 4 and 12 months for the multimodal rehabilitation and Web Behavior Change Program for Activity (MMR+WEB) (n=55) and the MMR (n=44) groups.

Item[a]	MMR+WEB		MMR		*P* value
	Mean (SD)	n	Mean (SD)	n	
Satisfied with my multimodal rehabilitation at 4 months	85 (19)	46	65 (25)	35	<.001
Satisfied with own efforts in my multimodal rehabilitation at 4 months	73 (26)	46	66 (26)	35	.20
Satisfied with my multimodal rehabilitation at 12 months	82 (24)	50	66 (28)	39	.003
Satisfied with own efforts in my multimodal rehabilitation at 12 months	74 (25)	50	67 (24)	39	.19

[a] Score ranging from zero (disagree) to 100 (totally agree).

Multimodal Rehabilitation Treatment

The multimodal rehabilitation consisted of a mean 30 (SD 8) treatment sessions in the MMR+WEB group and mean 26 (SD 6) in the MMR group. In the MMR+WEB group, 96% (53/55) of the participants had physiotherapy treatment; in the MMR group, it was 95% (42/44). Occupational therapy was attended by 93% (51/55) of the participants in the MMR+WEB group compared to 86% (38/44) in the MMR group. Overall, 78% (43/55) of participants in the MMR+WEB group and 80% (35/44) in the MMR group were treated with psychosocial counseling. In the MMR+WEB group, 96% (53/55) of the participants had treatments by a physician compared to 98% (43/44) in the MMR group; 7% of participants in both the MMR+WEB group (4/55) and the MMR group (3/44) were treated by nurse. The number of team conference meetings were a mean 3 (SD 1) for the MMR+WEB group and mean 2 (SD 1) for the MMR group. In both study groups, 75% (74/99) of all treatments were given during the first 4 months of rehabilitation. At 4 months, 60% (33/55) of the participants in the MMR+WEB group and 70% (31/44) in the MMR group had completed the MMR. At 12 months, the percentage of participants that had completed their rehabilitation was 91% (50/55) in the MMR+WEB group and 95% (42/44) in the MMR group.

Web Behavior Change Program for Activity Adherence

The mean time spent in the Web-BCPA for all eight modules was 304 minutes (SD 267) or approximately 5 hours. The mean number of modules opened was 5.1 (SD 2.9). A total of 20 of 55 (36%) persons opened all eight modules in the program. The number of users, as well as time spent, decreased with each module. In module 1, mean time spent was 79 (SD 67) minutes, whereas in module 8 the mean time was only 14 (SD 37) minutes. One participant did not open any module (Table 3).

Web Behavior Change Program for Activity Feasibility and Treatment Satisfaction

Participants rated easiness to comprehend and to log in to the Web-BCPA 90/100. Easiness to use the program and guiding themselves in the program, as well as the graphical design of the Web-BCPA and the applicability of the texts, were rated between 82/100 to 86/100. The lowest mean score was found on the applicability of the exercises and videos (Table 4).

Participants assessed satisfaction with the administrative support in the Web-BCPA from the rehabilitation coordinator as 93/100 and that the Web-based intervention could be recommended to others in similar situation was rated 88/100. Satisfaction with own efforts in the Web-BCPA had the lowest rating (Table 4).

Satisfaction with the MMR was rated significantly higher in the MMR+WEB group at 4 months ($P<.001$) and 12 months ($P=.003$) than in the MMR group. There were no significant differences between the groups at 4 or 12 months regarding participants' satisfaction with their own efforts in the MMR (Table 5).

Pain Intensity

Descriptive statistics of mean, minimum, and maximum pain in last 7 days are presented in Table 6. There were no significant differences between groups at baseline for pain variables; however, ratings in the MMR+WEB group tended to be somewhat higher (*P* values not shown). There were no treatment effects between the intervention groups over time (time*group) for mean pain ($P=.52$), minimum pain ($P=.27$), or maximum pain ($P=.55$). There were also not any significant between-group differences in mean changes at the time points 4 and 12 months for pain intensity (Table 6).

Table 6. Effects of multimodal rehabilitation and Web Behavior Change Program for Activity (MMR+WEB) on pain intensity as measured with the Visual Analog Scale (VAS) at baseline, 4 months, and 12 months, and mean differences between intervention groups with effect sizes (Cohen *d*).

Outcome measures	MMR+WEB (n=55)	MMR (n=43)	*P* value		Difference MMR+WEB–MMR		Effect size (*d*)
	Mean (SD)	Mean (SD)	Time*group	Time	Mean (95% CI)	*P* value	
VAS mean[a]			.52	<.001			
Baseline	66.1 (16.7)	64.7 (16.2)					
4 months	59.6 (21.0)	54.8 (21.9)			3.4 (–10.2 to 3.4)	.32	–0.22
12 months	57.9 (21.8)	56.9 (22.0)			–0.4 (–7.2 to 7.9)	.92	0.02
VAS minimum[a]			.27	.47			
Baseline	42.1 (24.3)	32.8 (23.8)					
4 months	41.5 (25.6)	29.1 (23.7)			3.1 (–10.5 to 4.3)	.40	–0.13
12 months	40.3 (26.6)	34.3 (24.9)			–3.2 (–4.9 to 11.3)	.43	0.14
VAS maximum[a]			.55	.002			
Baseline	82.5 (13.5)	79.7 (18.1)					
4 months	75.8 (19.2)	73.8 (21.3)			–0.8 (–6.4 to 8.0)	.83	0.05
12 months	75.5 (17.2)	76.5 (18.8)			–3.9 (–3.9 to 11.6)	.32	0.24

[a] Pain intensity in last 7 days; zero=no pain or discomfort, 100=unbearable pain or discomfort.

Table 7. Effects of ultimodal rehabilitation and Web Behavior Change Program for Activity (MMR+WEB) on self-efficacy as measured with the Arthritis Self-Efficacy Scale (ASES) and the General Self-Efficacy Scale (GSE) at baseline, 4 months, and 12 months, and mean differences between intervention groups with effect sizes (Cohen *d*).

Outcome measures	MMR+WEB (n=55)	MMR (n=44)	*P* value		Difference MMR+WEB–MMR		Effect size (*d*)
	Mean (SD)	Mean (SD)	Time*group	Time	Mean (95% CI)	*P* value	
ASES pain			.04	.28			
Baseline	45.8 (21.6)	49.0 (20.4)					
4 months	50.0 (23.4)	49.3 (21.9)			3.9 (–2.5 to 10.3)	.23	0.19
12 months	53.2 (22.3)	46.9 (22.2)			9.5 (1.2 to 17.7)	.02	0.45
ASES other symptoms			.89	.01			
Baseline	52.6 (19.2)	52.0 (16.7)					
4 months	58.1 (21.5)	56.1 (19.8)			1.4 (–4.7 to 7.5)	.65	0.08
12 months	57.5 (20.5)	55.8 (21.8)			1.2 (–6.7 to 9.0)	.78	0.06
GSE[a]			.30	.12			
Baseline	2.90 (0.60)	2.97 (0.46)					
4 months	2.88 (0.58)	3.06 (0.53)			–0.10 (–0.22 to 0.02)	.11	–0.10
12 months	2.93 (0.62)	3.08 (0.56)			–0.07 (–0.22 to 0.07)	.33	–0.15

[a] MMR+WEB group (n=54) and MMR group (n=43).

Table 8. Effects of multimodal rehabilitation and Web Behavior Change Program for Activity (MMR+WEB) on coping as measured with the two-item Coping Strategies Questionnaire (CSQ) at baseline, 4 months, and 12 months, and mean differences between intervention groups with effect sizes (Cohen *d*).

CSQ subscales	MMR+WEB (n=54)	MMR (n=44)	*P* value		Difference MMR+WEB–MMR		Effect size (*d*)
	Mean (SD)	Mean (SD)	Time*group	Time	Mean (95% CI)	*P* value	
Diverting attention[a]			.61	.14			
Baseline	2.9 (1.4)	2.8 (1.5)					
4 months	3.2 (1.4)	2.9 (1.7)			0.2 (–0.2 to 0.6)	.36	0.14
12 months	3.1 (1.5)	3.0 (1.7)			–0.0 (–0.6 to 0.5)	.92	–0.00
Reinterpreting pain sensations[a,b]			.63	.12			
Baseline	1.8 (1.4)	1.7 (1.4)					
4 months	2.1 (1.3)	1.8 (1.4)			0.2 (–0.3 to 0.6)	.46	0.14
12 months	2.1 (1.4)	2.0 (1.4)			–0.0 (–0.6 to 0.6)	.98	–0.00
Catastrophizing			.003	.002			
Baseline	3.2 (1.4)	2.8 (1.2)					
4 months	2.8 (1.4)	2.8 (1.4)			–0.4 (–0.9 to 0.0)	.06	0.31
12 months	2.4 (1.4)	2.8 (1.4)			–0.8 (–0.3 to –1.3)	.001	0.61
Ignoring sensations[a]			.03	.30			
Baseline	2.7 (1.2)	2.8 (1.2)					
4 months	2.9 (1.1)	2.9 (1.3)			0.1 (–0.3 to 0.5)	.06	0.08
12 months	3.0 (1.3)	2.5 (1.3)			0.6 (0.1 to 1.0)	.02	0.50
Praying or hoping			.78	.33			
Baseline	2.7 (1.6)	2.6 (1.5)					
4 months	2.8 (1.6)	2.5 (1.7)			0.2 (–0.3 to 0.6)	.52	0.13
12 months	2.6 (1.6)	2.4 (1.5)			0.1 (–0.4 to 0.6)	.77	0.06
Coping self-statements			.48	.42			
Baseline	3.1 (1.1)	3.1 (1.3)					
4 months	3.0 (1.2)	2.9 (1.3)			0.0 (–0.4 to 0.4)	.93	0.25
12 months	3.2 (1.3)	2.9 (1.4)			0.2 (–0.2 to 0.7)	.32	0.13
Increased behavioral activities[a]			.10	.15			
Baseline	3.3 (1.1)	3.3 (1.2)					
4 months	3.4 (1.0)	3.1 (1.3)			0.4 (0.00 to 0.8)	.047	0.26
12 months	3.5 (1.0)	3.4 (1.4)			0.2 (–0.2 to 0.1)	.39	0.09

[a] MMR group (n=43).

[b] MMR+WEB group (n=53).

An overall significant improvement over time (time) was found in the whole study group for mean (*P*<.001) and maximum pain (*P*=.002) (Table 6).

Self-Efficacy

Table 7 shows the descriptive statistics for ASES pain, ASES other symptoms, and GSE. There were no significant differences between groups at baseline for variables of self-efficacy (*P* values not shown). There were no treatment effects over time (time*group) between the MMR+WEB group and the MMR group for ASES pain (*P*=.04), ASES other symptoms (*P*=.89), and GSE (*P*=.30). There were also not any between-group differences in mean changes at the time points 4 and 12 months for ASES pain, ASES other symptoms, and GSE (Table 7).

There were no improvements over time (time) for the whole study group regarding ASES pain (*P*=.28), ASES other symptoms (*P*=.01), and GSE (*P*=.12).

Coping

Descriptive statistics for the seven subscales of the two-item CSQ is presented in Table 8. There were no significant differences between groups at baseline for CSQ subscales (*P* values not shown). The catastrophizing subscale demonstrated significant treatment effects between groups over time (time*group; *P*=.003) in favor of the MMR+WEB group. The differences between the groups in mean changes were not significant at time point 4 months (*P*=.06, *d*=0.31), whereas they were significant at 12 months (*P*=.001) with a medium to large effect size (*d*= 0.61). There were no treatment effects between the groups over time (time*group) for diverting attention, reinterpreting pain sensations, ignoring sensations, praying or hoping, coping self-statements, and increased behavioral activities subscales (Table 8).

Treatment effects over time (time) for the whole study group was found regarding catastrophizing (*P*=.002). There were no significant improvements over time for the whole study group regarding diverting attention, reinterpreting pain sensations, ignoring sensations, praying or hoping, coping self-statements, and increased behavioral activities subscales (Table 8).

Discussion

Principal Findings

This RCT studied the effects of the self-guided Web-BCPA in combination with MMR for participants with persistent musculoskeletal pain in primary health care. Overall, we found decreased catastrophizing in the MMR+WEB group compared to the MMR group. Previously, both self-guided [39] and therapist-guided [33,34,57] Web-based interventions for chronic pain have reported treatment effects of decreased catastrophizing, The treatment effects of catastrophizing in our study showed an effect size of *d*=0.61. This is higher than the reported Hedge’s *g*=.33 in the systematic review of Web-based interventions for chronic pain by Buhrman et al [5] and is in line with the findings of Dear et al [57] from a therapist-supported Web intervention. There were no treatment effects of any other of the CSQ subscales, which is in line with Buhrman et al [33,34]. This indicates that content and form of delivery does not seem to affect coping strategies except for catastrophizing. With the limit of significance set to *P*<.01, we did not find any treatment effects regarding self-efficacy for pain, self-efficacy for other symptoms, or general self-efficacy. Increased self-efficacy to control pain has been reported for a Web-based intervention for pain management with therapist support [57], but Chiauzzi et al [36] found no treatment effects of self-efficacy from a self-guided Web-based intervention. However, the reduction of catastrophizing indicated that the Web-BCPA content had changed the participants’ negative beliefs about pain. The educational text in the first module of the Web-BCPA explained persistent pain from the physiological and psychological perspective, and most participants may have assimilated this knowledge. In addition, assignments in the Web-BCPA focused on personal goals in life and not on pain experiences, which is supported by earlier research that decreased focusing on pain signals are effective in pain rehabilitation [24,26,29].

Decreased pain intensity has previously been demonstrated from self-guided Web-based interventions for pain management compared with standard care by physician [37,39]. In this study, we found no effects on pain intensity from the Web-BCPA. There were overall effects over time for the whole study group regarding mean and maximum pain intensity in the last 7 days, which indicates that MMR can be an effective intervention to reduce perceived pain. Because this was observed without a placebo control group this should be interpreted cautiously; however, it is in line with the findings from Kamper et al [19] that MMR reduced pain compared to standard treatment. Participants in both study groups had MMR according to national and regional guidelines with the mean number of treatments above the recommended lower limit and 75% of the treatments within the first 4 months of rehabilitation. The majority of the participants were treated with psychosocial counseling in their MMR, which may have included coaching according to cognitive behavioral therapy. The fact that both intervention groups received MMR treatment may have reduced the therapeutic power of the Web-BCPA intervention. There were no overall effects over time for the whole study group regarding any of the self-efficacy scales (although self-efficacy to control other symptoms showed a statistical value close to significant; *P*=.01) or regarding six of seven CSQ subscales.

We found that participants in the MMR+WEB group were more satisfied with their MMR both at 4 and 12 months (mean 82/100, SD 24, *P*=.003) compared to persons in the MMR group (mean 66/100, SD 28). On the other hand, we found no differences regarding satisfaction with own effort in the MMR. The Web-BCPA treatment satisfaction and feasibility were rated good to excellent. Satisfaction with treatment has been found to relate to adherence and compliance to treatment [58,59], and is associated with patients’ perceptions of a positive patient-health care professional relationship [58]. The participants may have perceived a more complete rehabilitation by taking part in both MMR and the Web-BCPA. However, we found that the mean time spent in the Web-BCPA was less than we had expected (approximately 5 hours during a treatment period of 16 weeks). The measure of time spent in Web-based programs is rarely reported in the literature; therefore, there are few references to compare our results with. Lorig et al [60] tested a 6-week Web intervention for patients with persistent pain, with the recommendation to spend 1 to 2 hours each week in the program divided by three log-in occasions. The number of log-ins was measured and, assuming that the participants in the Lorig et al study had followed the recommendations [60], those participants would have spent at least 10 to 20 hours in their Web-based program. In our study, only nine participants reached that time range in the Web-BCPA. The Web-BCPA adherence decreased with each module, but this do not indicate if participants discontinued the Web-BCPA over time because most assignments and exercises were introduced in the early modules and then repeated in the sequential modules. It is likely that a participant who had started on a behavior change plan or relaxation exercises in one of the first modules returned to the same module to continue their work. The minutes spent in the Web-based program were monitored for each module and not related to week. There may be more appropriate ways to assess adherence in Web-based interventions, such as measuring number of log-ins and clicks in relation to time spent within the module, but this was not an option in our study due to limitations of the program software. However, the lower usage of later modules suggests that many participants did not assimilate all the educational texts and missed information about controlling other symptoms such as fatigue, stress, and sleep disturbance. Another limitation in this study is that we did not assess aspects of cognitive activity in the Web-BCPA, such as the acquiring of skills and knowledge, goal setting, and solving problems. Ruehlman et al [39] assessed pain knowledge (topics addressed within the Web-based intervention) and found improvements among participants in a Web-based intervention compared with treatment as usual.

Strengths and Limitations

The strengths in our study are the RCT design and that the Web-BCPA was implemented in a MMR context in primary health care, which to our knowledge is the first reported in the field. However, the number of participants in the analysis reached 77% of the calculated number needed, thus the study is underpowered to detect small improvements in outcome variables and increases the risk of type II errors. Because the dropout rate at 12 months was modest (18%) and we used ITT analysis, our findings may be less prone to bias. But all missing data mean uncertainty and reduced reliability and interpretability of the results. In this study, we had an ITT approach and used the LOCF method for imputation of data. LOCF has limitations, but handles data in a conservative way by assuming no treatment effects over time, which reduces the risk of overestimating of results. Because LOCF underestimates variance, it is possible that methods such as multiple imputation would generate more appropriate results. For exploratory reasons, we also performed per protocol analyses, which generated similar results as the LOCF analyses. We also decided to be more conservative with a significance level of $P<.01$ due to the number of variables in our data collection to minimize the risk of overestimating results.

The Web-BCPA was redesigned with alterations made to fit participants with persistent pain in an early stage, with less developed chronicity [12]. We believed that being in an early stage of persistent pain would entail better physical and psychosocial resources to self-guide in the Web-based program and to assimilate the content. However, partly because of organizational factors at the health care centers, the participants in our study suffered from longer pain duration (approximately 6.5 years) and higher levels of pain than we anticipated when designing the study. The levels of pain intensity were higher than was previously reported in other MMR interventions [61-63]. Together with the participants' high ÖMPSQ scores, this may indicate symptoms of exhaustion and stress among the participants [12], symptoms that have been found to reduce participation in Web-based interventions [3]. This may be a possible explanation for the low adherence of the Web-BCPA, together with a probably variable motivation level of participants randomized to the Web-BCPA. Most earlier studies using Web-based intervention have used a voluntary application for inclusion, whereas in our study participants searched health care for pain management and could end up with the Web-BCPA. This nonvoluntary randomization to Web-BCPA might partly explain the low adherence. Also, it is possible that the Web-BCPA content was extensive and may have been difficult for this group of patients to take on. Time and motivation are reported reasons for not using Web-based treatments [64], and patients with pain problems may prefer face-to-face therapy when there is a choice [64,65]. Our experience was that persons accepted treatment with MMR but declined participation in the study. The proportion of men that started MMR but declined participation in the study was higher (30%) than the percentage of men included in the study (15%). In addition, they were of lower age both compared to nonparticipant women and the total study population. Similar characteristics (male gender and young age) have previously been found to be predictors of not completing Web-based interventions [3], and Web-based interventions have suffered from high dropout rates, also with optional participation [3,65]. In this study, the Web-BCPA was self-guided, which may also have affected adherence. The participants may have needed more professional support, such as an extended introduction and/or counseling in the Web-BCPA content, to find the program valuable.

The two-item CSQ was used to assess the participant's coping strategies and, to our knowledge, this is the first time it was tested on a Swedish population. The internal consistency of the catastrophizing and reinterpreting pain sensations subscales was acceptable (alpha=.7), but the other five subscales did not have a satisfying Cronbach alpha. Considering this, our results must be regarded with caution. The two-item CSQ needs to be further tested for reliability and validity.

Conclusion

In this study, the self-guided Web-BCPA was added to MMR. There were no treatment effects regarding self-efficacy, perceived pain intensity, or most coping strategies in this study group of persons with long-lasting pain conditions. However, participants treated with MMR in combination with the Web-BCPA reduced their catastrophic thinking compared to participants in MMR. In addition, they were more satisfied with their MMR. The Web-BCPA adherence was low and may have been influenced by participants' baseline characteristics and their symptom panorama. It may be important to consider the individual's motivation and ability when suggesting a Web-based intervention. Adding counseling to the Web-BCPA might increase adherence and the use of the Web-based intervention.

Acknowledgments

This paper is included in a research project entitled Effects of a Web Behavior Change Program for Activity (Web-BCPA) for Persistent Pain in Primary Health Care and is included in the REHSAM (REHabilitering och SAMordning) national research project in Sweden. The study was performed in cooperation between Luleå University of Technology and the County Council of Norrbotten, and was financed by the REHSAM research project, a cooperation between the Swedish Social Insurance Agency, the Ministry of Health and Social Affairs, the Swedish Association of Local Authorities and Regions, and the Vårdal Foundation.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshot of the web-BCPA.

[PNG File, 270KB - jmir_v18i10e265_app1.png]

Multimedia Appendix 2

Video file of the web-BCPA.

[MP4 File (MP4 Video), 146MB - jmir_v18i10e265_app2.mp4]

References

1. Murray E, May C, Mair F. Development and formative evaluation of the e-Health Implementation Toolkit (e-HIT). BMC Med Inform Decis Mak 2010;10:61 [FREE Full text] [doi: 10.1186/1472-6947-10-61] [Medline: 20955594]
2. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 [FREE Full text] [doi: 10.2196/jmir.1030] [Medline: 18725354]
3. Macea DD, Gajos K, Daglia Calil YA, Fregni F. The efficacy of Web-based cognitive behavioral interventions for chronic pain: a systematic review and meta-analysis. J Pain 2010 Oct;11(10):917-929. [doi: 10.1016/j.jpain.2010.06.005] [Medline: 20650691]
4. Eccleston C, Fisher E, Craig L, Duggan GB, Rosser BA, Keogh E. Psychological therapies (Internet-delivered) for the management of chronic pain in adults. Cochrane Database Syst Rev 2014;2:CD010152. [doi: 10.1002/14651858.CD010152.pub2] [Medline: 24574082]
5. Buhrman M, Gordh T, Andersson G. Internet interventions for chronic pain including headache: a systematic review. Internet Intervent 2016 May;4:17-34. [doi: 10.1016/j.invent.2015.12.001]
6. Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D. Survey of chronic pain in Europe: prevalence, impact on daily life, and treatment. Eur J Pain 2006 May;10(4):287-333. [doi: 10.1016/j.ejpain.2005.06.009] [Medline: 16095934]
7. The Swedish Council on Health Technology Assessment (SBU). Rehabilitation for Long-Lasting Pain. A Literature Review. Stockholm: The Swedish Council on Health Technology Assessment (SBU); 2010:198.
8. Sallinen M, Kukkurainen ML, Peltokallio L, Mikkelsson M. “I'm tired of being tired” Fatigue as experienced by women with fibromyalgia. Adv Phys 2015 May 04;13(1):11-17. [doi: 10.3109/14038196.2010.546880]
9. Ekman M, Jönhagen S, Hunsche E, Jönsson L. Burden of illness of chronic low back pain in Sweden: a cross-sectional, retrospective study in primary care setting. Spine (Phila Pa 1976) 2005 Aug 1;30(15):1777-1785. [Medline: 16094281]
10. Barham L. Economic burden of chronic pain across Europe. J Pain Palliat Care Pharmacother 2012 Mar 07;26(1):70-72. [doi: 10.3109/15360288.2011.650364]
11. Linton SJ. A review of psychological risk factors in back and neck pain. Spine (Phila Pa 1976) 2000 May 1;25(9):1148-1156. [Medline: 10788861]
12. Boersma K, Linton S. Early assessment of psychological factors: the Örebro Screening Questionnaire for Pain. In: Linton SJ, editor. New Avenues for the Prevention of Chronic Musculoskeletal Pain and Disability. Amsterdam: Elsevier; 2002.
13. Gatchel RJ, Peng YB, Peters ML, Fuchs PN, Turk DC. The biopsychosocial approach to chronic pain: scientific advances and future directions. Psychol Bull 2007 Jul;133(4):581-624. [doi: 10.1037/0033-2909.133.4.581] [Medline: 17592957]
14. Dominick CH, Blyth FM, Nicholas MK. Unpacking the burden: understanding the relationships between chronic pain and comorbidity in the general population. Pain 2012 Feb;153(2):293-304. [doi: 10.1016/j.pain.2011.09.018] [Medline: 22071318]
15. Guzmán J, Esmail R, Karjalainen K, Malmivaara A, Irvin E, Bombardier C. Multidisciplinary rehabilitation for chronic low back pain: systematic review. BMJ 2001 Jun 23;322(7301):1511-1516 [FREE Full text] [Medline: 11420271]
16. The National Board of Health and Welfare. National Medical Indications: Indications for Multimodal Rehabilitation for Long-Lasting Pain. 2011. URL: https://www.socialstyrelsen.se/SiteCollectionDocuments/nationella-indikationer-multimodal-rehabilitering.pdf [accessed 2016-01-07] [WebCite Cache ID 6eM4Ugm7F]
17. Swedish Association of Local Authorities and Regions. The Rehabilitation Warranty 2012 (in Swedish). 2013 Dec 12. URL: http://skl.se/download/18.430f8b0b145ac911ed68f7bc/1400163556476/SKL+bilaga+%C3%B6verenskommelse+Rehabiliteringsgaranti+2014.pdf [accessed 2016-02-01] [WebCite Cache ID 6ey1WJHfm]

18. Scascighini L, Toma V, Dober-Spielmann S, Sprott H. Multidisciplinary treatment for chronic pain: a systematic review of interventions and outcomes. Rheumatology (Oxford) 2008 May;47(5):670-678 [FREE Full text] [doi: 10.1093/rheumatology/ken021] [Medline: 18375406]
19. Kamper SJ, Apeldoorn AT, Chiarotto A, Smeets RJ, Ostelo RW, Guzman J, et al. Multidisciplinary biopsychosocial rehabilitation for chronic low back pain: Cochrane systematic review and meta-analysis. BMJ 2015;350:h444 [FREE Full text] [Medline: 25694111]
20. Hållstam A, Stålnacke BM, Svensen C, Löfgren M. “Change is possible”: patients' experience of a multimodal chronic pain rehabilitation programme. J Rehabil Med 2015 Mar;47(3):242-248 [FREE Full text] [doi: 10.2340/16501977-1926] [Medline: 25502883]
21. Sjöström R, Asplund R, Alricsson M. Evaluation of a multidisciplinary rehabilitation program with emphasis on musculoskeletal disorders: a 5-year follow-up. Work 2013;45(2):175-182. [doi: 10.3233/WOR-121551] [Medline: 23324705]
22. Busch H, Bodin L, Bergström G, Jensen IB. Patterns of sickness absence a decade after pain-related multidisciplinary rehabilitation. Pain 2011 Aug;152(8):1727-1733. [doi: 10.1016/j.pain.2011.02.004] [Medline: 21507573]
23. Kääpä EH, Frantsi K, Sarna S, Malmivaara A. Multidisciplinary group rehabilitation versus individual physiotherapy for chronic nonspecific low back pain: a randomized trial. Spine (Phila Pa 1976) 2006 Feb 15;31(4):371-376. [doi: 10.1097/01.brs.0000200104.90759.8c] [Medline: 16481945]
24. Jensen MP, Turner JA, Romano JM. Changes in beliefs, catastrophizing, and coping are associated with improvement in multidisciplinary pain treatment. J Consult Clin Psychol 2001 Aug;69(4):655-662. [Medline: 11550731]
25. Turner JA, Holtzman S, Mancl L. Mediators, moderators, and predictors of therapeutic change in cognitive-behavioral therapy for chronic pain. Pain 2007 Feb;127(3):276-286. [doi: 10.1016/j.pain.2006.09.005] [Medline: 17071000]
26. Börsbo B, Gerdle B, Peolsson M. Impact of the interaction between self-efficacy, symptoms and catastrophising on disability, quality of life and health in with chronic pain patients. Disabil Rehabil 2010;32(17):1387-1396. [doi: 10.3109/09638280903419269] [Medline: 20513205]
27. Costa LC, Maher CG, McAuley JH, Hancock MJ, Smeets RJ. Self-efficacy is more important than fear of movement in mediating the relationship between pain and disability in chronic low back pain. Eur J Pain 2011 Feb;15(2):213-219. [doi: 10.1016/j.ejpain.2010.06.014] [Medline: 20655254]
28. Bandura A. Health promotion by social cognitive means. Health Educ Behav 2004 Apr;31(2):143-164. [doi: 10.1177/1090198104263660] [Medline: 15090118]
29. Jensen MP, Nielson WR, Turner JA, Romano JM, Hill ML. Readiness to self-manage pain is associated with coping and with psychological and physical functioning among patients with chronic pain. Pain 2003 Aug;104(3):529-537. [Medline: 12927625]
30. Miles CL, Pincus T, Carnes D, Homer KE, Taylor SJ, Bremner SA, et al. Can we identify how programmes aimed at promoting self-management in musculoskeletal pain work and who benefits? A systematic review of sub-group analysis within RCTs. Eur J Pain 2011 Sep;15(8):e1-e11. [doi: 10.1016/j.ejpain.2011.01.016] [Medline: 21354838]
31. Livanda. Livanda Internet Clinic Ltd URL: https://www.livanda.se/ [accessed 2016-02-01] [WebCite Cache ID 6ey2VvC9B]
32. Ström L, Pettersson R, Andersson G. A controlled trial of self-help treatment of recurrent headache conducted via the Internet. J Consult Clin Psychol 2000 Aug;68(4):722-727. [Medline: 10965647]
33. Buhrman M, Fältenhag S, Ström L, Andersson G. Controlled trial of Internet-based treatment with telephone support for chronic back pain. Pain 2004 Oct;111(3):368-377. [doi: 10.1016/j.pain.2004.07.021] [Medline: 15363881]
34. Buhrman M, Nilsson-Ihrfeldt E, Jannert M, Ström L, Andersson G. Guided internet-based cognitive behavioural treatment for chronic back pain reduces pain catastrophizing: a randomized controlled trial. J Rehabil Med 2011 May;43(6):500-505 [FREE Full text] [doi: 10.2340/16501977-0805] [Medline: 21533329]
35. Rini C, Williams DA, Broderick JE, Keefe FJ. Meeting them where they are: Using the Internet to deliver behavioral medicine interventions for pain. Transl Behav Med 2012 Mar;2(1):82-92 [FREE Full text] [doi: 10.1007/s13142-011-0107-2] [Medline: 22924084]
36. Chiauzzi E, Pujol LA, Wood M, Bond K, Black R, Yiu E, et al. painACTION-back pain: a self-management website for people with chronic back pain. Pain Med 2010 Jul;11(7):1044-1058. [doi: 10.1111/j.1526-4637.2010.00879.x] [Medline: 20545873]
37. Williams DA, Kuper D, Segar M, Mohan N, Sheth M, Clauw DJ. Internet-enhanced management of fibromyalgia: a randomized controlled trial. Pain 2010 Dec;151(3):694-702 [FREE Full text] [doi: 10.1016/j.pain.2010.08.034] [Medline: 20855168]
38. Carpenter KM, Stoner SA, Mundt JM, Stoelb B. An online self-help CBT intervention for chronic lower back pain. Clin J Pain 2012 Jan;28(1):14-22 [FREE Full text] [doi: 10.1097/AJP.0b013e31822363db] [Medline: 21681084]
39. Ruehlman LS, Karoly P, Enders C. A randomized controlled evaluation of an online chronic pain self management program. Pain 2012 Feb;153(2):319-330 [FREE Full text] [doi: 10.1016/j.pain.2011.10.025] [Medline: 22133450]
40. Boonstra AM, Reneman MF, Schiphorst PH, Waaksma BR, Stewart RE. Differences between patients with chronic musculoskeletal pain treated in an inpatient or an outpatient multidisciplinary rehabilitation program. Int J Rehabil Res 2014 Jun;37(2):187-191. [doi: 10.1097/MRR.0000000000000047] [Medline: 24792483]

41. Huskisson E. Visual analogue scale. In: Melzack R, editor. Pain Measurement and Assessment. New York: Raven Press; 1983:33-37.
42. Stone AA, Broderick JE, Schwartz JE. Validity of average, minimum, and maximum end-of-day recall assessments of pain and fatigue. Contemp Clin Trials 2010 Sep;31(5):483-490. [doi: 10.1016/j.cct.2010.06.004] [Medline: 20620239]
43. Hawker GA, Mian S, Kendzerska T, French M. Measures of adult pain: Visual Analog Scale for Pain (VAS Pain), Numeric Rating Scale for Pain (NRS Pain), McGill Pain Questionnaire (MPQ), Short-Form McGill Pain Questionnaire (SF-MPQ), Chronic Pain Grade Scale (CPGS), Short Form-36 Bodily Pain Scale (SF-36 BPS), and Measure of Intermittent and Constant Osteoarthritis Pain (ICOAP). Arthritis Care Res (Hoboken) 2011 Nov;63 Suppl 11:S240-S252. [doi: 10.1002/acr.20543] [Medline: 22588748]
44. Lorig K, Chastain RL, Ung E, Shoor S, Holman HR. Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis Rheum 1989 Jan;32(1):37-44. [Medline: 2912463]
45. Lomi C, Nordholm LA. Validation of a Swedish version of the Arthritis Self-efficacy Scale. Scand J Rheumatol 1992;21(5):231-237. [Medline: 1439631]
46. Lomi C, Burckhardt C, Nordholm L, Bjelle A, Ekdahl C. Evaluation of a Swedish version of the arthritis self-efficacy scale in people with fibromyalgia. Scand J Rheumatol 1995;24(5):282-287. [Medline: 8533042]
47. Schwarzer R, Jerusalem M. Generalised Self-Efficacy Scale. In: Johnston M, Wright S, Weinman J, editors. Measures in Health Psychology: A User's Portfolio. Windsor: Nfer-Nelson; 1995:35-37.
48. Koskinen-Hagman M, Schwarzer R, Jerusalem M. Swedish Version of the General Self-Efficacy Scale. 1999. URL: http://userpage.fu-berlin.de/health/swedish.htm [accessed 2016-02-01] [WebCite Cache ID 6ey3E7yR4]
49. Löve J, Moore CD, Hensing G. Validation of the Swedish translation of the General Self-Efficacy scale. Qual Life Res 2012 Sep;21(7):1249-1253. [doi: 10.1007/s11136-011-0030-5] [Medline: 21984467]
50. Scholz U, Gutiérrez Doña B, Sud S, Schwarzer R. Is general self-efficacy a universal construct? Eur J Psychol Assess 2002 Sep 1;18(3):242-251. [doi: 10.1027//1015-5759.18.3.242]
51. Jensen MP, Keefe FJ, Lefebvre JC, Romano JM, Turner JA. One- and two-item measures of pain beliefs and coping strategies. Pain 2003 Aug;104(3):453-469. [Medline: 12927618]
52. Jensen IB, Linton SJ. Coping strategies questionnaire (CSQ): reliability of the swedish version of the CSQ. Scand J Behav Ther 1993 Jan;22(3-4):139-145. [doi: 10.1080/16506079309455940]
53. Gould R, Ilmarinen J, Järvisalo J, Koskinen S. Results of the Health Survey, Helsinki. 2000. Dimensions of work ability URL: http://www.etk.fi/fi/gateway/PTARGS_0_2712_459_440_3034_43/http%3B/content.etk.fi%3B7087/publishedcontent/publish/etkfi/fi/julkaisut/tutkimusjulkaisut/erillisjulkaisut/dimensions_of_work_ability_7.pdf [accessed 2016-02-03] [WebCite Cache ID 6f1aMjVUL]
54. Stanford Patient Education Research Center. Arthritis Self-Efficacy Scale URL: http://patienteducation.stanford.edu/research/searthritis.html [accessed 2016-04-14] [WebCite Cache ID 6glAXe1LE]
55. Durlak JA. How to select, calculate, and interpret effect sizes. J Pediatr Psychol 2009 Oct;34(9):917-928 [FREE Full text] [doi: 10.1093/jpepsy/jsp004] [Medline: 19223279]
56. EasyCalculation.com. Effect size calculator URL: https://www.easycalculation.com/statistics/effect-size.php [accessed 2016-02-01] [WebCite Cache ID 6ey3cxlBH]
57. Dear BF, Titov N, Perry KN, Johnston L, Wootton BM, Terides MD, et al. The Pain Course: a randomised controlled trial of a clinician-guided Internet-delivered cognitive behaviour therapy program for managing chronic pain and emotional well-being. Pain 2013 Jun;154(6):942-950. [doi: 10.1016/j.pain.2013.03.005] [Medline: 23688830]
58. Safran DG, Taira DA, Rogers WH, Kosinski M, Ware JE, Tarlov AR. Linking primary care performance to outcomes of care. J Fam Pract 1998 Sep;47(3):213-220. [Medline: 9752374]
59. Hirsh AT, Atchison JW, Berger JJ, Waxenberg LB, Lafayette-Lucey A, Bulcourf BB, et al. Patient satisfaction with treatment for chronic pain: predictors and relationship to compliance. Clin J Pain 2005;21(4):302-310. [Medline: 15951647]
60. Lorig KR, Ritter PL, Laurent DD, Plant K. The internet-based arthritis self-management program: a one-year randomized trial for patients with arthritis or fibromyalgia. Arthritis Rheum 2008 Jul 15;59(7):1009-1017 [FREE Full text] [doi: 10.1002/art.23817] [Medline: 18576310]
61. Lambeek LC, van Mechelen W, Knol DL, Loisel P, Anema JR. Randomised controlled trial of integrated care to reduce disability from chronic low back pain in working and private life. BMJ 2010;340:c1035 [FREE Full text] [Medline: 20234040]
62. Shipton E, Ponnamperuma D, Wells E, Trewin B. Demographic characteristics, psychosocial measures, and pain in a sample of patients with persistent pain referred to a New Zealand tertiary pain medicine center. Pain Med 2013 Jul;14(7):1101-1107 [FREE Full text] [doi: 10.1111/pme.12113] [Medline: 23581616]
63. Verkerk K, Luijsterburg PA, Ronchetti I, Miedema HS, Pool-Goudzwaard A, van Wingerden JP, et al. Course and prognosis of recovery for chronic non-specific low back pain: design, therapy program and baseline data of a prospective cohort study. BMC Musculoskelet Disord 2011;12:252 [FREE Full text] [doi: 10.1186/1471-2474-12-252] [Medline: 22047019]
64. Steele R, Mummery KW, Dwyer T. Development and process evaluation of an internet-based physical activity behaviour change program. Patient Educ Couns 2007 Jul;67(1-2):127-136. [doi: 10.1016/j.pec.2007.02.013] [Medline: 17416479]

65. Mohr DC, Siddique J, Ho J, Duffecy J, Jin L, Fokuo JK. Interest in behavioral and psychological treatments delivered face-to-face, by telephone, and by internet. Ann Behav Med 2010 Aug;40(1):89-98 [FREE Full text] [doi: 10.1007/s12160-010-9203-7] [Medline: 20652466]
66. Ludden GD, van Rompay TJ, Kelders SM, van Gemert-Pijnen JE. How to increase reach and adherence of Web-based interventions: a design research viewpoint. J Med Internet Res 2015;17(7):e172 [FREE Full text] [doi: 10.2196/jmir.4201] [Medline: 26163456]

Abbreviations

ASES: Arthritis Self-Efficacy Scale
BMI: body mass index
CSQ: Coping Strategies Questionnaire
GSE: General Self-Efficacy Scale
ITT: intention-to-treat
LOCF: last observation carried forward
MMR: multimodal rehabilitation
MMR+WEB: multimodal rehabilitation and Web-BCPA
ÖMPSQ: Örebro Musculoskeletal Pain Screening Questionnaire
RCT: randomized controlled trial
VAS: Visual Analog Scale
Web-BCPA: Web Behavior Change Program for Activity

Edited by G Eysenbach; submitted 11.02.16; peer-reviewed by C Gustavsson, M Buhrman; comments to author 06.04.16; revised version received 02.05.16; accepted 07.09.16; published 05.10.16.

Please cite as:
Nordin CA, Michaelson P, Gard G, Eriksson MK
Effects of the Web Behavior Change Program for Activity and Multimodal Pain Rehabilitation: Randomized Controlled Trial
J Med Internet Res 2016;18(10):e265
URL: http://www.jmir.org/2016/10/e265/
doi:10.2196/jmir.5634
PMID:27707686

Original Paper

Do Web-Based Interventions Improve Well-Being in Type 2 Diabetes? A Systematic Review and Meta-Analysis

Michelle Hadjiconstantinou[1], MSc (hon); Jo Byrne[2], PhD; Danielle H Bodicoat[3], PhD; Noelle Robertson[4], DClinPsy; Helen Eborall[5], PhD; Kamlesh Khunti[3], MD; Melanie J Davies[3], MD

[1]Diabetes Research Centre, Department of Health Sciences, University of Leicester, Leicester, United Kingdom

[2]Leicester Diabetes Centre, NHS Trust, University Hospitals of Leicester, Leicester, United Kingdom

[3]Diabetes Research Centre, College of Medicine, Biological Sciences and Psychology, University of Leicester, Leicester, United Kingdom

[4]School of Clinical Psychology, University of Leicester, Leicester, United Kingdom

[5]Social Science Applied to Healthcare Improvement Research (SAPPHIRE) Group, Department of Health Sciences, University of Leicester, Leicester, United Kingdom

Corresponding Author:
Michelle Hadjiconstantinou, MSc (hon)
Diabetes Research Centre
Department of Health Sciences
College of Medicine, Biological Sciences and Psychology
University of Leicester
Leicester, LE5 4PW
United Kingdom
Phone: 44 1162584394
Fax: 44 1162584394
Email: mh333@le.ac.uk

Abstract

Background: Poor diabetes self-care can have a negative impact on psychological well-being and quality of life. Given the scarcity of traditional psychological support and the barriers to uptake of and attendance at face-to-face education programs, Web-based interventions are becoming a popular approach to provide an additional platform for psychological support in long-term conditions. However, there is limited evidence to assess the effect of Web-based psychological support in people with type 2 diabetes.

Objective: This systematic review is the first review to critically appraise and quantify the evidence on the effect of Web-based interventions that aim to improve well-being in people with type 2 diabetes.

Methods: Searches were carried out in the following electronic databases: MEDLINE, EMBASE, CINAHL, PsycINFO, and Cochrane Library. Reference lists were hand-searched. A meta-analysis was conducted for depression and distress outcomes.

Results: A total of 16 randomized controlled studies met the inclusion criteria for the systematic review and 9 were included in the meta-analyses. Theories were applied to the majority of the interventions. The most common behavior change techniques were “General information” and “Tracking/monitoring.” Interventions with a duration of 2-6 months providing professional-led support with asynchronous and synchronous communication appeared to be associated with significant well-being outcomes. The pooled mean (95% confidence interval) difference between the intervention and control arms at follow-up on depression score was -0.31 (-0.73 to 0.11). The pooled mean difference on distress scores at follow-up was -0.11 (-0.38 to 0.16). No significant improvements in depression (*P*=.15) or distress (*P*=.43) were found following meta-analyses.

Conclusions: While the meta-analyses demonstrated nonsignificant results for depression and distress scores, this review has shown that there is a potential for Web-based interventions to improve well-being outcomes in type 2 diabetes. Further research is required to confirm the findings of this review.

(J Med Internet Res 2016;18(10):e270) doi:10.2196/jmir.5991

KEYWORDS

type 2 diabetes; Web-based intervention; Internet; well-being; systematic review; meta-analysis

Introduction

Diabetes has become a global health concern, with 415 million people estimated to be living with diabetes worldwide. This figure is estimated to rise to around 642 million by 2040, with approximately 90% of those cases being type 2 diabetes mellitus [1-3]. Despite a growing number of treatment and therapy options available to people with type 2 diabetes, the number of diabetes-related complications continues to rise [4]. Risk of such complications can be reduced by making appropriate lifestyle changes in addition to diabetes therapies [5]. However, for some, making these changes can become overwhelming, as they must adjust to a new lifestyle and live with diabetes for the rest of their life [6-8]. National and international surveys highlight that poor diabetes self-care and the daily demands of diabetes management can lead to low quality of life and poor well-being [9-12]. The prevalence of poor psychological health is evident, with depression twice as common in people with type 2 diabetes, than those without the condition [13-16], and with distress affecting 10-30% of people with type 2 diabetes [17], leading to poor glycemic control, medication adherence, and overall low health outcomes [18-22].

Well-Being

The Diabetes Management and Impact for Long-term Empowerment and Success report defines well-being as how satisfied an individual is with their quality of life. Other sources state that quality of life is not the end-all definition of well-being but is in fact one of many elements of well-being [23]. The World Health Organization defines well-being as when an individual "…can cope with the normal stresses in life, can work productively and is able to make a contribution to his/her community" [24], whereas the National Institute for Health and Care Excellence guidelines define well-being as when a person is happy and confident with no feelings of anxiety or depression, managing their feelings and emotions and being resilient [25].

It is evident that well-being remains a complex, multifaceted construct that is used interchangeably with various definitions existing across the literature demonstrating subjectively experienced domains and constructs [26,27]. The unclear definition of well-being creates difficulties in measuring this construct, and as a consequence, there are currently numerous questionnaires that measure a wide range of psychological constructs that include aspects of well-being, such as depression, distress, and quality of life [26].

Web-Based Programs

Diabetes self-management education, including structured education and behavior change programs, can prevent or prolong diabetes-related complications [28,29]. However, there is a reported gap in these services' provision of support focusing on well-being [10,30]. Attendance rates at self-management programs are reported to be low due to logistical or infrastructure issues that may contribute to low uptake [31,32]. Given the scarcity of psychological support provided through local services and the barriers to uptake at traditional education programs, Web-based interventions are becoming an additional or alternative provider of support to people with long-term conditions, including type 2 diabetes [33-36].

Evidence on Web-Based Interventions in Type 2 Diabetes and Well-Being

Web-based interventions are described as self-guided programs that aim to change and improve knowledge and awareness around a health condition. Evidence indicates that such interventions are cost-effective, able to reach a wide range of audiences, especially those with a more restrictive lifestyle [37,38]. Recent reviews of Web-based interventions in type 2 diabetes have suggested positive impacts for outcomes of depression and anxiety [35,39]. Other studies and meta-analyses that looked at Web-based interventions for depression also reported effectiveness in elevating lowered mood [40,41]. Some recent reviews, however, have demonstrated no significant improvement in depression or distress [33,34]. Overall, current literature illustrates that there is limited evidence around the effect of such interventions on well-being in people with type 2 diabetes.

According to Corbin and Strauss, self-management programs, whether face-to-face or online, must consist of three constructs: medical, emotional, and role management. For example, they must include tasks around medical or diet adherence (medical self-management), tasks in changing or maintaining new behavioral/life roles within social relationships (role management), or tasks in coping with the emotional burden of living with a long-term condition (emotional management) [42]. To our knowledge, existing reviews mostly focus on medical management [43]. For instance, a recent review that explored online self-management interventions around lifestyle modification examined outcomes that were behavioral (role) and physiological (medical), excluding psychological and emotional management [44].

The aim of this paper is to report the first systematic review to identify and evaluate the current literature on Web-based programs or interventions for emotional management in type 2 diabetes and their impact on well-being.

Methods

Reporting Standards

This systematic review has been registered on PROSPERO (No. CRD42015020281) and meets the requirements of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [45].

Data Sources and Search Methods

The search strategy was carried out to identify relevant studies using the following five databases: MEDLINE, Embase, CINAHL, PsycINFO, and Cochrane Library.

Databases were searched using a combination of Medical Subject Headings (MeSH) topics and free-text terms. An example of the full electronic search strategy used for the databases is included in Multimedia Appendix 1. Publication year was between 1995 and 2016; this limitation was based on the recognition that the Internet became mainstream in 1995 with the launch of Windows 95; therefore, any use of the Internet prior to 1995 would not have met the study criteria [46].

After conducting the search, duplicates were removed and 2 reviewers (MH and JB) independently checked the titles and abstracts. The full text of the remaining papers was retrieved and again independently assessed for inclusion by the same 2 reviewers. Discrepancies were resolved through a third reviewer (DB). Reference lists of included papers were hand-searched. Experts in this topic area were contacted to ensure recent publications were included in this review.

Study Selection

We included studies that were randomized controlled trials (RCTs), including RCT feasibility or pilot studies, with a follow-up of at least 2 months (8 weeks). Due to inconsistent usage of the term “well-being” across the literature and to ensure that no relevant papers were omitted and that the deficits and assets of the term “well-being” were captured, it was decided to use “well-being” as an umbrella term and include the following outcomes: well-being, distress, depression, anxiety, quality of life, self-efficacy, and social support. We incorporated studies that used validated tools to measure the above outcomes.

For the purpose of this review, Web-based interventions are defined as an intervention that may comprise modules or can be a health-related website that aims to change an outcome. Studies were included if they evaluated one Web-based/online intervention, with a combination of other modes, such as telephone calls or SMS (short message service) texts, that provided information, education, peer support, and/or overall therapeutic components to people with type 2 diabetes over the age of 18 years. Studies with any participants with type 2 diabetes (including studies with both type 1 diabetes and type 2 diabetes) were included in the review. Studies were excluded if they were computer-based and not Internet-based, such as studies using a computer for glucose monitoring. Also, studies were excluded if they were not RCTs and if they did not measure well-being or its constructs as a primary or secondary outcome.

Data Extraction and Quality Assessment

An appropriate quality assessment tool was used to assess the validity of the methodology following the Centre for Reviews and Dissemination guidelines [47]. The quality appraisal checklist, the Jadad scale, is used to help assess the quality of the design and conduct of RCTs. The Jadad scale is a 7-item scale and consists of questions indicating whether the quality of the trial is good or poor. Despite the negative criticism of this scale around allocation concealment, this scale has a strong emphasis on the report of trials and was considered appropriate for the review of RCTs [48]. The quality assessment was carried out independently by 2 researchers (MH and JB). A third assessor was consulted in the case of a disagreement (DB).

A standardized data extraction form was used for this review. Qualitative information, including a summary of the interventions and results, was extracted separately. Two reviewers (MH and JB) independently extracted the data and discussed any discrepancies. Where data were missing for the meta-analysis, authors of the eligible studies were contacted.

Data Synthesis

Due to the heterogeneity of the study designs, interventions, and outcomes, qualitative data were summarized and collated using a descriptive data synthesis. Due to the inconsistency of outcome measures across the studies, a meta-analysis was carried out for two outcomes (ie, depression and distress), as these outcomes were reported in the majority of the studies. Both depression and distress were treated as separate constructs. Measures that were used for depression and distress were validated and were as follows. For depression, we included studies that used questionnaires such as the Center for Epidemiologic Studies Depression Scale (CES-D), the Patient Health Questionnaire (PHQ-9), or the Hospital Anxiety and Depression Scale (HADS). For distress, we included studies that used questionnaires such as the Problem Areas in Diabetes Questionnaire (PAID), the Diabetes Distress scale (DDS), or the Health Distress Scale (HDS).

Pooled mean depression and distress scores were estimated separately using random-effects meta-analysis to account for the large heterogeneity that was observed. Standardized means were used to account for the different scales used to measure depression and distress. Publication bias was assessed using the Egger test, and heterogeneity was assessed using the I^2statistic. There were insufficient data to allow subgroup analyses or meta-regression analyses to be performed.

Sensitivity analyses were performed by pooling means depression and distress scores: (1) excluding pilot/feasibility studies, and (2) excluding trials with type 1 diabetes and type 2 diabetes.

All analyses were performed in Stata version 14 (StataCorp), using the METAN command for continuous data.

Results

Study Selection

The search identified 1172 potentially eligible articles (Figure 1). Of these, 63 full texts were assessed for eligibility. Figure 1 illustrates the main reasons for exclusion of articles. Three papers by different first authors reported the same study with identical study population [49-51]; therefore, only one paper was included in the review [50]. A total of 16 studies met the predefined criteria and were included in the review [50,52-66] (Figure 1).

Study Characteristics

A total of 15 studies used a parallel RCT design, with one study using a crossover design [52]. We identified 14 studies that recruited patients diagnosed with type 2 diabetes [50,52,54-65], while four out of those studies recruited participants with both type 2 diabetes and type 1 diabetes [60,61,63,64]. Two studies did not specify the type of diabetes [53,66]. Studies were reported between 2002 and 2015 and were predominantly based in the United States (n=12), with one study carried out in each of the following countries: Canada [65], Norway [63], Germany [60], and the Netherlands [61]. The total number of participants across the studies was 3612 with a range of 17-761 (mean 220.32, SD 172.15). All 16 studies recruited more women

(2208/3612, 61.13%) than men (1404/3612, 38.87%). The mean age across the studies was 53.4 years (range 23.9-67.2 years). Seven out of 16 studies (47%) reported having a predominantly white population (Table 1). A total of six studies (40%) did not report the ethnicity of their study population [57,58,62-64]. The interventions and control groups are described in Multimedia Appendix 2.

Figure 1. Study selection process.

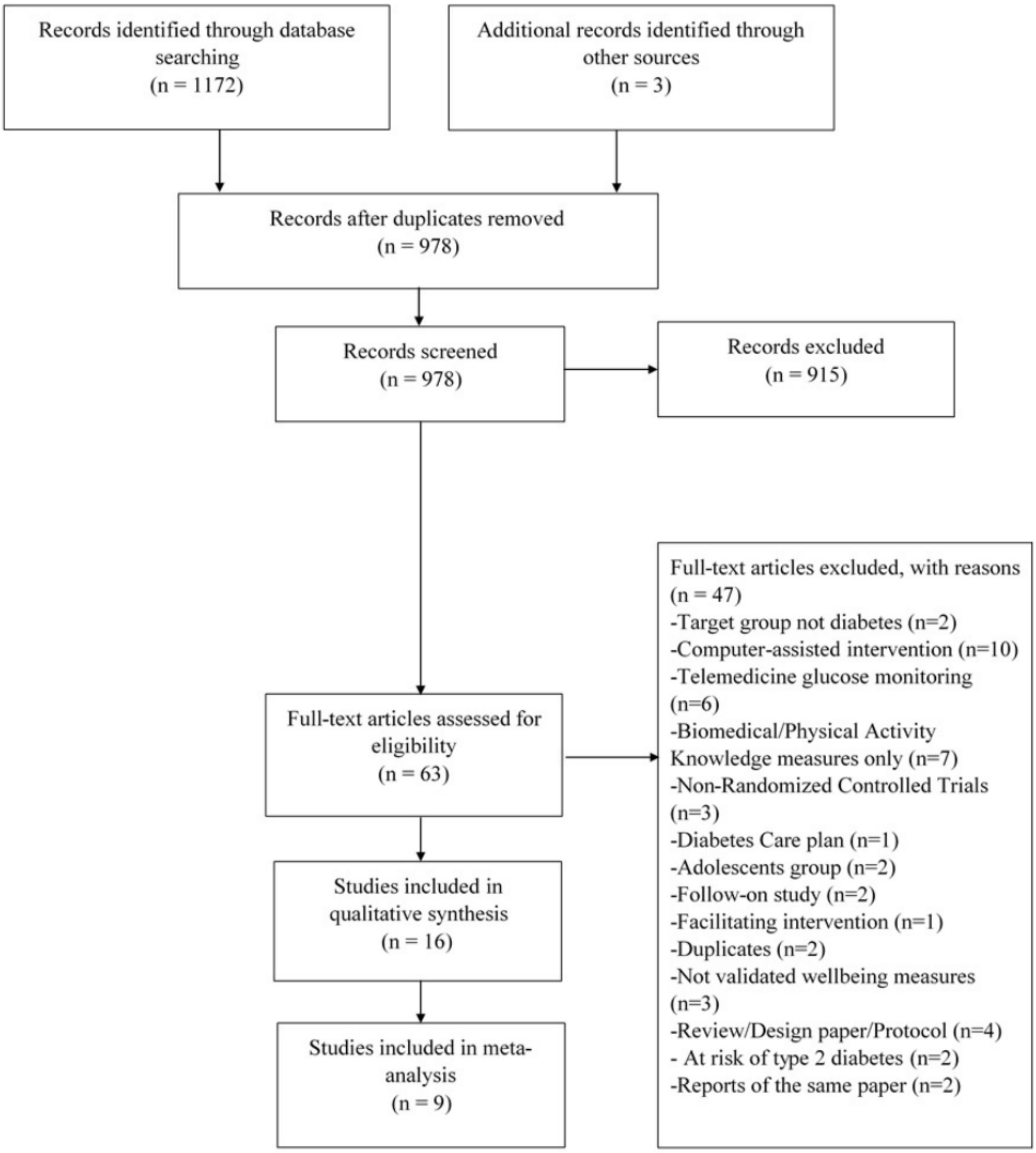


Table 1. Characteristics of the studies included in the review.

Study (year) and location	Name of intervention	Well-being outcome	Type of diabetes	Duration of intervention, months	Total N	Usage over time
Bond (2010) USA [53]	—	Depression Self-efficacy Quality of life Social support	Not specified	6	62	Not reported
Tang (2013) USA [54]	EMPOWER-D	Depression Distress	Type 2	12	415	Not reported
Heisler (2014) USA [55]	iDecide	Distress Self-efficacy	Type 2	3	188	Not reported
Glasgow (2012) USA [56]	CASM	Quality of life Self-efficacy	Type 2	12	463	Declined
McMahon (2012) USA [57]	—	Distress	Type 2	12	151	
McKay (2001) USA [50]	D-Net	Depression	Type 2	2	78	Declined
McKay (2002) USA [58]	D-Net	Depression Quality of life	Type 2	3	160	Declined
Lorig (2010) USA [59]	IDSMP	Depression Distress Self-efficacy	Type 2	6-18	761	Not reported
Nobis (2015) Germany [60]	GET.ON Mood	Depression Distress	Both types 1 and 2 (76% T2D[a])	2	260	—
Van Bastelaar (2011) Netherlands [61]	—	Depression Distress	Both types 1 and 2 (82% T2D)	2	255	Not reported
Fisher (2013) USA [62]	REDEEM (CASM)	Distress	Type 2	12	392	Not reported
Wangberg (2008) Norway [63]	—	Self-efficacy	Both types 1 and 2 (28% T2D)	1	64	—
Hunt (2014) USA [52]	—	Self-efficacy	Type 2	3	17	Not reported
Smith (2000) USA [64]	Women to Women	Quality of life Social Support	Both types 1 and 2 (80% T2D)	5	30	Declined
Pacaud (2012) Canada [65]	—	Quality of life Self-efficacy	Type 2	12	68	Not reported
Fonda (2009) USA [66]	MyCare Team	Distress	Not specified	12	104	Not reported

[a] T2D: type 2 diabetes

Table 2. Methodological quality assessment per intervention.

Study (year)	Criteria							
	Eligibility criteria	Method of randomization	Single-blinded	Description of intervention	Description of withdrawals	Timing of assessment	Sample size calculation	Intention-to-treat analysis
Bond (2010) [53]	✓	✓	✓	✓	x	✓	✓	x
Tang (2013) [54]	✓	✓	✓	✓	✓	x	✓	✓
Heisler (2014) [55]	x	✓	x	✓	✓	✓	✓	x
Glasgow (2012) [56]	✓	✓	x	✓	✓	✓	✓	✓
McMahon (2012) [57]	✓	✓	x	✓	✓	✓	x	✓
McKay (2001) [50]	✓	✓	x	✓	✓	✓	x	x
McKay (2002) [58]	✓	x	x	✓	✓	✓	x	x
Lorig (2010) [59]	✓	✓	✓	✓	✓	✓	✓	x
Nobis (2015) [60]	✓	✓	x	✓	✓	✓	✓	x
Van Bastelaar (2011) [61]	✓	✓	✓	✓	✓	✓	✓	✓
Fisher (2013) [62]	✓	✓	✓	✓	✓	✓	x	x
Wangberg (2008) [63]	✓	x	x	✓	x	x	✓	x
Hunt (2014) [52]	✓	✓	x	✓	✓	✓	x	x
Smith (2000) [64]	✓	✓	x	✓	✓	✓	x	x
Pacaud (2012) [65]	x	x	x	x	x	✓	x	✓
Fonda (2009) [66]	x	x	x	✓	x	✓	x	x

Methodological Quality Assessment

The methodological quality of the studies was generally high (Table 2). Nevertheless, some aspects, such as intention-to-treat, single-blinding, and sample size calculation, were not clearly reported in some studies.

Descriptive Data Synthesis

The most common duration of the interventions was 12 months [54,56,57,62,65,66]. Compliance rates ranged between 42-100%, while attrition rates were reported by the majority of the studies (n=13); these ranged from 6-22%. A few studies (n=4) reported a decline of intervention adherence over time [50,56,58,64]; reporting that the usage declined over 8 weeks [50], 5 months [64], and 12 months [56] (Table 1).

Modes of Communication and Type of Intervention Providers

The communication between intervention provider and/or peers was synchronous (eg, telephone calls) and/or asynchronous (eg, bulletin boards). Intervention providers were those involved in running the online intervention and often had direct or indirect contact with the users. They varied across the studies as follows: psychologists (n=4), nurses (n=6), dieticians (n=3), diabetes educators (n=2), coaches (n=2), social worker (n=1), physician (n=1), pharmacist (n=1), and endocrinologist (n=1). Two studies included nonprofessional providers [59,62], such as lay people and graduates, whereas three studies failed to report any characteristics of their intervention providers [55,63,65].

10 studies provided both asynchronous and synchronous communication [53,56-60,62,64-66], whereas six studies provided communication both with providers and other users [50,53,56,59,64,65]. Out of the seven studies that provided peer

support, four were moderated [56,58,59,64], one was not moderated [53], and two studies did not report on moderation [50,65]. The intervention modules varied between 6-8 sessions. Half the studies specified the duration of their modules (which were online sessions); these varied from 45-120 minutes [54-56,59-62,65].

Theories and Behavior Change Techniques

Six studies failed to report whether their intervention was theory based [42,53,57,64-66]. The remaining ten studies were based on at least one theory: the Chronic Care Model [54], Motivational Interviewing [55,62], Social Cognitive Theory [56,63], Social Ecological Model [50,56], Self-Efficacy Theory [58], Social Support Theory [51], Systematic Behavioral Activation [60], Cognitive Behavioral Theory [61], or Self-Determination Theory [52].

All studies explicitly reported at least one behavior change technique, which we attempted to map onto Michie's taxonomy [67] as follows: information provision (n=14); tracking/self-monitoring (n=12); providing motivation (n=12); providing feedback (n=9); goal setting (n=9); problem solving (n=9); action planning (n=7); social support (n=7); emotional control training (n=6); and prompt review of behavioral goals (n=1) (Table 3).

Table 3. Behavior change techniques used in interventions.

Study (year)	Behavior change techniques									
	General information	Goal setting	Action planning	Problem solving/ barrier	Prompt review of behavioral goals	Prompt self-monitoring/ tracking	Social support	Emotional control training	Motivational approach	Provide feedback on performance
Bond (2010) [53]	✓	✓	✓	✓	x	✓	✓	✓	✓	x
Tang (2013) [54]	✓	✓	✓	x	x	x	x	✓	✓	x
Heisler (2014) [55]	✓	✓	✓	✓	x	✓	x	x	✓	x
Glasgow (2012) [56]	✓	✓	✓	✓	x	✓	✓	x	✓	✓
McMahon (2012) [57]	✓	x	x	x	✓	✓	x	x	✓	✓
McKay (2001) [50]	x	✓	✓	✓	x	✓	✓	x	✓	✓
McKay (2002) [58]	✓	✓	x	✓	x	✓	✓	✓	✓	✓
Lorig (2010) [59]	✓	x	✓	✓	x	✓	✓	✓	✓	x
Nobis (2015) [60]	✓	✓	x	✓	x	x	x	✓	✓	✓
Van Bastelaar (2011) [61]	✓	x	x	x	x	x	x	x	x	✓
Fisher (2013) [62]	x	✓	✓	✓	x	✓	x	x	✓	✓
Wangberg (2008) [63]	✓	x	x	x	x	x	x	x	x	✓
Hunt (2014) [52]	x	x	x	x	x	✓	x	x	x	x
Smith (2000) [64]	✓	x	x	x	x	x	✓	x	x	x
Pacaud (2012) [65]	✓	x	x	x	x	✓	✓	x	x	x
Fonda (2009) [66]	✓	x	x	x	x	✓	x	x	x	x

Table 4. Primary targets and outcomes (primary or secondary) for each intervention.

Study (year)	Primary target	Outcome				
		Depression	Distress	Quality of life	Self-efficacy	Social support
Bond (2010) [53]	Psychosocial well-being	Primary		Primary	Primary	Primary
Tang (2013) [54]	Disease management	Secondary	Secondary			
Heisler (2014) [55]	Unspecified		Secondary		Secondary	
Glasgow (2012) [56]	Psychosocial outcomes			Primary	Primary	
McMahon (2012) [57]	Diabetes-related outcomes		Secondary			
McKay (2001) [50]	Physical activity levels	Primary				
McKay (2002) [58]	Unspecified	Primary		Primary		
Lorig (2010) [59]	HbA_{1c}, exercise, self-efficacy, patient activation	Secondary	Secondary		Secondary	
Nobis (2015) [60]	Depression	Primary	Secondary			
Van Bastelaar (2011) [61]	Depression	Primary	Secondary			
Fisher (2013) [62]	Diabetes distress, self-management		Primary			
Wangberg (2008) [63]	Diabetes self-care behaviors				Secondary	
Hunt (2014) [52]	Self-efficacy, self-management, diabetes outcomes				Primary	
Smith (2000) [64]	Attitudes			Primary		Primary
Pacaud (2012) [65]	Unspecified			Secondary	Secondary	
Fonda (2009) [66]	Diabetes distress		Primary			

Outcomes and Measures

There was a variety of questionnaires used across studies to measure the same outcome. For depression, the following measures were used: CES-D [50,53,58,60,61], PHQ-9 [54,59], and HADS [60]. For distress, studies used PAID [54,57,60,61,66], DDS [55,62], and HDS [59]. Quality of life was assessed by using PAID [53], DDS [56], the Short Form-12 (SF-12) [58], the Quality of Life Index (QoL Index) [64], and the Diabetes Quality of Life Questionnaire [65]. Social support was assessed using the Diabetes Support Scale [53] and the Personal Resource Question [64], whereas self-efficacy was assessed by using the Diabetes Empowerment Scale [53], the Diabetes Self-Efficacy Scale [56,59], the Perceived Competence Scale [63], the Diabetes Management Self-Efficacy Scale [52], and the Rosenberg Self-Esteem Scale [65].

Improvements in Outcomes

Outcomes were measured as primary and/or secondary across the studies (Table 4). Five studies reported significant improvements in distress [55,60-62,66]. Three studies reported nonsignificant/significant improvements in depression [53,60,61]. Self-efficacy improved in four studies [53,56,59,65]. Quality of life showed some or little improvement in the majority of the studies [53,56,58,64]. Social support was significantly improved in one study [53] and "positively influenced" in another study [64].

A subset of the studies that had significant improvement in distress or depression shared some common characteristics [53,59-61]; that is, the interventions combined synchronous and asynchronous communication, with the intervention running between 2 and 6 months. Providers were mostly psychologists, and studies including peer support were moderated. General information was the most common behavior change technique.

Meta-Analysis

Pairwise meta-analysis was carried out on a total of nine studies, with five studies included for depression scores only [50,53,58-60], six for distress scores only [54,55,57,59,60,62], and two studies analyzed for both outcomes [59,60]. The remaining seven studies from the qualitative data synthesis were excluded from the meta-analysis as there were not enough data to analyze each outcome.

Depression

From the five studies with outcome data for depression, the pooled mean (95% confidence interval) difference between the intervention and control arms on depression score was -0.31 (-0.73 to 0.11; Figure 2). The effect was not significant (P=.15). There was considerable heterogeneity (I^2= 89%, P<.001). The funnel plot (Multimedia Appendix 3) and Egger's test (P=.60) show no obvious publication bias.

Distress

From the six studies that reported outcome data for distress, the pooled mean (95% confidence interval) difference between the intervention and control arms on distress scores was -0.11 (-0.38 to 0.16; Figure 3). This effect was not significant (P=.43). There was considerable heterogeneity (I^2=87.7%, P<.001). Egger's test (P=.98) showed some indication of publication bias, but the funnel plot (Multimedia Appendix 4) suggests that some of the studies with a small negative standardized mean difference have not been reported. This suggests that the pooled mean may have been biased towards studies showing no effect or that control is preferable to intervention.

Sensitivity Analyses

When studies with type 1 diabetes and type 2 diabetes participants were excluded for the outcomes depression and distress, the effect size was attenuated and was close to zero (Table 5). Excluding feasibility/pilot studies did not affect the main results (Table 5).

Figure 2. Forest plot of mean difference in depression score between the intervention and control arms at follow-up for studies including Web-based interventions and participants with type 2 diabetes mellitus. SMD: standardized mean difference.

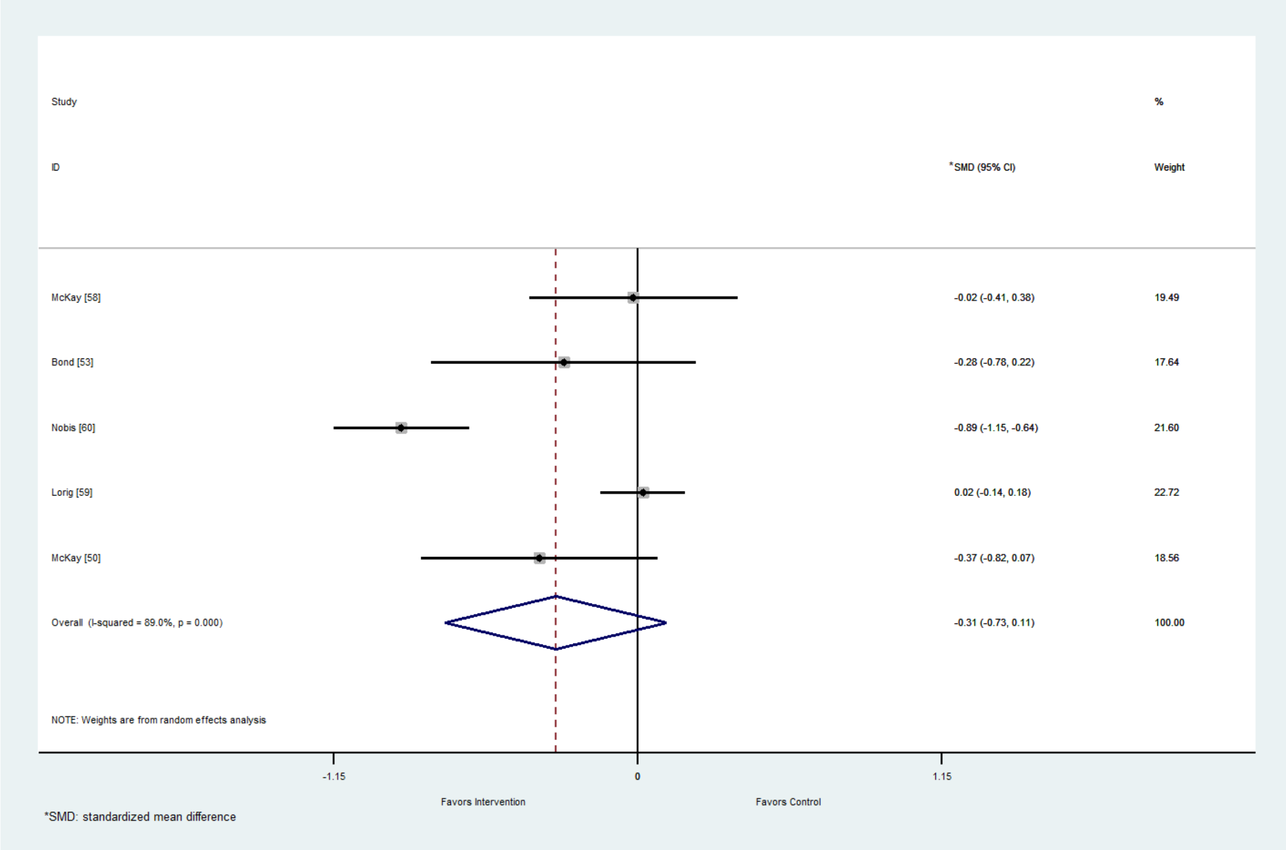


Figure 3. Forest plot of mean difference in distress score between the intervention and control arms at follow-up for studies including Web-based interventions and participants with type 2 diabetes mellitus. SMD: standardized mean difference.

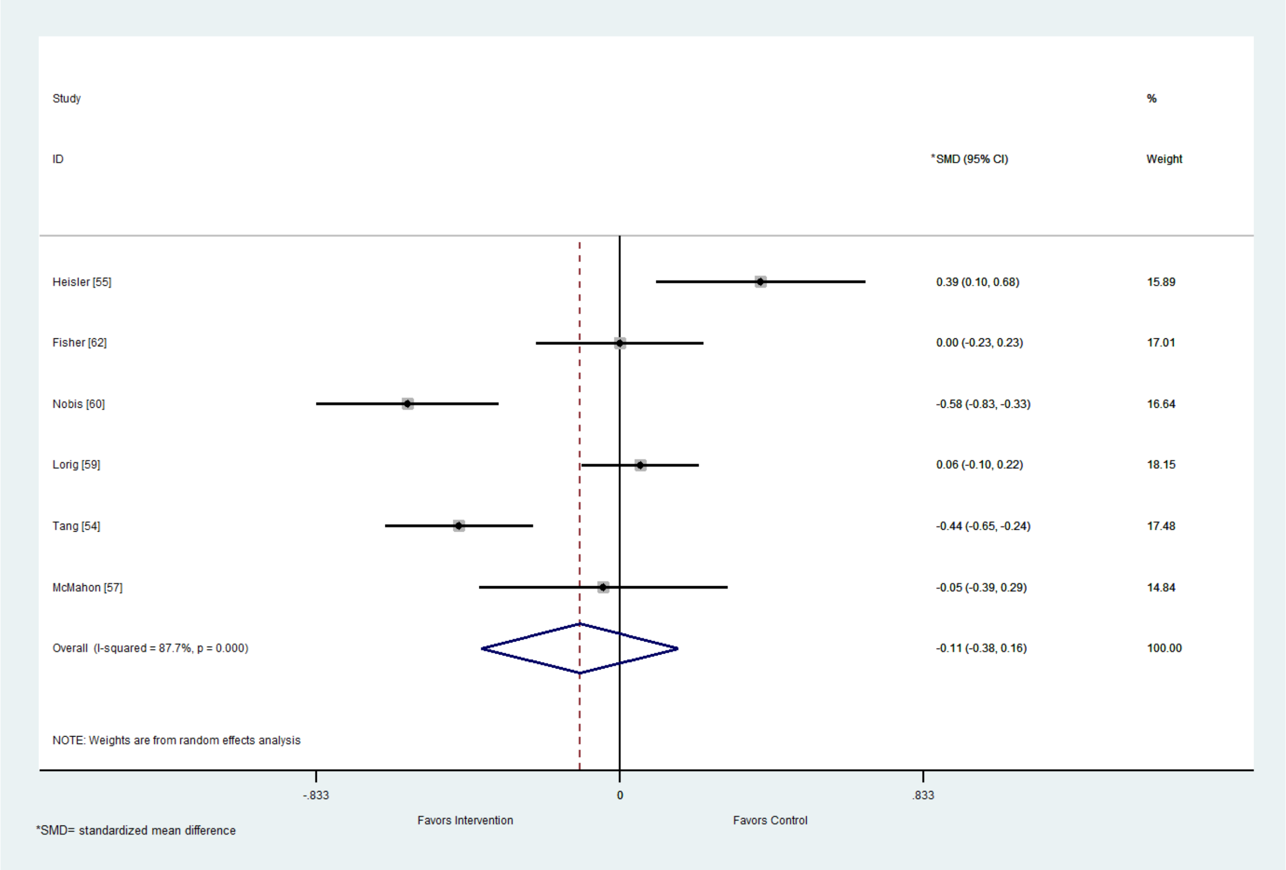


Table 5. Supporting table of pooled values.

Analysis	Depression	Distress
Main analyses	-0.31 (-0.73 to 0.11)	-0.11 (-0.38 to -0.16)
Without feasibility/pilot studies	-0.30 (-0.80 to 0.21)	-0.11 (-0.38 to -0.16)
Without T1D[a] and T2D[b] studies	-0.05 (-0.24 to 0.14)	-0.02 (-0.28 to 0.24)

[a] T1D: type 1 diabetes

[b] T2D: type 2 diabetes

Discussion

Principal Findings

To our knowledge, this is the first systematic review exploring solely the emotional management construct, specifically the following selected well-being elements: depression, distress, self-efficacy, quality of life, and social support. Individually, a number of studies obtained significant improvements in well-being measures. This improvement was not supported by the meta-analysis for the outcomes of depression and distress, confirming previous findings that Web-based interventions have little effect on distress [34] and emotional outcomes overall [33].

Theories and Behavior Change Techniques

Unlike previous reviews on self-management Web-based interventions in type 2 diabetes [33], our review identified a number of theories across the majority of the papers. Evidence indicates that theory-based Web-based interventions are more effective [36] than non theory-based interventions [67,68]; however, there were no conclusive results regarding which theory was associated with the most improved outcomes. Theory-based interventions can help identify behavior change strategies that are also an important element during the development of a condition-specific intervention. In this case, we concluded that Web-based interventions included activities informed by behavior change techniques, with information provision and tracking as the most common techniques. It was evident that there was a wide range of common behavior change techniques used by the majority of the studies, resulting in an inability to identify which behavior change techniques are primarily used, and which are the most effective for this type of intervention. A similar result found in previous reviews on self-management type 2 diabetes interventions [33,36,69].

Type of Intervention Providers

The current evidence around mental health support and online interventions remains divided, with some studies supporting that a professional-led intervention can be beneficial [40], while others suggesting that a non professional-led intervention can perform equally well [41,70]. In this review, the majority of studies that provided professional support showed more promising results than those providing nonprofessional support. This conclusion may be influenced by variation in the roles that these providers had in each study, but also the fact that the ratio of professional- and non professional-led support was uneven across each intervention, with the majority of the studies including professional-led support.

The Need for Shared Definitions

Issues defining “well-being” and its constructs were iterated in our review. For example, one study [54] that stated it was exploring the well-being outcome, in fact did not assess well-being, nor did it use a well-being measure. Instead, the study measured the constructs “depression” and “distress” with depression- and distress-specific scales. Despite depression being considered as a more established construct and being separate to the construct distress, current literature has argued that both depression and distress are still being used interchangeably [17,71]. Depression and distress are both real established constructs, and even though they may overlap with one another, it is important that they be assessed independently.

The Use of Appropriate Specific Outcome Measures

Another issue is the use of incorrect measures for specific outcomes. With distress becoming an established construct [17], it can be measured with validated and reliable distress questionnaires. Specifically, the DDS and PAID measures are both appropriate tools to assess and quantify the construct of distress. However, despite having existing validated measures for this specific construct, it appeared that some questionnaires were used for other outcomes. For example, in two studies, PAID and DDS scales (both distress measures) were used to measure quality of life. Incorrect use of outcome-specific measures can create barriers to distinguishing aspects of well-being.

Strengths and Limitations

This review has used a robust search strategy, which identified a satisfactory number of studies and is reported in accordance with PRISMA guidelines [72] to determine the usefulness of such interventions for this patient group and to highlight key recommendations for future research in this area. The search was conducted on multiple electronic databases, reference lists were hand-searched, and experts in the area were contacted. The review was based on a strict inclusion and exclusion criteria, and 2 independent authors reviewed quality check and potential articles, and extracted data. Studies with participants with both type 1 diabetes and type 2 diabetes were considered in order to include people with type 2 diabetes and to be consistent with previous reviews. To ensure that the effect of changes was examined, sensitivity analyses were carried out excluding studies with participants with type 1 diabetes and type 2 diabetes. Sensitivity analyses were also carried out to exclude pilot/feasibility studies. Both sensitivity analyses further suggested that Web-based interventions demonstrate little improvement in depression and distress.

As with all systematic reviews, there are some limitations to consider. At a study level, the number of studies included in the meta-analysis was low, and there was considerable heterogeneity across studies with regard to intervention design and measurement of outcomes. This could relate to the fact that the primary aim within interventions varied, with some studies focusing on medical management tasks and other studies focusing on emotional management tasks. At a review level, especially when determining what studies should be included, the terms “well-being” and “Web-based interventions” were based on an in-depth review of the literature and in-depth discussions between 2 independent reviewers throughout the process. The lack of comparable data across all outcomes also led to a less reliable descriptive data synthesis being performed rather than a more robust meta-analysis; therefore, any conclusions must be considered with caution. To minimize bias, this review attempted to explain the results in a logical way for each of the included studies.

Implications

Multicomponent interventions may be useful and may seem effective in studies (eg, Web-based, phone-based), but this creates a challenge for researchers to identify whether the intervention as a whole or only certain aspects contribute to the effect of the intervention. Several implications for the conduct of research in this area can be considered.

- Future RCTs looking at similar outcomes should consider using a similar approach to study and/or intervention design in order to make the comparison between interventions much easier, avoiding bias, and in essence producing more reliable conclusions; for example, robust reporting data in line with the Consolidated Standards of Reporting Trials (CONSORT) guidelines and measuring outcomes with similar questionnaires.
- Further research may be needed to examine the effect of Web-based interventions in well-being for people with type 2 diabetes, including long-term studies with larger sample sizes.
- Future studies may provide a full and detailed description of the intervention including its components to help determine why some studies have some effect and other studies have little or no effect on their outcome.
- The majority of RCTs measure psychological outcomes as secondary outcomes, focusing less on the emotional management tasks and more on the medical management. Future studies may aim to approach self-management interventions in a more holistic approach including all three constructs (medical, role, emotional) equally.
- Further research may require more consistent definitions of “well-being” and its constructs and may require consistent validated specific measures for each outcome.
- Michie’s Taxonomy of Behavior Change Techniques could be considered as a guide for a robust classification system.

Conclusion

The findings of this review collated information and highlighted key issues with the evaluation of Web-based interventions for promoting well-being in people with type 2 diabetes (see Multimedia Appendix 5 for a summary of key findings). It has proposed some recommendations for future research to develop effective interventions. Such interventions could allow stakeholders and health care providers to provide effective, integrated, ongoing Web-based support to promote valuable emotional and general management of type 2 diabetes. Web-based interventions could supplement traditional face-to-face support to improve reach and sustainability and in turn create a more holistic approach to diabetes self-management, bridging the gap between diabetes support and diabetes self-care.

Acknowledgments

The authors acknowledge support from the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care – East Midlands (NIHR CLAHRC – EM), the Leicester Clinical Trials Unit, and the NIHR Leicester-Loughborough Diet, Lifestyle and Physical Activity Biomedical Research Unit, which is a partnership between University Hospitals of Leicester NHS Trust, Loughborough University, and the University of Leicester. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health.

The authors would also like to acknowledge Keith Nockels, learning and teaching services librarian of the University of Leicester; Selina Lock, research information advisor of the University of Leicester; and Dr Alison Dunkley, research associate in nursing of the University of Leicester, for their input to the search strategy.

The research was funded by the Diabetes Research Centre, University of Leicester.

Authors' Contributions

MH developed the study protocol, carried out the scientific literature search, extracted and analyzed data, interpreted the results, and drafted the report. JB extracted the data, interpreted the results, and reviewed the report. DB analyzed the data, interpreted the results, and reviewed the report. NR, HE, KK, and MJD contributed to the study protocol and reviewed the report.

Conflicts of Interest

MJD has acted as consultant, advisory board member, and speaker for Novo Nordisk, Sanofi-Aventis, Lilly, Merck Sharp & Dohme, Boehringer Ingelheim, AstraZeneca, and Janssen and as a speaker for Mitsubishi Tanabe Pharma Corporation and Takeda Pharmaceuticals International Inc.
KK has acted as a consultant and speaker for AstraZeneca, Novartis, Novo Nordisk, Sanofi-Aventis, Lilly, Merck Sharp & Dohme, Janssen, and Boehringer Ingelheim. He has received grants in support of investigator and investigator instigated trials from AstraZeneca, Novartis, Novo Nordisk, Sanofi-Aventis, Lilly, Boehringer Ingelheim, Merck Sharp & Dohme, and Roche. KK has served on advisory boards for AstraZeneca, Novartis, Novo Nordisk, Sanofi-Aventis, Lilly, Merck Sharp & Dohme, Janssen, and Boehringer Ingelheim.

Multimedia Appendix 1

Search strategy.

[PDF File (Adobe PDF File), 24KB - jmir_v18i10e270_app1.pdf]

Multimedia Appendix 2

Description of intervention and control groups per study.

[PDF File (Adobe PDF File), 26KB - jmir_v18i10e270_app2.pdf]

Multimedia Appendix 3

Funnel plot for depression.

[PDF File (Adobe PDF File), 21KB - jmir_v18i10e270_app3.pdf]

Multimedia Appendix 4

Funnel plot for distress.

[PDF File (Adobe PDF File), 22KB - jmir_v18i10e270_app4.pdf]

Multimedia Appendix 5

Summary of key findings.

[PDF File (Adobe PDF File), 22KB - jmir_v18i10e270_app5.pdf]

References

1. World Health Organization. 2016. Diabetes Key Facts URL: http://www.who.int/mediacentre/factsheets/fs312/en/ [accessed 2016-09-30] [WebCite Cache ID 6kuSMACRp]
2. Diabetes.co.uk. Diabetes Prevalence URL: http://www.diabetes.co.uk/diabetes-prevalence.html [accessed 2016-09-30] [WebCite Cache ID 6kuSVdFxR]
3. World Health Organization. 2016. Diabetes Media Centre URL: http://www.who.int/mediacentre/factsheets/fs312/en/ [accessed 2016-09-30] [WebCite Cache ID 6kuSdvzdN]
4. Endocrine Web. 2014. Type 2 Diabetes Complications URL: http://www.endocrineweb.com/conditions/type-2-diabetes/type-2-diabetes-complications [accessed 2016-09-30] [WebCite Cache ID 6kuSjDeVL]
5. Russell LB, Suh D, Safford MA. Time requirements for diabetes self-management: too much for many? J Fam Pract 2005 Jan;54(1):52-56. [Medline: 15623407]
6. Bohlen K, Scoville E, Shippee N, May C, Montori V. Overwhelmed patients: a videographic analysis of how patients with type 2 diabetes and clinicians articulate and address treatment burden during clinical encounters. Diabetes Care 2012;35(1):a-9.
7. Brown JB, Nichols GA, Perry A. The burden of treatment failure in type 2 diabetes. Diabetes Care 2004 Jul;27(7):1535-1540. [Medline: 15220224]
8. Franciosi M, Pellegrini F, DeBerardis G, Belfiglio M, Cavaliere D, DiNardo B, QuED Study Group. The impact of blood glucose self-monitoring on metabolic control and quality of life in type 2 diabetic patients: an urgent need for better educational strategies. Diabetes Care 2001 Nov;24(11):1870-1877. [Medline: 11679449]
9. Schram M, Baan C, Pouwer F. Depression and quality of life in patients with diabetes: a systematic review from the European depression in diabetes (EDID) research consortium. Curr Diabetes Rev 2009 May;5(2):112-119 [FREE Full text] [Medline: 19442096]
10. Diabetes UK. Minding the Gap: The Provision of Psychological Support and Care for People With Diabetes in the UK. London: Diabetes UK; 2008. URL: https://www.diabetes.org.uk/Documents/Reports/Minding_the_Gap_psychological_report.pdf [accessed 2016-09-30] [WebCite Cache ID 6kuTMwERu]
11. Karlsen B, Idsoe T, Dirdal I, Rokne HB, Bru E. Effects of a group-based counselling programme on diabetes-related stress, coping, psychological well-being and metabolic control in adults with type 1 or type 2 diabetes. Patient Educ Couns 2004 Jun;53(3):299-308. [doi: 10.1016/j.pec.2003.10.008] [Medline: 15186867]
12. Naess S, Midthjell K, Moum T, Sørensen T, Tambs K. Diabetes mellitus and psychological well-being. Results of the Nord-Trøndelag health survey. Scand J Soc Med 1995 Sep;23(3):179-188. [Medline: 8602488]
13. Snoek FJ, Pouwer F, Welch GW, Polonsky WH. Diabetes-related emotional distress in Dutch and U.S. diabetic patients: cross-cultural validity of the problem areas in diabetes scale. Diabetes Care 2000 Sep;23(9):1305-1309 [FREE Full text] [Medline: 10977023]
14. Grigsby A, Anderson R, Freedland K, Clouse R, Lustman P. Prevalence of anxiety in adults with diabetes: a systematic review. J Psychosom Res 2002 Dec;53(6):1053-1060. [Medline: 12479986]
15. Anderson RJ, Freedland KE, Clouse RE, Lustman PJ. The prevalence of comorbid depression in adults with diabetes: a meta-analysis. Diabetes Care 2001 Jun;24(6):1069-1078. [Medline: 11375373]
16. National Institute for Health and Care Excellence. Depression in Adults With a Chronic Physical Health Problem: Recognition and Management. Clinical guideline CG91. London, UK. NICE. 2009. URL: https://www.nice.org.uk/Guidance/CG91 [accessed 2016-09-30] [WebCite Cache ID 6kuTWwP3u]
17. Snoek F, Bremmer M, Hermanns N. Constructs of depression and distress in diabetes: time for an appraisal. Lancet Diabetes Endocrinol 2015;3(6):450-460. [doi: 10.1016/S2213-8587(15)00135-7] [Medline: 25995123]
18. Adriaanse MC, Pouwer F, Dekker JM, Nijpels G, Stehouwer CD, Heine RJ, et al. Diabetes-related symptom distress in association with glucose metabolism and comorbidity: the Hoorn Study. Diabetes Care 2008 Dec;31(12):2268-2270 [FREE Full text] [doi: 10.2337/dc08-1074] [Medline: 18728236]
19. Fisher L, Skaff MM, Mullan JT, Arean P, Glasgow R, Masharani U. A longitudinal study of affective and anxiety disorders, depressive affect and diabetes distress in adults with Type 2 diabetes. Diabet Med 2008 Sep;25(9):1096-1101 [FREE Full text] [doi: 10.1111/j.1464-5491.2008.02533.x] [Medline: 19183314]
20. Garay-Sevilla ME, Malacara JM, Gutiérrez-Roa A, González E. Denial of disease in Type 2 diabetes mellitus: its influence on metabolic control and associated factors. Diabet Med 1999 Mar;16(3):238-244. [Medline: 10227570]
21. Lustman P, Anderson R, Freedland K, de Groot M, Carney R, Clouse R. Depression and poor glycemic control: a meta-analytic review of the literature. Diabetes Care 2000 Jul;23(7):934-942 [FREE Full text] [Medline: 10895843]
22. Snoek FJ, Pouwer F, Welch GW, Polonsky WH. Diabetes-related emotional distress in Dutch and U.S. diabetic patients: cross-cultural validity of the problem areas in diabetes scale. Diabetes Care 2000 Sep;23(9):1305-1309 [FREE Full text] [Medline: 10977023]

23. Speight J, Browne JL, Holmes-Truscott E, Hendrieckx C, Pouwer F, on behalf of the Diabetes MILES-Australia reference group. Diabetes MILES Study: Diabetes MILES-Australia 2011 Survey Report. Melbourne, VIC: Diabetes Australia; 2011. URL: https://static.diabetesaustralia.com.au/s/fileassets/diabetes-australia/4e052ae5-2d13-421e-b6f8-5e323b5c48a6.pdf [WebCite Cache ID 6kuU3FgZb]
24. World Health Organization. 2015. Mental Health: A State of Well-Being URL: http://www.who.int/features/factfiles/mental_health/en/ [accessed 2016-09-30] [WebCite Cache ID 6kuU78jq1]
25. National Institute for Health and Care Excellence (NICE). 2013. Social and Emotional Wellbeing for Children and Young People URL: https://www.nice.org.uk/advice/lgb12/chapter/introduction [accessed 2016-09-30] [WebCite Cache ID 6kuUPW4Dw]
26. Winefield H, Gill T, Taylor A, Pilkington R. Psychological well-being and psychological distress: is it necessary to measure both? Psychology of Well-Being: Theory, Research and Practice 2012;2(1):3. [doi: 10.1186/2211-1522-2-3]
27. Pollard E, Lee P. Child well-being: A systematic review of the literature. Social Indicators Research 2003;61(1):A-78. [doi: 10.1023/A:1021284215801]
28. Funnell M, Brown T, Childs B, Haas L, Hosey G, Jensen B, et al. National Standards for Diabetes Self-Management Education. Diabetes Care 2010;33(Suppl 1):S89-S96. [Medline: 20042780]
29. Department of Health.: UK Government; 2001. National Service Framework for Diabetes: Standards URL: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/198836/National_Service_Framework_for_Diabetes.pdf [accessed 2016-09-30] [WebCite Cache ID 6kuUfh2qE]
30. Nicolucci A, Kovacs BK, Holt RIG, Comaschi M, Hermanns N, Ishii H, et al. Diabetes Attitudes, Wishes and Needs second study (DAWN2™): cross-national benchmarking of diabetes-related psychosocial outcomes for people with diabetes. Diabet Med 2013 Jul;30(7):767-777. [doi: 10.1111/dme.12245] [Medline: 23711019]
31. Diabetes UK. Diabetes.org.uk. 2009. Improving Supported Self-Management for People with Diabetes URL: https://www.diabetes.org.uk/Documents/Reports/Supported_self-management.pdf [accessed 2016-09-30] [WebCite Cache ID 6kuUqSED1]
32. Wantland D, Portillo C, Holzemer W, Slaughter R, McGhee E. The effectiveness of Web-based vs. non-Web-based interventions: a meta-analysis of behavioral change outcomes. J Med Internet Res 2004 Nov 10;6(4):e40 [FREE Full text] [doi: 10.2196/jmir.6.4.e40] [Medline: 15631964]
33. Pal K, Eastwood S, Michie S, Farmer A, Barnard ML, Peacock R, et al. Computer-based interventions to improve self-management in adults with type 2 diabetes: a systematic review and meta-analysis. Diabetes Care 2014 Jun;37(6):1759-1766. [doi: 10.2337/dc13-1386] [Medline: 24855158]
34. Beatty L, Lambert S. A systematic review of internet-based self-help therapeutic interventions to improve distress and disease-control among adults with chronic health conditions. Clin Psychol Rev 2013 Jun;33(4):609-622. [doi: 10.1016/j.cpr.2013.03.004] [Medline: 23603521]
35. Griffiths F, Lindenmeyer A, Powell J, Lowe P, Thorogood M. Why are health care interventions delivered over the internet? A systematic review of the published literature. J Med Internet Res 2006;8(2):e10 [FREE Full text] [doi: 10.2196/jmir.8.2.e10] [Medline: 16867965]
36. Van Vugt M, De Wit M, Cleijne WJ, Snoek FJ. Use of behavioral change techniques in web-based self-management programs for type 2 diabetes patients: systematic review. J Med Internet Res 2013;15(12):e279 [FREE Full text] [doi: 10.2196/jmir.2800] [Medline: 24334230]
37. Murray E. Web-based interventions for behavior change and self-management: potential, pitfalls, and progress. Med 2 0 2012;1(2):e3 [FREE Full text] [doi: 10.2196/med20.1741] [Medline: 25075231]
38. Paul C, Carey M, Sanson-Fisher R, Houlcroft L, Turon H. The impact of web-based approaches on psychosocial health in chronic physical and mental health conditions. Health Educ Res 2013 Jun;28(3):450-471 [FREE Full text] [doi: 10.1093/her/cyt053] [Medline: 23660463]
39. Barak A, Klein B, Proudfoot JG. Defining internet-supported therapeutic interventions. Ann Behav Med 2009 Aug;38(1):4-17. [doi: 10.1007/s12160-009-9130-7] [Medline: 19787305]
40. Spek V, Cuijpers P, Nyklícek I, Riper H, Keyzer J, Pop V. Internet-based cognitive behaviour therapy for symptoms of depression and anxiety: a meta-analysis. Psychol Med 2007 Mar;37(3):319-328. [doi: 10.1017/S0033291706008944] [Medline: 17112400]
41. Richards D, Richardson T. Computer-based psychological treatments for depression: a systematic review and meta-analysis. Clin Psychol Rev 2012 Jun;32(4):329-342. [doi: 10.1016/j.cpr.2012.02.004] [Medline: 22466510]
42. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med 2003 Aug;26(1):1-7. [Medline: 12867348]
43. Lepard M, Joseph A, Agne A, Cherrington A. Diabetes self-management interventions for adults with type 2 diabetes living in rural areas: a systematic literature review. Curr Diab Rep 2015 Jun;15(6):608. [doi: 10.1007/s11892-015-0608-3] [Medline: 25948497]
44. Cotter A, Durant N, Agne A, Cherrington A. Internet interventions to support lifestyle modification for diabetes management: a systematic review of the evidence. J Diabetes Complications 2014;28(2):243-251 [FREE Full text] [doi: 10.1016/j.jdiacomp.2013.07.003] [Medline: 24332469]

45. Liberati A, Altman D, Tetzlaff J, Mulrow C, Gotzsche P, Ioannidis J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. BMJ 2009 Jul 21;339(jul21 1):b2700-b2700. [doi: 10.1136/bmj.b2700]
46. Leiner B, Cerf V, Clark D, Kahn R, Kleinrock L, Lynch D, et al. The past and future history of the Internet. Commun. ACM 1997;40(2):102-108. [doi: 10.1145/253671.253741]
47. Centre for Reviews and Dissemination. Systematic Reviews: CRD's Guidance for Undertaking Reviews in Health care. York, UK: York Publishing Services Ltd; 2008 URL: https://www.york.ac.uk/media/crd/Systematic_Reviews.pdf [accessed 2016-09-30] [WebCite Cache ID 6kuVJ2uJ6]
48. Cochrane reviews. 2016. Quality Scales and Cochrane Reviews URL: http://handbook.cochrane.org/chapter_8/8_3_3_quality_scales_and_cochrane_reviews.htm [accessed 2016-09-30] [WebCite Cache ID 6kuVQGzIm]
49. Glasgow RE, Boles SM, McKay HG, Feil EG, Barrera M. The D-Net diabetes self-management program: long-term implementation, outcomes, and generalization results. Prev Med 2003 Apr;36(4):410-419. [Medline: 12649049]
50. McKay H, King D, Eakin E, Seeley J, Glasgow R. The diabetes network internet-based physical activity intervention: a randomized pilot study. Diabetes Care 2001 Aug;24(8):1328-1334. [Medline: 11473065]
51. Barrera J, Glasgow RE, McKay HG, Boles SM, Feil EG. Do Internet-based support interventions change perceptions of social support?: An experimental trial of approaches for supporting diabetes self-management. Am J Community Psychol 2002 Oct;30(5):637-654. [doi: 10.1023/A:1016369114780] [Medline: 12188054]
52. Hunt C, Sanderson B, Ellison K. Support for diabetes using technology: a pilot study to improve self-management. Medsurg Nurs 2014;23(4):a-7.
53. Bond G, Burr R, Wolf F, Feldt K. The effects of a web-based intervention on psychosocial well-being among adults aged 60 and older with diabetes: a randomized trial. Diabetes Educ 2010;36(3):446-456. [doi: 10.1177/0145721710366758] [Medline: 20375351]
54. Tang P, Overhage J, Chan A, Brown N, Aghighi B, Entwistle B, et al. Online disease management of diabetes: engaging and motivating patients online with enhanced resources-diabetes (EMPOWER-D), a randomized controlled trial. J Am Med Inform Assoc 2013 May 1;20(3):526-534 [FREE Full text] [doi: 10.1136/amiajnl-2012-001263] [Medline: 23171659]
55. Heisler M, Choi H, Palmisano G, Mase R, Richardson C, Fagerlin A, et al. Comparison of community health worker-led diabetes medication decision-making support for low-income Latino and African American adults with diabetes using e-health tools versus print materials: a randomized, controlled trial. Ann Intern Med 2014 Nov 18;161(10 Suppl):S13-S22 [FREE Full text] [doi: 10.7326/M13-3012] [Medline: 25402398]
56. Glasgow RE, Kurz D, King D, Dickman JM, Faber AJ, Halterman E, et al. Twelve-month outcomes of an Internet-based diabetes self-management support program. Patient Educ Couns 2012 Apr;87(1):81-92 [FREE Full text] [doi: 10.1016/j.pec.2011.07.024] [Medline: 21924576]
57. McMahon GT, Fonda SJ, Gomes HE, Alexis G, Conlin PR. A randomized comparison of online- and telephone-based care management with internet training alone in adult patients with poorly controlled type 2 diabetes. Diabetes Technol Ther 2012 Nov;14(11):1060-1067 [FREE Full text] [doi: 10.1089/dia.2012.0137] [Medline: 22953754]
58. McKay HG, Glasgow RE, Feil EG, Boles SM, Barrera JM. Internet-based diabetes self-management and support: Initial outcomes from the Diabetes Network project. Rehabilitation Psychology 2002;47(1):31-48. [doi: 10.1037/0090-5550.47.1.31]
59. Lorig K, Ritter P, Laurent D, Plant K, Green M, Jernigan V, et al. Online diabetes self-management program: a randomized study. Diabetes Care 2010 Jun;33(6):1275-1281 [FREE Full text] [doi: 10.2337/dc09-2153] [Medline: 20299481]
60. Nobis S, Lehr D, Ebert D, Baumeister H, Snoek F, Riper H, et al. Efficacy of a web-based intervention with mobile phone support in treating depressive symptoms in adults with type 1 and type 2 diabetes: a randomized controlled trial. Diabetes Care 2015 May;38(5):776-783. [doi: 10.2337/dc14-1728] [Medline: 25710923]
61. Van Bastelaar KM, Pouwer F, Cuijpers P, Riper H, Snoek FJ. Web-based depression treatment for type 1 and type 2 diabetic patients: a randomized, controlled trial. Diabetes Care 2011 Feb;34(2):320-325 [FREE Full text] [doi: 10.2337/dc10-1248] [Medline: 21216855]
62. Fisher L, Hessler D, Glasgow R, Arean P, Masharani U, Naranjo D, et al. REDEEM: a pragmatic trial to reduce diabetes distress. Diabetes Care 2013 Sep;36(9):2551-2558 [FREE Full text] [doi: 10.2337/dc12-2493] [Medline: 23735726]
63. Wangberg SC. An Internet-based diabetes self-care intervention tailored to self-efficacy. Health Educ Res 2008 Feb;23(1):170-179 [FREE Full text] [doi: 10.1093/her/cym014] [Medline: 17412717]
64. Smith L, Weinert C. Telecommunication support for rural women with diabetes. Diabetes Educ 2000;26(4):645-655. [Medline: 11140073]
65. Pacaud D, Kelley H, Downey A, Chiasson M. Successful delivery of diabetes self-care education and follow-up through eHealth media. Can J Diabetes 2012;36(5):257-262.
66. Fonda SJ, McMahon GT, Gomes HE, Hickson S, Conlin PR. Changes in diabetes distress related to participation in an internet-based diabetes care management program and glycemic control. J Diabetes Sci Technol 2009 Jan;3(1):117-124 [FREE Full text] [Medline: 20046656]
67. Michie S, Johnston M, Francis J, Hardeman W, Eccles M. From theory to intervention: Mapping theoretically derived behavioural determinants to behaviour change techniques. Appl Psychol 2008;57(4):660-680. [doi: 10.1111/j.1464-0597.2008.00341.x]

68. Webb T, Joseph J, Yardley L, Michie S. Using the internet to promote health behavior change: a systematic review and meta-analysis of the impact of theoretical basis, use of behavior change techniques, and mode of delivery on efficacy. J Med Internet Res 2010;12(1):e4 [FREE Full text] [doi: 10.2196/jmir.1376] [Medline: 20164043]
69. Ramadas A, Quek K, Chan CKY, Oldenburg B. Web-based interventions for the management of type 2 diabetes mellitus: a systematic review of recent evidence. Int J Med Inform 2011 Jun;80(6):389-405. [doi: 10.1016/j.ijmedinf.2011.02.002] [Medline: 21481632]
70. Johansson R, Andersson G. Internet-based psychological treatments for depression. Expert Rev Neurother 2012 Jul;12(7):861-9; quiz 870. [doi: 10.1586/ern.12.63] [Medline: 22853793]
71. Fisher L, Gonzalez J, Polonsky W. The confusing tale of depression and distress in patients with diabetes: a call for greater clarity and precision. Diabet Med 2014 Jul;31(7):764-772 [FREE Full text] [doi: 10.1111/dme.12428] [Medline: 24606397]
72. Cochrane Community. 2016. Reporting Guidelines URL: https://community-archive.cochrane.org/about-us/evidence-based-health-care/webliography/books/reporting [accessed 2016-09-30] [WebCite Cache ID 6kuWArNIU]

Abbreviations

CES-D: Center for Epidemiologic Studies Depression Scale
CONSORT: Consolidated Standards of Reporting Trials
DDS: Diabetes Distress Scale
HADS: Hospital Anxiety and Depression Scale
HDS: Health Distress Scale
MeSH: Medical Subject Headings
PAID: Problem Areas in Diabetes Questionnaire
PHQ-9: Patient Health Questionnaire
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
QoL Index: Quality of Life Index
RCT: randomized controlled trial
SF-12: Short Form-12
SMS: short message service
WHO: World Health Organization

Edited by G Eysenbach; submitted 25.05.16; peer-reviewed by D Richards, D Lehr; comments to author 28.07.16; revised version received 19.08.16; accepted 07.09.16; published 21.10.16.

Please cite as:
Hadjiconstantinou M, Byrne J, Bodicoat DH, Robertson N, Eborall H, Khunti K, Davies MJ
Do Web-Based Interventions Improve Well-Being in Type 2 Diabetes? A Systematic Review and Meta-Analysis
J Med Internet Res 2016;18(10):e270
URL: http://www.jmir.org/2016/10/e270/
doi:10.2196/jmir.5991
PMID:27769955

Original Paper

Influence of Pedometer Position on Pedometer Accuracy at Various Walking Speeds: A Comparative Study

Frederic Ehrler[1*], PhD; Chloé Weber[1*], MSc; Christian Lovis[1,2], MPH, MD

[1]Division of Medical Information Sciences, University Hospitals of Geneva, Geneva, Switzerland
[2]Faculty of Medicine, University of Geneva, Geneva, Switzerland
[*]these authors contributed equally

Corresponding Author:
Frederic Ehrler, PhD
Division of Medical Information Sciences
University Hospitals of Geneva
Gabrielle-Perret-Gentil, 4
Geneva, 1205
Switzerland
Phone: 41 22 37 28697
Fax: 41 22 37 26255
Email: frederic.ehrler@hcuge.ch

Abstract

Background: Demographic growth in conjunction with the rise of chronic diseases is increasing the pressure on health care systems in most OECD countries. Physical activity is known to be an essential factor in improving or maintaining good health. Walking is especially recommended, as it is an activity that can easily be performed by most people without constraints. Pedometers have been extensively used as an incentive to motivate people to become more active. However, a recognized problem with these devices is their diminishing accuracy associated with decreased walking speed. The arrival on the consumer market of new devices, worn indifferently either at the waist, wrist, or as a necklace, gives rise to new questions regarding their accuracy at these different positions.

Objective: Our objective was to assess the performance of 4 pedometers (iHealth activity monitor, Withings Pulse O2, Misfit Shine, and Garmin vívofit) and compare their accuracy according to their position worn, and at various walking speeds.

Methods: We conducted this study in a controlled environment with 21 healthy adults required to walk 100 m at 3 different paces (0.4 m/s, 0.6 m/s, and 0.8 m/s) regulated by means of a string attached between their legs at the level of their ankles and a metronome ticking the cadence. To obtain baseline values, we asked the participants to walk 200 m at their own pace.

Results: A decrease of accuracy was positively correlated with reduced speed for all pedometers (12% mean error at self-selected pace, 27% mean error at 0.8 m/s, 52% mean error at 0.6 m/s, and 76% mean error at 0.4 m/s). Although the position of the pedometer on the person did not significantly influence its accuracy, some interesting tendencies can be highlighted in 2 settings: (1) positioning the pedometer at the waist at a speed greater than 0.8 m/s or as a necklace at preferred speed tended to produce lower mean errors than at the wrist position; and (2) at a slow speed (0.4 m/s), pedometers worn at the wrist tended to produce a lower mean error than in the other positions.

Conclusions: At all positions, all tested pedometers generated significant errors at slow speeds and therefore cannot be used reliably to evaluate the amount of physical activity for people walking slower than 0.6 m/s (2.16 km/h, or 1.24 mph). At slow speeds, the better accuracy observed with pedometers worn at the wrist could constitute a valuable line of inquiry for the future development of devices adapted to elderly people.

(J Med Internet Res 2016;18(10):e268) doi:10.2196/jmir.5916

KEYWORDS

frail elderly; mHealth; walking; motor activity

Introduction

Physical activity is universally recognized as playing an essential role in primary, secondary, and tertiary health prevention. This has been highlighted for patients with cardiovascular disease, diabetes, or osteoporosis, among other health hazards [1]. With the widespread increase in life expectancy, these diseases become more frequent [2], thereby exerting greater pressure and generating increasing costs on the health care system. One recognized way to reduce the cost associated with this progressively frail population is to improve their independence and health by keeping them physically active [3]. Physical activity decreases the incidence of chronic diseases such as diabetes, hypertension, and obesity, among others [4], and reduces hospitalization as well as the mortality rate [5,6]. It has been demonstrated that elderly people who remain physically active reduce their risk of falling, have decreased disability, succumb less to diseases, and maintain their independence longer [7,8]. Walking is a suitable physical activity for frail individuals, as well as being one of the preferred activities among older adults [9]. Therefore, any intervention able to encourage walking activities should be promoted among this population. Goal-setting theory teaches us that measuring one’s activity, setting suitable goals, and receiving positive feedback on it is a motivating factor toward undertaking more physical activities [10]. The low cost, small size, and simple ergonomics of pedometers make them particularly suited to motivate people to stay active by monitoring their activities [11]. However, in order to successfully apply goal-setting theory, it is reasonable to expect a minimum level of accuracy from the selected pedometer. Indeed, irrelevant feedback can frustrate users and lead them to give up their objectives.

Frail individuals, such as diabetic, obese patients or those with heart failure, often walk at a slow pace (around 0.6 m/s [12] and as low as 25 m/min, or 0.4 m/s, for community ambulation [13]). At such a pace, many pedometers show a lack of accuracy with relative errors going from 30% to 60% [12,14-17]. A study on a group of patients with chronic heart failure testing the accuracy of the Omron HJ-720ITC pedometer reported an error close to 24% at 0.66 m/s, approximately 9% at 0.83 m/s, 5% at 1 m/s, approximately 3% at 1.16 m/s, and 1% at 1.33 m/s [12]. The study of Marschollek et al [14] compared 4 freely accessible pedometer algorithms on healthy people and on mobility-impaired geriatric inpatients in free walking. With healthy people, an error between 8.4% and 30.8% was observed, whereas with the geriatric population the error was between 28.1% and 62.1%. Another study [15] comparing 5 pedometers (Omron HJ-105, Yamax Digiwalker 200, SportLine330, New-Lifestyles 2000, and ActiCal) on older adults reported a mean error of 9% for all devices at a self-selected speed. This error rose to 19% at 80 steps/min, 40% at 66 steps/min, and 56% at 50 steps/min. Fitbit Ultra worn on the wrist and on the hip was tested with the Samsung GT-19300 mobile phone in a study conducted by Lauritzen et al [16]. This device was tested on 3 distinct populations: healthy adults, elderly people with normal mobility, and elderly people with reduced mobility using a rollator. The count produced for elderly people using a rollator had a greater than 60% error. Other studies have been conducted to investigate the influence of the position of the pedometer on its accuracy [18,19]. For instance, a study by Abel et al [18] tested a pedometer at 3 positions at the waist (anterior, midaxillary, and posterior) for 3 different speeds (59, 72, and 86 m/s and at own pace) and took into account the influence of the waist circumference. Whereas the placement had no influence for a low waist circumference, the posterior position was best with a high waist circumference. Another study evaluated the Yamax SW-200 pedometer in 5 different positions at the waist (left midaxillary, left midthigh, umbilical, right midthigh, and right midaxillary). The tests of using the pedometer while walking on a treadmill on flat ground, as well as ascending and descending stairs, indicated a better performance when the pedometer was positioned in the left midaxillary position [19].

Although, until recently, most pedometers were worn at the waist, a new generation entering the market offers more versatility and can be worn not only at the waist but also at the wrist or as a necklace. These new pedometer positions raise questions regarding their accuracy compared with the one worn at the waist. In order to investigate the influence of the position (wrist, waist, or necklace) in relation to the speed of movement, we conducted a comparative study of several pedometers by exploring the accuracy of their readings depending on the position of the device and the speed of movement.

Methods

We tested 4 commercially available pedometers at 4 different walking speeds: 3 at controlled speed (0.4 m/s, 0.6 m/s, and 0.8 m/s) and 1 at uncontrolled speed (natural speed of the participants) on a normalized 100 m long floor with equidistant marks. Each experiment was videotaped at normalized speed and synchronized to the participants. Pedometers were reset between each experiment and used with full charge power. The number of steps indicated by the pedometer was compared with the number of steps manually counted using the video.

Participants

From previous similar studies, we have identified that a minimum of 20 participants [20] is necessary to demonstrate significant differences between the experimental settings. Since slow walks simulated by adults do not produce acceleration patterns significantly different from those of frail individuals with reduced walking speed [21,22], we decided to recruit healthy people and ask them to walk at controlled paces. Participants were recruited on a voluntary basis with the only inclusion criterion being that they should be able to walk at least 500 m and not have any walking disabilities.

Instruments

We used 4 different devices during this study: iHealth activity monitor (IH; iHealth Labs Inc, Mountain View, CA, USA), Withings Pulse O2 (WI; Withings, Issy-les-Moulineaux, France), Misfit Shine (MF; Misfit, Inc, Burlingame, CA, USA), and Garmin vívofit (GA; Garmin Ltd, Southampton, UK). Table 1 lists their specifications. We selected these devices according to the following criteria: (1) 2 devices that can be worn at several positions, can count steps during an entire day, and can be integrated into a complete solution of health monitoring, (2) 1 device that is especially small, and (3) 1 device that integrates into a wide-ranging sport ecosystem.

iHealth Activity Monitor

iHealth is a brand specialized in health devices such as a glucometer and a blood pressure monitor. The IH can register the total number of steps during a day, distance travelled, and calories burned. It tracks sleep quality and can be placed either at the wrist or at the waist on a belt.

Withings Pulse O2

Withings commercializes devices such as a blood pressure monitor, a sleep monitor, a scale, and a pedometer. The WI can be placed at the wrist, on a belt, or on a shirt collar. This device tracks the number of steps, elevation, running time, calories burned, and distance travelled. It tracks users' sleep quality, heart rate, and blood oxygen level.

Misfit Shine

Misfit doesn't offer the same range of monitoring device as the 2 previous brands. We chose the MF for its very small size, an interesting feature that favors its acceptance by elderly people who are especially sensitive to stigmatization. It can be worn at the wrist, on a belt, or as a necklace. The device tracks the number of steps, distance travelled, calories burned, and the sleep pattern.

Garmin Vívofit

Garmin is a brand that covers a very large ecosystem of devices for sporting activities. The GA tracks the number of steps, calories burned, distance travelled, and sleep pattern. It can only be placed at the wrist.

Procedure

The study took place in a flat area where ground markings indicated distances. We performed the study in 2 phases. In the first phase, we requested participants to walk 200 m at their preferred pace in order to assess the performance of the pedometers at natural speed. In the second phase, participants walked for a distance of 100 m at a controlled speed wearing all pedometers simultaneously. We selected 3 different walking speeds (0.4 m/s, 0.6 m/s, and 0.8 m/s) for our experiment. The slowest speed was set to 0.4 m/s, since several studies have recognized this speed as the minimum necessary for performing everyday activities [13,23,24]. The fastest speed was limited to 0.9 m/s, since this is the limit that defines normal speed [24]. We relied on the methodology defined by Martin et al [15] and used a metronome to constrain the cadence of the walker. In order to minimize intra- and interparticipant variation, their step length was also constrained using a string attached between their legs at the level of their ankles. As footstep length and cadence are related [25], the string also enables footstep length to be limited in order to keep a natural ratio with cadence that should be adopted at a specific speed.

According to research, the relation between footstep length and cadence is 0.55 steps/min [25]. Consequently, for each targeted speed, footstep length can be determined using the ratio in equation 1 expressing the relation between footstep length, speed, and cadence (Figure 1, equation 2). Once footstep length is calculated, the cadence can be simply derived by transforming the equation 1 (Figure 1, equation 3).

Based on equations 2 and 3, we calculated the various settings of the experiment, presented in Table 2.

Table 1. Device specifications.

Specification	Device			
	iHealth activity monitor	Withings Pulse O2	Misfit Shine	Garmin vívofit
Screen	Yes	Yes	No	Yes
Time	Yes	Yes	Yes	Yes
Steps	Yes	Yes	Yes	Yes
Calories	Yes	Yes	Yes	Yes
Distance	Yes	Yes	Yes	Yes
Sleep	Yes	Yes	Yes	Yes
Other	None	Elevation Heart rate Blood oxygen	Cycling Running Swimming	None
Position	Wrist, belt	Wrist, belt, shirt collar	Wrist, belt, necklace	Wrist
Battery life	7 days	2 days	3 months	1 year

Table 2. Calculated relations between speed, footstep length, and cadence.

	Speed (m/s)		
	0.4	0.6	0.8
Footstep length (cm)	36	44	51
Cadence (steps/min)	66	82	93

Figure 1. Equations for determining footstep length (stepLength; equation 1), and the relationship between speed, cadence, and footstep length (equations 2 and 3). The relative error between the real number of steps (nbRealSteps) and the number of steps registered by the pedometer (nbStepsPedometer) is calculated by equation 4.

$$stepLength = speed/cadence \qquad (1)$$

$$\begin{aligned} stepLength\ (cm) &= \sqrt{speed * stepLength/cadence} \\ &= \sqrt{speed\ (m/s) * 3300} \end{aligned} \qquad (2)$$

$$Cadence \left(\frac{steps}{min}\right) = \frac{speed \left(\frac{m}{s}\right) * 6000}{stepLength\ (cm)} \qquad (3)$$

$$relativeError\ (\%) = \left(1 - \frac{nbStepsPedometer}{nbRealSteps}\right) \qquad (4)$$

Each participant was encouraged to practice walking under these conditions as long as required until they considered they could walk the 100 m comfortably at the desired speed. Each walk was videotaped in order to count the number of steps precisely during the analysis stage.

Statistical Analysis

The actual footsteps were counted manually using the videotape by 2 independent (CW and FE) observers. If the number of steps counted did not match, the counting was restarted until they corresponded. This measure was then considered as the real step count to be compared with the count returned by the pedometers.

We calculated the relative error between real number of steps and steps registered by the pedometers according to equation 4.

For each speed and each position, we calculated the mean of the error. A 1-way analysis of variance (ANOVA) was conducted to evaluate whether there was a significant difference between the position for each speed and speed for each position of the group. The confidence interval was set at 95%.

Because we collected no personal data, we did not request institutional review board approval.

Results

A total of 21 people participated in the study, 12 women and 9 men. The average age of the participants was 34.5 years (SD 15.7).

The results are presented in terms of the mean relative counting error at each speed and for each pedometer, as well as the average error for all participants (Table 3). The results are also presented graphically in Figure 2 and Figure 3. Figure 2 contains a set of bar graphs highlighting the influence of speed on accuracy by position, and Figure 3 contains a set highlighting the influence of position on accuracy by speed.

Table 3. Absolute mean relative error between real number of steps and steps registered by each pedometer, worn in different positions, as a percentage and standard deviation.

Pedometer	Location	Speed (m/s)			
		Natural speed	0.8	0.6	0.4
IH[a]	Wrist	10.21 (19.67)	14.79 (26.03)	26.97 (34.06)	62.64 (41.94)
	Belt	0.55 (0.67)	5.12 (11.63)	16.29 (20.99)	56.45 (27.20)
WI[b]	Wrist	14.37 (23.78)	30.20 (31.43)	64.07 (41.76)	88.51 (25.35)
	Belt	0.87 (0.80)	18.27 (29.07)	80.92 (27.00)	99.34 (3.79)
	Necklace	1.52 (2.95)	29.07 (27.55)	88.46 (25.73)	99.84 (0.50)
MF[c]	Wrist	37.16 (47.81)	55.08 (8.10)	40.18 (32.67)	55.90 (33.19)
	Belt	39.05 (48.54)	40.93 (41.62)	49.87 (39.41)	70.51 (45.08)
	Necklace	10.93 (26.05)	34.93 (34.60)	53.09 (36.18)	63.32 (35.13)
GA[d]	Wrist	3.08 (5.65)	5.31 (9.38)	12.24 (16.92)	80.14 (25.41)

[a] IH: iHealth activity monitor.

[b] WI: Withings Pulse O2.

[c] MF: Misfit Shine.

[d] GA: Garmin vívofit.

The MF pedometer generated an error higher than 30% in all cases, except at a natural pace when worn as a necklace (11%). When pedometers were worn at the wrist, the error was higher than 10% independently of the walking speed, except for GA. At a natural pace, every pedometer worn at the belt generated errors below 5%, except for MF. GA placed at the wrist and IH placed at the belt still had an error below 6% at 0.8 m/s and below 20% at 0.6 m/s. IH at the wrist and WI at the belt had an error below 20% at 0.8 m/s.

Table 4 presents the mean error in terms of position and speed, with the results of a 1-way ANOVA.

Results According to Speed

The general tendency observed in Figure 2 highlights the correlation between the decrease of speed and the increase of mean error. This tendency was verified for every pedometer at every position except for MF at the wrist. For this pedometer, there was similar relative error at 0.4 m/s and 0.8 m/s (approximately 55%), as well as at 0.6 m/s and at natural speed (approximately 40%).

Results According to Position

At a natural pace, when pedometers were placed at the wrist, the mean relative error was higher than when they are located at the 2 other positions (Figure 3). At the belt, pedometers were less accurate than at the collar. At 0.8 m/s, the belt position generated results with the best accuracy, followed by the wrist and then the necklace. At 0.6 m/s, the wrist position generated the lowest error, followed by the belt and the necklace positions. The same tendency was observed at 0.4 m/s.

The 1-way ANOVA showed that at each position, the mean error differed at each selected speed, except at the belt, where it was at the limit of confidence. On the other hand, 1-way ANOVA didn't reveal a significant difference in accuracy at the various positions for a given speed.

Table 4. Mean relative error between walking speed and position of the pedometers as a percentage.

Position	Speed (m/s)				Average	*P* value
	Natural speed	0.8	0.6	0.4		
Wrist	16.21	26.35	35.87	71.80	37.56	<.05
Belt	13.49	21.44	49.03	75.43	39.85	.05
Necklace	6.23	32.00	70.78	81.58	47.65	<.05
Average	11.98	26.60	51.89	76.27		
P value	.49	.79	>.99	.59		

Figure 2. Mean relative error in terms of speed for each position (each pedometer is represented by a different shade, from the brightest to the darkest: iHealth activity monitor, Withings Pulse O2, Misfit Shine, Garmin vivofit). The largest black bar represents the average for all pedometers.

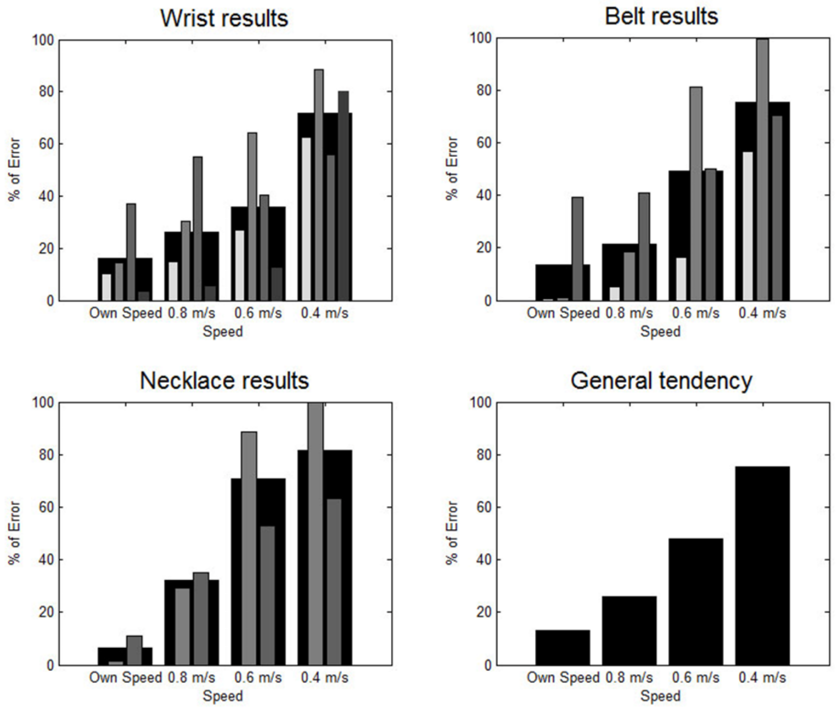
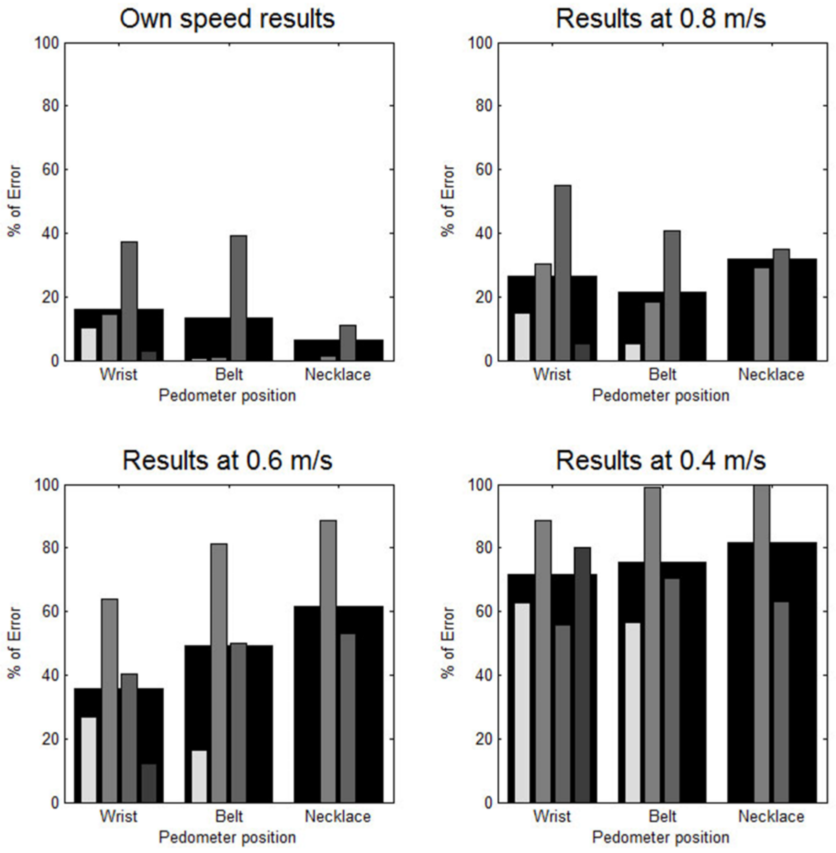


Figure 3. Mean relative error in terms of position for each speed (each pedometer is represented by a different shade, from the brightest to the darkest: iHealth activity monitor, Withings Pulse O2, Misfit Shine, Garmin vivofit). The largest black bar represents the average for all pedometers.



Discussion

The influence of speed on accuracy can be clearly observed in Figure 2, regardless of which pedometer or position was selected. The mean relative error significantly increased when speed decreased until it attained more than 50% at the slowest pace. The MF placed at the wrist did not show the same tendency, since the error at 0.6 m/s was lower than the error at 0.8 m/s. We attribute this phenomenon to the strong unreliability of this pedometer, which produced a high rate of error when worn at the wrist even at a user-preferred speed.

The reason for the important error at low speed may stem from the type of algorithm used in most pedometers. In order to count steps, many algorithms rely on vertical acceleration. As the vertical acceleration diminishes according to the walking speed, it is more difficult to detect every footstep at a slow pace. MF may not use this kind of algorithm, since it did not show the same result.

We did not observe a significant influence of the pedometer position on the accuracy of the readings. Generally speaking, at normal speed, wearing a pedometer at the wrist decreased the accuracy more noticeably than wearing it at the belt or as a necklace. When the speed decreased, however, pedometers worn at the wrist had the best accuracy, and those worn as a necklace had the worst. This can be explained by the fact that, during slow walking, the vertical acceleration of the body is low but the arms are usually still moving.

It should be noted that this study was conducted on healthy adults and not on individuals walking slowly due to some impairment. Controlling the walking speed by constraining cadence and pace length using a string and a metronome can potentially change the natural way of walking. In fact, it is difficult to normalize walking because everybody reacts differently to the string between their feet. Some participants easily adopted the required cadence, whereas others needed more concentration. Nevertheless, participants were allowed to practice walking with the string using the metronome cadence until they felt comfortable and were able to adopt a natural walk before the beginning of the experiment.

It remains questionable whether the tested pedometers are suitable for a slow-walking population. Responding to this question would require identifying which level of error remains acceptable while monitoring walking activity.

Other studies have shown a similar evolution of error in terms of speed [12,15,26]), that is, the error increases when speed decreases. The Omron HJ-720ITC pedometer was tested on patients with chronic heart failure [12], producing an error close to 24% at 0.66 m/s, approximately 9% at 0.83 m/s, 5% at 1 m/s, approximately 3% at 1.16 m/s, and 1% at 1.33 m/s. Thus, when the speed increased, the error decreased. A study on older adults, comparing 5 pedometers [15], reported mean errors from 9% for all devices at a self-selected speed to 56% at 50 steps/min. At 80 steps/min, the error was 19%, and at 66 steps/min, the error was approximately 40%. A study comparing 7 pedometers [26], the DynaPort Movemonitor, Jawbone UP, Fitbit One, activPAL, Tractivity, Nike+ FuelBand, and Sensewear Armband, reported that the error increased during slow walking (around 1.6 km/h, or 0.4 m/s). But the error differences between speeds was pedometer dependent. Jawbone UP, Tractivity, Nike+ FuelBand, and Sensewear Armband showed a significant difference between slow speed and self-selected, fast speed. DynaPort Movemonitor, Fitbit One, and activPAL showed an error close to the other speeds with an error under 3.2% at every speed.

The main achievement of this study was to compare the influence of walking speed and pedometer position on the accuracy of pedometer readings. To our knowledge, ours is the first study that formally investigated this relation. This study showed that a reduction of walking speed negatively influenced the accuracy of the tested pedometers. Although this result would require a larger study to be confirmed, we observed that the position ensuring the best pedometer accuracy depended on the speed. At a normal pace, pedometers worn at the belt or as a necklace are more accurate, whereas for slow walkers, wearing pedometers at the wrist is the best choice. This study could open a valuable line of inquiry for the development of future devices for frail people, relying on the acceleration of arm movement to improve accuracy. Apart from this suggestion, this study underlines the conclusion that, before being used, a pedometer should first be assessed individually according to expected speed of movement before deciding on where to position of the device.

Conflicts of Interest

None declared.

References

1. Booth FW, Roberts CK, Laye MJ. Lack of exercise is a major cause of chronic diseases. Compr Physiol 2012 Apr;2(2):1143-1211 [FREE Full text] [doi: 10.1002/cphy.c110025] [Medline: 23798298]
2. Christensen K, Doblhammer G, Rau R, Vaupel JW. Ageing populations: the challenges ahead. Lancet 2009 Oct 3;374(9696):1196-1208 [FREE Full text] [doi: 10.1016/S0140-6736(09)61460-4] [Medline: 19801098]
3. Sugihara N, Watanabe M, Tomioka M, Braun KL, Pang L. Cost-benefit estimates of an elderly exercise program on Kaua'i. Hawaii Med J 2011 Jun;70(6):116-120 [FREE Full text] [Medline: 22162608]
4. Garber CE, Blissmer B, Deschenes MR, Franklin BA, Lamonte MJ, Lee I, American College of Sports Medicine. American College of Sports Medicine position stand. Quantity and quality of exercise for developing and maintaining cardiorespiratory,

musculoskeletal, and neuromotor fitness in apparently healthy adults: guidance for prescribing exercise. Med Sci Sports Exerc 2011 Jul;43(7):1334-1359. [doi: 10.1249/MSS.0b013e318213fefb] [Medline: 21694556]

5. Garcia-Aymerich J, Lange P, Benet M, Schnohr P, Antó JM. Regular physical activity reduces hospital admission and mortality in chronic obstructive pulmonary disease: a population based cohort study. Thorax 2006 Sep;61(9):772-778 [FREE Full text] [doi: 10.1136/thx.2006.060145] [Medline: 16738033]
6. Garcia-Aymerich J, Lange P, Serra I, Schnohr P, Antó JM. Time-dependent confounding in the study of the effects of regular physical activity in chronic obstructive pulmonary disease: an application of the marginal structural model. Ann Epidemiol 2008 Oct;18(10):775-783. [doi: 10.1016/j.annepidem.2008.05.003] [Medline: 18708291]
7. Buchner DM, Wagner EH. Preventing frail health. Clin Geriatr Med 1992 Feb;8(1):1-17. [Medline: 1576567]
8. American College of Sports Medicine, Pescatello LS. ACSM's Guidelines for Exercise Testing and Prescription. Baltimore, MD: Wolters Kluwer/Lippincott Williams & Wilkins Health; 2014.
9. Yusuf HR, Croft JB, Giles WH, Anda RF, Casper ML, Caspersen CJ, et al. Leisure-time physical activity among older adults. United States, 1990. Arch Intern Med 1996 Jun 24;156(12):1321-1326. [Medline: 8651841]
10. Tudor-Locke C. Taking Steps Toward Increased Physical Activity: Using Pedometers to Measure and Motivate. President?s Council on Physical Fitness and Sports Research Digest, Series 3, No. Washington, DC: President's Council on Physical Fitness and Sports; 2002:17.
11. Cohen-Mansfield J, Werner P, Culpepper WJ, Wolfson M, Bickel E. Assessment of ambulatory behavior in nursing home residents who pace or wander: a comparison of four commercially available devices. Dement Geriatr Cogn Disord 1997;8(6):359-365. [Medline: 9370089]
12. Jehn M, Schmidt-Trucksäss A, Schuster T, Hanssen H, Halle M, Köhler F. Pedometer accuracy in patients with chronic heart failure. Int J Sports Med 2010 Mar;31(3):186-191. [doi: 10.1055/s-0029-1243641] [Medline: 20166006]
13. Perry J, Garrett M, Gronley JK, Mulroy SJ. Classification of walking handicap in the stroke population. Stroke 1995 Jun;26(6):982-989 [FREE Full text] [Medline: 7762050]
14. Marschollek M, Goevercin M, Wolf K, Song B, Gietzelt M, Haux R, et al. A performance comparison of accelerometry-based step detection algorithms on a large, non-laboratory sample of healthy and mobility-impaired persons. Conf Proc IEEE Eng Med Biol Soc 2008;2008:1319-1322. [doi: 10.1109/IEMBS.2008.4649407] [Medline: 19162910]
15. Martin JB, Krč KM, Mitchell EA, Eng JJ, Noble JW. Pedometer accuracy in slow walking older adults. Int J Ther Rehabil 2012 Jul 3;19(7):387-393 [FREE Full text] [Medline: 24795762]
16. Lauritzen J, Muñoz A, Luis Sevillano J, Civit A. The usefulness of activity trackers in elderly with reduced mobility: a case study. Stud Health Technol Inform 2013;192:759-762. [Medline: 23920659]
17. Campion MA, Lord RG. A control systems conceptualization of the goal-setting and changing process. Organ Behav Hum Perform 1982 Oct;30(2):265-287. [doi: 10.1016/0030-5073(82)90221-5]
18. Abel MG, Hannon JC, Eisenman PA, Ransdell LB, Pett M, Williams DP. Waist circumference, pedometer placement, and step-counting accuracy in youth. Res Q Exerc Sport 2009 Sep;80(3):434-444. [doi: 10.1080/02701367.2009.10599581] [Medline: 19791629]
19. Horvath S, Taylor DG, Marsh JP, Kriellaars DJ. The effect of pedometer position and normal gait asymmetry on step count accuracy. Appl Physiol Nutr Metab 2007 Jun;32(3):409-415. [doi: 10.1139/H07-001] [Medline: 17510675]
20. Bland JM, Altman DG. Measuring agreement in method comparison studies. Stat Methods Med Res 1999 Jun;8(2):135-160. [Medline: 10501650]
21. Kim WS, Kim EY. Comparing self-selected speed walking of the elderly with self-selected slow, moderate, and fast speed walking of young adults. Ann Rehabil Med 2014 Feb;38(1):101-108 [FREE Full text] [doi: 10.5535/arm.2014.38.1.101] [Medline: 24639933]
22. Arif M, Ohtaki Y, Nagatomi R, Inooka H. Estimation of the effect of cadence on gait stability in young and elderly people using approximate entropy technique. Meas Sci Rev 2004;4:29-40.
23. Castell M, Sánchez M, Julián R, Queipo R, Martín S, Otero A. Frailty prevalence and slow walking speed in persons age 65 and older: implications for primary care. BMC Fam Pract 2013;14:86 [FREE Full text] [doi: 10.1186/1471-2296-14-86] [Medline: 23782891]
24. Studenski S, Perera S, Patel K, Rosano C, Faulkner K, Inzitari M, et al. Gait speed and survival in older adults. JAMA 2011 Jan 5;305(1):50-58 [FREE Full text] [doi: 10.1001/jama.2010.1923] [Medline: 21205966]
25. Zijlstra A, de Bruin ED, Bruins N, Zijlstra W. The step length-frequency relationship in physically active community-dwelling older women. Eur J Appl Physiol 2008 Oct;104(3):427-434. [doi: 10.1007/s00421-008-0795-6] [Medline: 18553099]
26. Storm FA, Heller BW, Mazzà C. Step detection and activity recognition accuracy of seven physical activity monitors. PLoS One 2015;10(3):e0118723 [FREE Full text] [doi: 10.1371/journal.pone.0118723] [Medline: 25789630]

Abbreviations

ANOVA: analysis of variance
IH: iHealth activity monitor
GA: Garmin vívofit

MF: Misfit Shine
WI: Withings Pulse O2

Edited by G Eysenbach; submitted 28.04.16; peer-reviewed by L Griebel, R Freak-Poli, P Elliott; comments to author 26.05.16; revised version received 20.08.16; accepted 14.09.16; published 06.10.16.

Please cite as:
Ehrler F, Weber C, Lovis C
Influence of Pedometer Position on Pedometer Accuracy at Various Walking Speeds: A Comparative Study
J Med Internet Res 2016;18(10):e268
URL: http://www.jmir.org/2016/10/e268/
doi:10.2196/jmir.5916
PMID:27713114

Original Paper

Using Intensive Longitudinal Data Collected via Mobile Phone to Detect Imminent Lapse in Smokers Undergoing a Scheduled Quit Attempt

Michael S Businelle[1,2], PhD; Ping Ma[3], PhD; Darla E Kendzor[1,2], PhD; Summer G Frank[2], PhD; David W Wetter[4], PhD; Damon J Vidrine[1,2], DrPH

[1]Department of Family and Preventive Medicine, University of Oklahoma Health Sciences Center, Oklahoma City, OK, United States
[2]Stephenson Cancer Center, Oklahoma Tobacco Research Center, Oklahoma City, OK, United States
[3]Children’s Medical Center, Division of Population Health, Dallas, TX, United States
[4]Department of Population Health Sciences and the Huntsman Cancer Institute, University of Utah, Salt Lake City, UT, United States

Corresponding Author:
Michael S Businelle, PhD
Department of Family and Preventive Medicine
University of Oklahoma Health Sciences Center
655 Research Parkway, Suite 400
Oklahoma City, OK, 73104
United States
Phone: 1 4052718001 ext 50460
Fax: 1 4052718001
Email: michael-businelle@ouhsc.edu

Abstract

Background: Mobile phone based real-time ecological momentary assessments (EMAs) have been used to record health risk behaviors, and antecedents to those behaviors, as they occur in near real time.

Objective: The objective of this study was to determine if intensive longitudinal data, collected via mobile phone, could be used to identify imminent risk for smoking lapse among socioeconomically disadvantaged smokers seeking smoking cessation treatment.

Methods: Participants were recruited into a randomized controlled smoking cessation trial at an urban safety-net hospital tobacco cessation clinic. All participants completed in-person EMAs on mobile phones provided by the study. The presence of six commonly cited lapse risk variables (ie, urge to smoke, stress, recent alcohol consumption, interaction with someone smoking, cessation motivation, and cigarette availability) collected during 2152 prompted or self-initiated postcessation EMAs was examined to determine whether the number of lapse risk factors was greater when lapse was imminent (ie, within 4 hours) than when lapse was not imminent. Various strategies were used to weight variables in efforts to improve the predictive utility of the lapse risk estimator.

Results: Participants (N=92) were mostly female (52/92, 57%), minority (65/92, 71%), 51.9 (SD 7.4) years old, and smoked 18.0 (SD 8.5) cigarettes per day. EMA data indicated significantly higher urges (*P*=.01), stress (*P*=.002), alcohol consumption (*P*<.001), interaction with someone smoking (*P*<.001), and lower cessation motivation (*P*=.03) within 4 hours of the first lapse compared with EMAs collected when lapse was not imminent. Further, the total number of lapse risk factors present within 4 hours of lapse (mean 2.43, SD 1.37) was significantly higher than the number of lapse risk factors present during periods when lapse was not imminent (mean 1.35, SD 1.04), *P*<.001. Overall, 62% (32/52) of all participants who lapsed completed at least one EMA wherein they reported ≥3 lapse risk factors within 4 hours of their first lapse. Differentially weighting lapse risk variables resulted in an improved risk estimator (weighted area=0.76 vs unweighted area=0.72, *P*<.004). Specifically, 80% (42/52) of all participants who lapsed had at least one EMA with a lapse risk score above the cut-off within 4 hours of their first lapse.

Conclusions: Real-time estimation of smoking lapse risk is feasible and may pave the way for development of mobile phone based smoking cessation treatments that automatically tailor treatment content in real time based on presence of specific lapse triggers. Interventions that identify risk for lapse and automatically deliver tailored messages or other treatment components in real time could offer effective, low cost, and highly disseminable treatments to individuals who do not have access to other more standard cessation treatments.

(J Med Internet Res 2016;18(10):e275) doi:10.2196/jmir.6307

KEYWORDS

smartphone; mobile app; mhealth; ecological momentary assessment; smoking cessation; socioeconomic disadvantage, risk estimation

Introduction

Smoking is the leading preventable cause of death and disease in the United States [1], and the prevalence of smoking is much higher in socioeconomically disadvantaged adults (26.3% smoke) than in the general US population (16.8% smoke) [2]. Multiple studies have indicated that smoking cessation interventions are less effective for socioeconomically disadvantaged adults [3-5] despite similar numbers of quit attempts among those with higher and lower socioeconomic status [6,7]. This disparity in treatment effectiveness is likely multicausal. For example, studies have indicated that lower socioeconomic status increases the likelihood of smoking lapse through its effects on increasing stress, nicotine cravings, and other variables [5,8]. In addition, characteristics of socioeconomic disadvantage (eg, lack of insurance, lack of a telephone number or stable address, unreliable transportation, comorbid illnesses) can preclude participation in clinical trials [9,10]. Thus, smoking cessation interventions may not be optimally designed for lower socioeconomic status populations [9,11]. Studies that specifically focus on improving our conceptual models regarding the predictors of smoking lapse and relapse in socioeconomically disadvantaged adults could inform novel treatments for this understudied and underserved population of smokers.

Researchers have developed models for assessing risk for many diseases including breast cancer [12,13], diabetes [14], and cardiovascular disease [15-18]. These risk estimation models often use personal characteristics (eg, family history, age, race or ethnicity), biological variables (eg, lab test results, genetic profile, weight), and current or historical health behaviors (eg, smoking status, heavy alcohol use) to estimate relative risk for particular diseases. These models have proven effective in identifying individuals who should be screened for disease and those who would be most likely to benefit from specific treatments [13-15,17]. Furthermore, risk estimation models have guided medical decision making in systems with limited resources, likely reducing morbidity and mortality. The nearly ubiquitous use of technology in daily life may pave the way toward the development and use of “just-in-time” risk estimation models, including pairing real-time risk estimation with novel behavior change interventions.

To date, most studies that have examined smoking and smoking cessation in socioeconomically disadvantaged smokers have used traditional questionnaire assessment methodology. Study participants typically arrive at a lab or clinic for their baseline visit and are asked to answer questions about their “average” or “recent” (eg, over the past 2 weeks) mood, level of stress, and smoking urges. Participants return to the lab or clinic for follow-up visits and are asked to report thoughts, feelings, and activities that occurred days or even weeks earlier (eg, “How stressed were you when you smoked your first cigarette after your quit date?”). This type of assessment methodology may result in biased or inaccurate estimates due to recall biases and errors in memory [19,20] and offers only a gross understanding of how biopsychosocial variables (eg, withdrawal, stress, craving, alcohol use) effect smoking lapses and relapse. A more nuanced picture of these symptoms may offer important insights that may be used to create or improve cessation interventions for socioeconomically disadvantaged smokers, who face unique and substantial challenges in quitting smoking.

Ecological momentary assessment (EMA) techniques use devices (eg, mobile phones) to repeatedly assess experiences in the natural environment [21]. Thus, EMAs reduce bias and reliance on memory to produce ecologically valid data. Many studies have used EMAs to identify predictors of smoking lapse risk in smokers undergoing a quit attempt. In fact, Schüz et al recently reported that 129 published studies used EMAs to examine smoking in just the past 3 years [22]. Findings from these studies have yielded insights into the lapse and relapse process that can be used to design new, innovative, and more effective smoking cessation interventions. For instance, studies have indicated that sudden stressors are better predictors of smoking lapse compared with more chronic background stress [23], acute and rising negative affect often precedes smoking lapse [24,25], and exposure to other smokers and environmental smoking cues contributes to specific lapse episodes [25]. Additionally, our research team recently showed that trajectories of four variables that were repeatedly measured via mobile phone (ie, negative affect, stress, restlessness, and positive coping expectancy) each predicted confirmed smoking cessation on the quit date in a sample of homeless adults seeking cessation treatment [26].

To date, no studies have used data collected in real time in real-life environments to monitor and assess current risk of smoking lapse, although mobile phone technologies now allow for this type of risk assessment. The development of real-time lapse risk estimators that have high discriminatory accuracy (ie, differentiating moments of high and low lapse risk) could lead to significant improvements in smoking cessation treatments and treatment delivery. For instance, real-time lapse risk assessments could be paired with treatment messages that are tailored to the current situation and needs of the individual and delivered in near real time, when they are most needed. This type of just-in-time adaptive intervention may improve upon tailored treatments, which are more effective than standard nontailored interventions [27], and may usher in the next generation of treatments that are tailored in real time for real-life situations [28,29]. The purpose of the current study was to use EMA data that were collected as part of a clinical trial conducted in a safety-net hospital tobacco cessation clinic to determine if commonly cited smoking lapse risk factors could be combined to create real-time smoking lapse risk estimators.

Methods

Participants and Procedure

Data for the current study are from a clinical trial that compared usual tobacco clinic care at a Dallas-based safety-net hospital (usual care [UC]; group counseling and smoking cessation pharmacotherapy) to UC plus small financial incentives for biochemically verified smoking abstinence (contingency management [CM]) [30]. Individuals were eligible to participate in the parent study if they were at least 18 years old, could read English at the 7th grade level or higher [31], smoked at least five cigarettes per day, provided an expired breath sample indicative of smoking (ie, carbon monoxide levels ≥8 parts per million [ppm]), and were willing to quit smoking 1 week after the baseline visit. The parent study randomized 146 participants to UC or CM.

Participant flow through the study is provided in detail elsewhere [30]. Briefly, individuals completed informed consent and were screened for study inclusion. Those who met study inclusion criteria completed in person visits on the day of study enrollment (ie, baseline visit) and each week thereafter for 5 weeks (six visits total). The quit date was scheduled to occur 1 week after the baseline visit. At the baseline visit, participants were instructed on how to use mobile phones provided by the study to complete five automatically prompted EMAs each day for 2 weeks (ie, 1 week pre-quit and 1 week postquit). Specifically, the phone automatically prompted a daily diary assessment by ringing and vibrating 30 minutes after each participant's self-reported usual waking time, and four additional assessments were prompted each day at random times during normal waking hours (ie, random assessments were prompted roughly every 4 hours). Participants were asked to self-initiate EMAs when they had an urge to smoke and when they were about to lapse. Data collected during the baseline and 1 week postquit visits and during EMAs that were collected during the first week after the scheduled quit date were used for the current study.

This study was approved by the Institutional Review Boards at the University of Texas School of Public Health and University of Texas Southwestern Medical Center. Data collection occurred from August 2011 through June 2013.

Measures

Demographic Characteristics

Participants answered a series of questions during the baseline visit using tablet or laptop computers provided by the study. Participants used headphones to listen to questions that were read aloud by the computer and answered items by using the mouse or tablet touch screen. Questions asked about age, race or ethnicity, sex, current smoking rate, years smoking, income, insurance status, and employment status.

Ecological Momentary Assessment Measures

Participants read assessment items that were displayed on the mobile phone screen and touched the screen to select answers to each question. Each EMA assessed current urge to smoke (ie, "I have an urge to smoke") [26,32], current stress (ie, "I feel stressed") [26,33], and current cessation motivation (ie, "I am committed to being smoke free") [26]. Each of these questions required a response on a 5-point Likert-type scale that ranged from strongly disagree to strongly agree. Participants were also asked about current cigarette availability (ie, "Cigarettes are available to me") with the following answer options: not at all, with extreme difficulty, with difficulty, fairly easily, easily available [25]. Participants responded "yes" or "no" to "Is anyone you are interacting with smoking?" [25,32] and "I drank alcohol within the last hour" [32]. Each of these EMA items have been associated with smoking cessation or lapse.

Smoking Status

Smoking status was assessed via EMA every day and in-person on the quit date (1 week after baseline) and 1 week after quit visits. In-person assessments of smoking status were verified using a Vitalograph carbon monoxide monitor. Participants who self-reported abstinence since 10 p.m. on the night prior to their quit date visit and provided a carbon monoxide sample with ≤10 ppm in expired breath were considered abstinent [30,33,34]. Participants who self-reported abstinence (ie, not smoking even a puff) since the quit date and provided a sample with <8 ppm at the 1 week postquit follow-up visit were considered abstinent. Participants who reported smoking cigarettes on any EMA during the postquit week but reported continuous abstinence since their quit date during in-person assessments were excluded from the current analyses.

Development of Lapse Risk Estimators and Statistical Analyses

The smoking lapse risk estimator was developed using a multistep process. First, for all participants who lapsed, the time and date of the first lapse were marked in the dataset. Second, all postquit EMAs collected prior to the first reported lapse were selected and retained in the dataset. All postquit EMAs for those who did not lapse were retained in the dataset. Third, the number of lapse risk factors present during each EMA was calculated to create a lapse risk score (ie, agreeing/strongly agreeing to the presence of smoking urges and feeling stressed each received 1 point, disagreeing/strongly disagreeing to a commitment to being smoke free received 1 point, endorsing fairly easily/easily available cigarettes received 1 point, interacting with someone who was smoking received 1 point, and consuming alcohol in the past hour received 1 point). Thus, the EMA-derived lapse risk score could range from 0 to 6 points. Fourth, lapse risk scores during EMAs that occurred within 4 hours prior to lapse for those who lapsed were compared to lapse risk scores for all other EMAs (ie, EMAs for those who did not lapse in the first postquit week and EMAs that were collected prior to the specified lapse time period) to determine if lapse risk scores were symptomatic of imminent lapse. Fifth, with consideration that some variables may have a larger impact on lapse than other variables, various techniques for weighting the lapse risk variables were examined to determine if the sensitivity and specificity of the unweighted lapse risk estimator could be improved. For example, iterative strategies examined the effects of applying various weights (eg, 0.1, 0.2, 0.3) to each lapse risk factor on the sensitivity and specificity of the risk estimator [18,35]. The area under the curve in the weighted and unweighted estimators was compared.

Demographic variables and EMA measures were summarized using the mean and standard deviation for continuous variables and frequency for categorical variables. The proximity of each EMA measure to the first lapse was identified. EMAs were categorized as occurring (1) within 4 hours of the first lapse, (2) more than 4 hours before the first lapse in those who lapsed during the first week after cessation, or (3) at any time for individuals who did not lapse during the first week after cessation. Mixed-effects regression analyses were conducted to identify differences in EMA-assessed risk factors (eg, urge, stress, low cessation motivation, cigarette availability, alcohol use, interaction with others smoking) and total number of lapse risk factors between the three groups defined by proximity to first lapse, accounting for treatment group (α=.05). Data were analyzed using STATA 13.0 (STATA Corp).

Results

Data from 92 participants were included in the current study. Specifically, participants consisted of 52 adults who identified the moment of their first smoking lapse during the first week of a smoking cessation attempt and 40 participants who maintained verified abstinence throughout the first postquit week. The remaining study participants (ie, 54 adults) were not included in the current study because the moment of their first smoking lapse could not be determined or the participant provided inconsistent information about abstinence (ie, EMA and in-person assessments of abstinence were inconsistent or carbon monoxide measurements did not support self-reported abstinence status).

Participants (N=92) were mostly female (57%, 52/92), African American or other racial or ethnic minority (71%, 65/92), and 51.9 years old (SD 7.4) on average. Most participants were socioeconomically disadvantaged: 88% (81/92) had annual household incomes below US $25,000, 54% (50/92) were uninsured, and 82% (75/92) were unemployed. Participants smoked 18.0 cigarettes (SD 8.5) per day and had been smoking for 30.1 years (SD 9.2) on average. Participants completed a total of 4005 EMAs (mean 43.5 EMAs per participant) during the 7-day postquit period. The total number of EMAs completed by lapsers (n=52) and nonlapsers (n=40) during the first postquit week did not differ (*P*=.64). In total, 108 assessments were completed within 4 hours of the first smoking lapse, lapsers completed 322 assessments more than 4 hours before the first lapse, and 1722 assessments were completed by participants who did not lapse during the first postquit week. This subset of 2152 EMAs were included in the analyses. Because the primary aim was to use EMA data to estimate imminent risk for initial smoking lapse, the 1833 EMAs that were collected after the first lapse were not included in the current analyses.

EMA data indicated significantly higher urges (*P*=.01), stress (*P*=.002), alcohol consumption (*P*<.001), interaction with someone smoking (*P*<.001), and lower cessation motivation (*P*=.03) within 4 hours of the first lapse compared with EMAs collected when lapse was not imminent. Further, the total number of lapse risk factors present within 4 hours of lapse (mean 2.43, SD 1.37) was significantly higher than the number of lapse risk factors present during periods when lapse was not imminent (mean 1.35, SD 1.04, *P*<.001). See Table 1 for the prevalence of lapse risk factors and differences between risk factors assessed during EMAs collected within 4 hours of lapse and when lapse was not imminent.

Table 1. EMA-assessed risk factors by proximity to first lapse (analyses controlled for treatment group).

	Lapsers, %		Abstainers, % n=1722
	Within 4 hours of first lapse n=108	4 hours before first lapse n=322	
Urge	59.3[a]	49.1[c]	32.8[a,c]
Stress	41.1[b]	18.8[b]	25.9
Low cessation motivation	17.3[a]	15.1[c]	1.0[a,c]
Cigarette availability	74.8[a]	70.4	52.6[a]
Alcohol use	19.1[a,b]	18.9[b,c]	3.4[a,c]
Interacting with others smoking	33.6[a,b]	12.9[b]	12.1[a]
Number of lapse risk factors	2.43[a,b]	1.83[b,c]	1.27[a,c]

[a] Risk factors different (*P*<.05) in EMAs collected ≤4 hours of first lapse and abstainers.

[b] Risk factors different (*P*<.05) in EMAs collected ≤4 and >4 hours of first lapse.

[c] Risk factors different (*P*<.05) in EMAs collected >4 hours of first lapse and abstainers.

As indicated in Figure 1, imminent lapse was much more common when participants endorsed at least 3 lapse risk factors. Specifically, lapsers endorsed ≥3 lapse risk factors in 47.2% (51/108) of EMAs completed within 4 hours of the first lapse. Participants who did not lapse during the first week of their cessation attempt endorsed ≥3 lapse risk factors in only 11.90% (205/1722) of all postquit EMAs (see Figure 1). Using a cut-off score of 3, the lapse risk estimator correctly identified imminent lapse in 47.2% (51/108) of all EMAs collected within 4 hours of lapse and correctly classified 85.18% (1741/2044) of all EMAs where lapse was not imminent. Importantly, 62% (32/52) of all participants who lapsed completed at least one EMA where they reported ≥3 lapse risk factors within 4 hours of their first lapse. The receiver operator characteristics (ROC) curve in Figure 2 indicates the sensitivity and specificity of the unweighted lapse risk estimator.

Various variable weighting strategies were examined to determine if weighting variables could improve the predictive ability of the lapse risk estimator. We settled on a strategy that weighted some variables more heavily than others and allowed variables to indicate increased or decreased risk of lapse. Specifically, we found that the best weighting (ie, maximizing sensitivity and specificity for the overall risk estimator) for "I have an urge to smoke" (response options ranged from 5=strongly agree, 3=neutral, and 1=strongly disagree) was to subtract 3 and multiply by 0.2 (ie, the effect of smoking urge on lapse was much smaller than some other variables included in the lapse risk estimator). This weighting allowed for low urge ratings to indicate reduced risk for lapse and high urge ratings to indicate heightened risk for lapse. The stress and cessation motivation items were weighted in a similar manner. However, interacting with other smokers and recent alcohol consumption received full points in the final lapse risk estimator formula. Interestingly, recent alcohol consumption, while much less frequently endorsed, had a much larger impact on smoking lapse risk. Finally, the best weighting of the cigarette availability item was to subtract 3 (ie, 3="with difficulty") and multiply by 0.7. The final weighted EMA lapse risk estimator formula is as follows:

Lapse risk score = (urge   3) x 0.2 + (stress   3) x 0.2 + (cigarette availability   3) x 0.7 + (interacting with someone smoking [yes =1; no=0]) + (recent alcohol use [yes=1; no=0])   (cessation motivation   3) x 0.2

Scores on the six-variable weighted lapse risk estimator could range from -2.6 to 4.2. As shown in Figure 3, imminent lapse was much more common when the weighted lapse risk score was greater than 1.0. Using a lapse risk cut-off score of 1.0, 62.0% (67/108) of all EMAs collected within 4 hours of a lapse were indicative of imminent lapse. Among EMAs in which lapse did not occur within 4 hours of the assessment, 16.98% (347/2044) were above the lapse risk cut-off score (see Figure 3). Thus, the weighted lapse risk estimator had a sensitivity of 62.0% and a specificity of 83.0%. Importantly, 80% (42/52) of all participants who lapsed had at least one EMA with a lapse risk score above the cut-off within 4 hours of their first lapse. The ROC displayed in Figure 2 indicates the sensitivity and specificity of the weighted lapse risk estimator. Analysis indicated that the area under the curve was larger in the weighted (area=0.76, 95% CI=0.71-0.81) compared to the unweighted (area=0.72, 95% CI=0.67-0.77) estimator (*P*<.004).

Figure 1. Number of lapse risk factors by imminent lapse status.

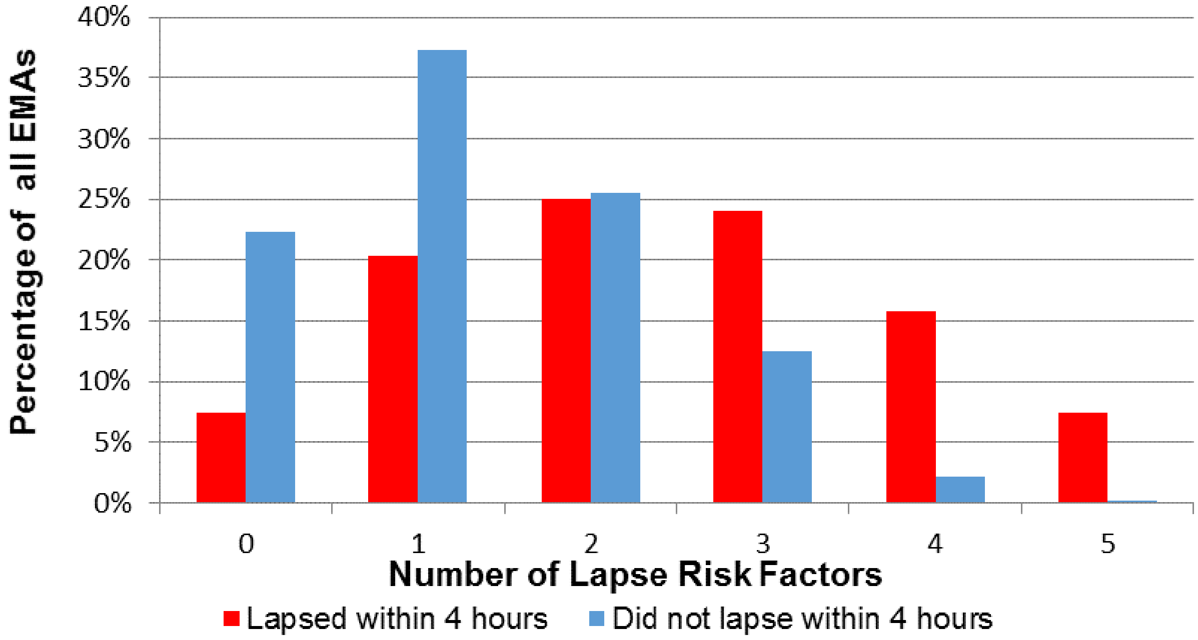


Figure 2. Receiver operator characteristics curve for weighted and unweighted risk estimators.

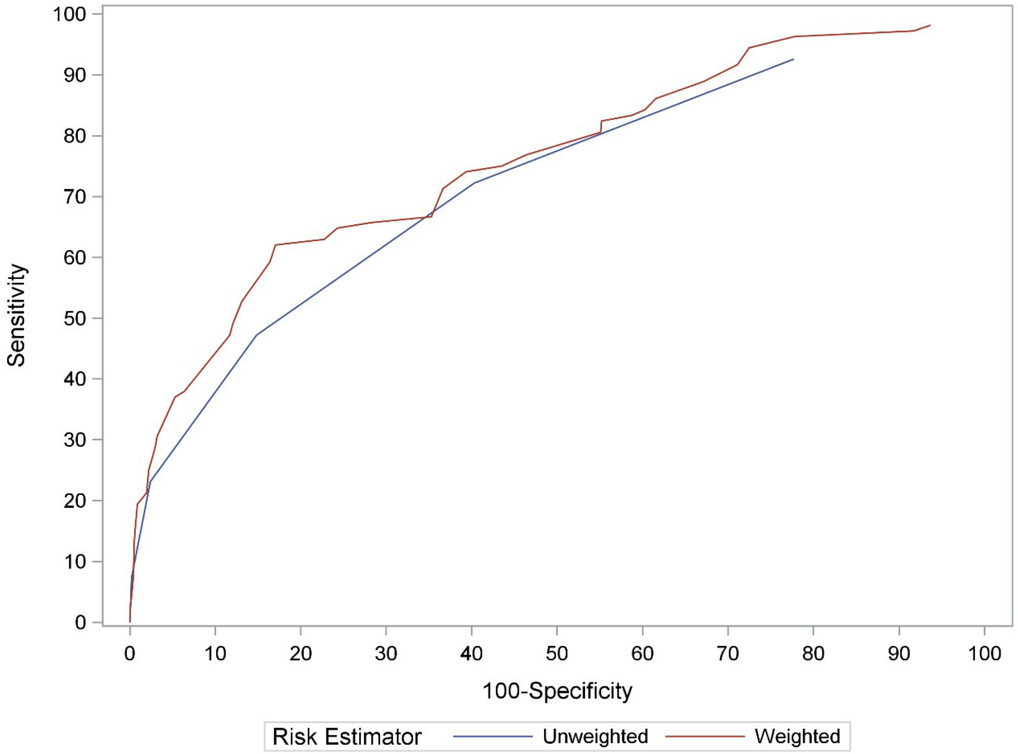
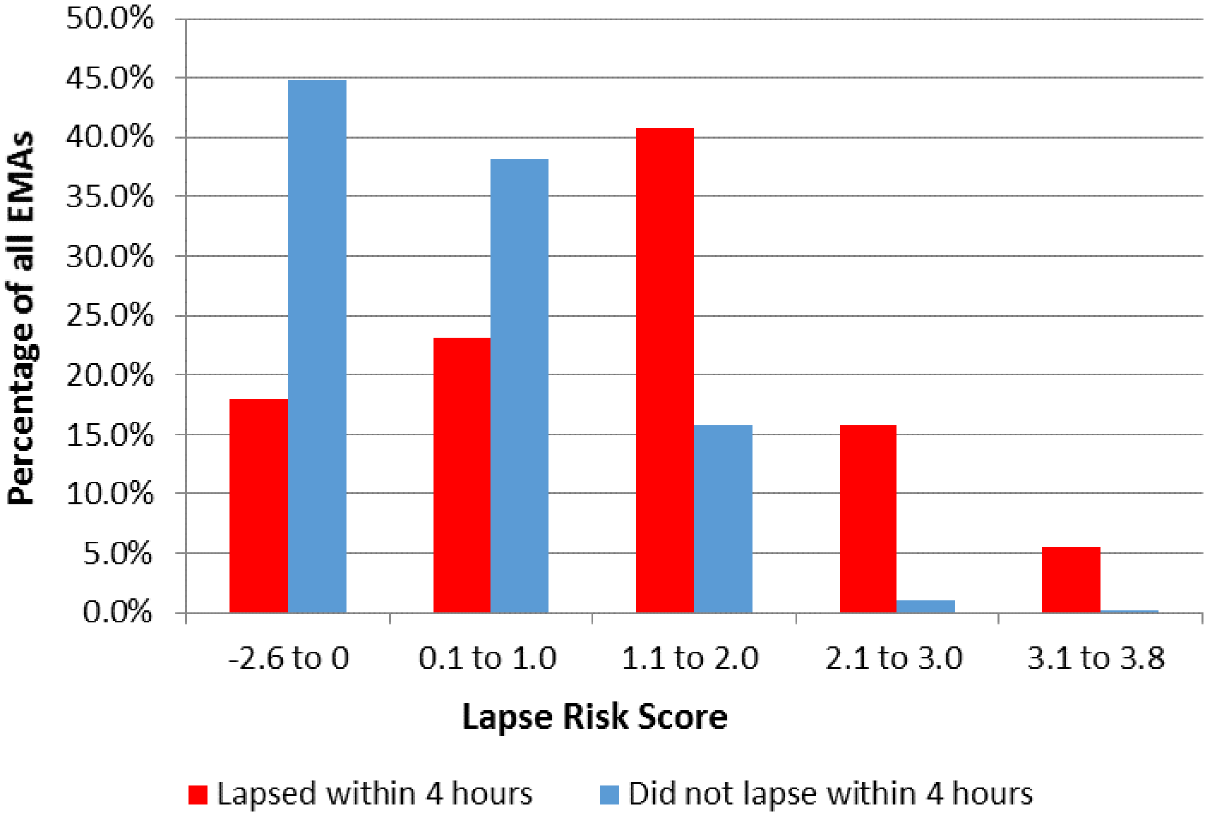


Figure 3. Weighted lapse risk scores by lapse status.



Discussion

Principal Findings

The current study used mobile phone based EMA data to estimate risk of imminent smoking lapse in a sample of smokers seeking cessation treatment at a safety-net hospital clinic. Six commonly cited smoking lapse risk factors were collected multiple times each day and used to assess risk for imminent (ie, within the next 4 hours) smoking lapse. Study results yielded three key findings. First, lapse risk estimation using real-time mobile phone based momentary assessments is feasible in socioeconomically disadvantaged smokers seeking cessation treatment. In fact, unweighted and weighted lapse risk estimators distinguished the majority of all lapsers within 4 hours of the first lapse. The presence of three or more lapse risk factors during momentary assessments was indicative of imminent lapse (ie, within 4 hours) in 62% of all lapsers during the first week of a scheduled quit attempt. However, the presence of three or more lapse risk factors did not always correspond to imminent lapse (ie, this was the case for 15% of all EMAs where lapse was not imminent). Second, differential weighting of lapse risk factors improved the lapse risk estimator. Specifically, the weighted lapse risk estimator identified 80% of all first lapses within 4 hours of the lapse while retaining a relatively low rate of false positives (ie, 17% false positive rate; 83% of true negatives were correctly identified as low risk for imminent lapse). Although choosing a lower lapse risk cut-off score would have increased the number of EMAs that were correctly identified as high risk for imminent lapse, the cost would be a greater proportion of false positives (ie, prediction of lapse when no lapse actually occurs; see ROCs in Figure 2). A third key study finding is that many participants were able to successfully cope with multiple lapse risk factors without lapsing. However, maintaining smoking abstinence in the presence of three or more of the identified lapse risk triggers was rare. Further examination of situations where participants successfully coped with heightened lapse risk is warranted and will be the focus of future analyses.

Across a range of health behaviors, tailored treatments are typically superior to the more commonly used “one-size-fits-all” treatment approach [36-38]. Treatment tailoring typically uses participant characteristics that are assessed at the baseline visit (eg, gender, level of dependence). Balmford and Borland recently used participant quitting stage (pre-quit, setting a quit date, around the quit date, and lapse) to tailor a text messaging smoking cessation intervention [39]. They also tailored the intervention to age, nicotine dependence, and gender. Most participants reported that this intervention was helpful (ie, 87.1%), and participants were willing to receive messages over long periods (ie, two thirds of participants received messages for 20-35 days) [39]. Future interventions may take this approach a step further through the use of dynamic tailoring, that is, tailoring based on data that are collected during successive EMAs. More specifically, tailored smoking cessation treatment messages (eg, text-and video-based treatment messages) may be delivered based on current lapse risk and currently present lapse risk factors (eg, stress, alcohol use, smoking urge) in real time in the natural environment.

The potential for EMA-informed treatments has only recently become possible due to the substantial increase in mobile phone ownership and use. Most Americans (ie, 72% in 2015) have active smartphones and the smartphone market share is rapidly increasing among socioeconomically disadvantaged populations [40]. For example, 50% of those who earned <US $30,000 per year reported active smartphones in 2015 [41]. Thus, mobile phone based smoking cessation apps that continuously assess for smoking lapse risk in near real time and automatically intervene may increase the ability to reach and intervene with socioeconomically disadvantaged smokers—a population with substantial barriers that hamper use of traditional smoking cessation treatments [42].

Limitations

Study findings should be considered with limitations. First, the sample was small, mostly African American, and impoverished; thus, results may not generalize to nonminority and higher income smokers. Second, many (n=54) individuals who participated in the parent study were excluded from the current analyses because the exact moment of lapse could not be determined or self-reported, and biologically confirmed abstinence was inconsistent. Identification of the moment of smoking lapse requires participant vigilance and is vulnerable to bias. Future studies should develop more passive ways to detect smoking lapse. For instance, wearable devices may be used to detect breathing patterns [43] or hand and arm gestures [44,45] that are suggestive of smoking. Third, participants were followed with EMA only during the first week after cessation, thus, the utility of the risk estimator beyond the first week after cessation is unknown. Fourth, participants received compensation for completing EMAs that were prompted by the mobile phone. Future research is needed to determine if smokers who are undergoing a smoking cessation attempt will complete brief EMAs multiple times per day without incentives. Fifth, weighting of risk estimation items was based on examination of the study data and may have resulted in overfitting the data. Unfortunately, the sample size was not large enough to conduct cross-validation analyses. Study findings should be replicated prior to use of this lapse risk estimator in other populations.

Conclusion

Real-time smoking lapse risk estimation is feasible in socioeconomically disadvantaged individuals seeking smoking cessation services. This type of lapse risk estimator may be used to estimate the likelihood of smoking lapses in near real time, enabling the creation of interventions that utilize EMA data to prompt tailored interventions that address patient needs in real time. Interventions that identify risk for lapse and automatically deliver tailored messages or other treatment components in real time could offer effective, low cost, and highly disseminable treatments to individuals without access to other more standard cessation treatments.

Acknowledgments

We thank the Director (Dr David Balis) and staff at the Parkland Hospital Tobacco Cessation Clinic for their work and support throughout the data collection portion of this project. Funding for this research was provided by the American Cancer Society grant MRSGT-12-114-01-CPPB (to MSB). Data analysis and manuscript preparation were additionally supported through MRSGT-10-104-01-CPHPS (to DEK). The contents of the manuscript are solely the responsibility of the authors and do not necessarily represent the official views of the sponsoring organizations.

Conflicts of Interest

None declared.

References

1. Mokdad AH, Marks JS, Stroup DF, Gerberding JL. Actual causes of death in the United States, 2000. JAMA 2004 Mar 10;291(10):1238-1245. [doi: 10.1001/jama.291.10.1238] [Medline: 15010446]
2. Jamal A, Homa DM, O'Connor E, Babb SD, Caraballo RS, Singh T, et al. Current Cigarette Smoking Among Adults - United States, 2005-2014. MMWR Morb Mortal Wkly Rep 2015;64(44):1233-1240 [FREE Full text] [doi: 10.15585/mmwr.mm6444a2] [Medline: 26562061]
3. Browning KK, Ferketich AK, Salsberry PJ, Wewers ME. Socioeconomic disparity in provider-delivered assistance to quit smoking. Nicotine Tob Res 2008 Jan;10(1):55-61. [doi: 10.1080/14622200701704905] [Medline: 18188745]
4. Hiscock R, Judge K, Bauld L. Social inequalities in quitting smoking: what factors mediate the relationship between socioeconomic position and smoking cessation? J Public Health (Oxf) 2011 Mar;33(1):39-47 [FREE Full text] [doi: 10.1093/pubmed/fdq097] [Medline: 21178184]
5. Businelle MS, Kendzor DE, Reitzel LR, Costello TJ, Cofta-Woerpel L, Li Y, et al. Mechanisms linking socioeconomic status to smoking cessation: a structural equation modeling approach. Health Psychol 2010 May;29(3):262-273 [FREE Full text] [doi: 10.1037/a0019285] [Medline: 20496980]
6. Kotz D, West R. Explaining the social gradient in smoking cessation: it's not in the trying, but in the succeeding. Tob Control 2009 Feb;18(1):43-46 [FREE Full text] [doi: 10.1136/tc.2008.025981] [Medline: 18936053]
7. Hyland A, Borland R, Li Q, Yong H, McNeill A, Fong GT, et al. Individual-level predictors of cessation behaviours among participants in the International Tobacco Control (ITC) Four Country Survey. Tob Control 2006 Jun;15 Suppl 3:iii83-iii94 [FREE Full text] [doi: 10.1136/tc.2005.013516] [Medline: 16754952]
8. Businelle MS, Kendzor DE, Reitzel LR, Vidrine JI, Castro Y, Mullen PD, et al. Pathways linking socioeconomic status and postpartum smoking relapse. Ann Behav Med 2013 Apr;45(2):180-191 [FREE Full text] [doi: 10.1007/s12160-012-9434-x] [Medline: 23086590]
9. Unger JM, Hershman DL, Albain KS, Moinpour CM, Petersen JA, Burg K, et al. Patient income level and cancer clinical trial participation. J Clin Oncol 2013 Feb 10;31(5):536-542 [FREE Full text] [doi: 10.1200/JCO.2012.45.4553] [Medline: 23295802]
10. Chen MS, Lara PN, Dang JHT, Paterniti DA, Kelly K. Twenty years post-NIH Revitalization Act: enhancing minority participation in clinical trials (EMPaCT): laying the groundwork for improving minority clinical trial accrual: renewing the case for enhancing minority participation in cancer clinical trials. Cancer 2014 Apr 1;120 Suppl 7:1091-1096 [FREE Full text] [doi: 10.1002/cncr.28575] [Medline: 24643646]
11. Fiore M, Jaen C, Baker T, Bailey W, Benowitz N, Curry S. Clinical Practice Guideline. Rockville, MD: US Department of Health and Human Services; 2008. Treating Tobacco Use and Dependence: 2008 Update URL: https://www.ncbi.nlm.nih.gov/books/NBK63952/ [accessed 2016-10-13] [WebCite Cache ID 6lEUsEUAC]
12. Gail MH, Brinton LA, Byar DP, Corle DK, Green SB, Schairer C, et al. Projecting individualized probabilities of developing breast cancer for white females who are being examined annually. J Natl Cancer Inst 1989 Dec 20;81(24):1879-1886. [Medline: 2593165]
13. Rockhill B, Spiegelman D, Byrne C, Hunter DJ, Colditz GA. Validation of the Gail et al. model of breast cancer risk prediction and implications for chemoprevention. J Natl Cancer Inst 2001 Mar 7;93(5):358-366 [FREE Full text] [Medline: 11238697]
14. Heikes KE, Eddy DM, Arondekar B, Schlessinger L. Diabetes Risk Calculator: a simple tool for detecting undiagnosed diabetes and pre-diabetes. Diabetes Care 2008 May;31(5):1040-1045. [doi: 10.2337/dc07-1150] [Medline: 18070993]
15. D'Agostino RB, Grundy S, Sullivan LM, Wilson P, CHD Risk Prediction Group. Validation of the Framingham coronary heart disease prediction scores: results of a multiple ethnic groups investigation. JAMA 2001 Jul 11;286(2):180-187. [Medline: 11448281]
16. Gordon T, Kannel WB. Multiple risk functions for predicting coronary heart disease: the concept, accuracy, and application. Am Heart J 1982 Jun;103(6):1031-1039. [Medline: 7044082]
17. Hippisley-Cox J, Coupland C, Vinogradova Y, Robson J, May M, Brindle P. Derivation and validation of QRISK, a new cardiovascular disease risk score for the United Kingdom: prospective open cohort study. BMJ 2007 Jul 21;335(7611):136 [FREE Full text] [doi: 10.1136/bmj.39261.471806.55] [Medline: 17615182]

18. Dranitsaris G, Rayson D, Vincent M, Chang J, Gelmon K, Sandor D, et al. The development of a predictive model to estimate cardiotoxic risk for patients with metastatic breast cancer receiving anthracyclines. Breast Cancer Res Treat 2008 Feb;107(3):443-450. [doi: 10.1007/s10549-007-9803-5] [Medline: 17978870]
19. Shiffman S, Hufford M, Hickcox M, Paty JA, Gnys M, Kassel JD. Remember that? A comparison of real-time versus retrospective recall of smoking lapses. J Consult Clin Psychol 1997 Apr;65(2):292-300. [Medline: 9086693]
20. Stone AA, Schwartz JE, Neale JM, Shiffman S, Marco CA, Hickcox M, et al. A comparison of coping assessed by ecological momentary assessment and retrospective recall. J Pers Soc Psychol 1998 Jun;74(6):1670-1680. [Medline: 9654765]
21. Shiffman S. Ecological momentary assessment (EMA) in studies of substance use. Psychol Assess 2009 Dec;21(4):486-497 [FREE Full text] [doi: 10.1037/a0017074] [Medline: 19947783]
22. Schüz N, Cianchi J, Shiffman S, Ferguson SG. Novel technologies to study smoking behavior: current developments in ecological momentary assessment. Curr Addict Rep 2015 Jan 18;2(1):8-14. [doi: 10.1007/s40429-015-0039-x]
23. Shiffman S, Waters AJ. Negative affect and smoking lapses: a prospective analysis. J Consult Clin Psychol 2004 Apr;72(2):192-201. [doi: 10.1037/0022-006X.72.2.192] [Medline: 15065954]
24. Ferguson SG, Shiffman S. Effect of high-dose nicotine patch on craving and negative affect leading up to lapse episodes. Psychopharmacology (Berl) 2014 Jul;231(13):2595-2602. [doi: 10.1007/s00213-013-3429-6] [Medline: 24408214]
25. Shiffman S, Paty JA, Gnys M, Kassel JA, Hickcox M. First lapses to smoking: within-subjects analysis of real-time reports. J Consult Clin Psychol 1996 Apr;64(2):366-379. [Medline: 8871421]
26. Businelle MS, Ma P, Kendzor DE, Reitzel LR, Chen M, Lam CY, et al. Predicting quit attempts among homeless smokers seeking cessation treatment: an ecological momentary assessment study. Nicotine Tob Res 2014 Oct;16(10):1371-1378 [FREE Full text] [doi: 10.1093/ntr/ntu088] [Medline: 24893602]
27. Noar SM, Benac CN, Harris MS. Does tailoring matter? Meta-analytic review of tailored print health behavior change interventions. Psychol Bull 2007 Jul;133(4):673-693. [doi: 10.1037/0033-2909.133.4.673] [Medline: 17592961]
28. Klasnja P, Hekler EB, Shiffman S, Boruvka A, Almirall D, Tewari A, et al. Microrandomized trials: An experimental design for developing just-in-time adaptive interventions. Health Psychol 2015 Dec;34 Suppl:1220-1228. [doi: 10.1037/hea0000305] [Medline: 26651463]
29. Nahum-Shani I, Smith S, Tewari A, Witkiewitz K, Collins L, Spring B, et al. Methodology Center technical report (14-126). University Park, PA: The Methodology Center; 2014. Just in time adaptive interventions (jitais): An organizing framework for ongoing health behavior support URL: https://methodology.psu.edu/media/techreports/14-126.pdf [accessed 2016-10-13] [WebCite Cache ID 6lEVaV6ND]
30. Kendzor DE, Businelle MS, Poonawalla IB, Cuate EL, Kesh A, Rios DM, et al. Financial incentives for abstinence among socioeconomically disadvantaged individuals in smoking cessation treatment. Am J Public Health 2015 Jun;105(6):1198-1205. [doi: 10.2105/AJPH.2014.302102] [Medline: 25393172]
31. Murphy P, Davis T, Long S, Jackson R, Decker B. Rapid Estimate of Adult Literacy in Medicine (REALM): A quick reading test for patients. Journal of Reading 1993;37:124-130. [doi: 10.2307/40033408]
32. Lam CY, Businelle MS, Aigner CJ, McClure JB, Cofta-Woerpel L, Cinciripini PM, et al. Individual and combined effects of multiple high-risk triggers on postcessation smoking urge and lapse. Nicotine Tob Res 2014 May;16(5):569-575 [FREE Full text] [doi: 10.1093/ntr/ntt190] [Medline: 24323569]
33. Bandiera FC, Atem F, Ma P, Businelle MS, Kendzor DE. Post-quit stress mediates the relation between social support and smoking cessation among socioeconomically disadvantaged adults. Drug Alcohol Depend 2016 Jun 1;163:71-76 [FREE Full text] [doi: 10.1016/j.drugalcdep.2016.03.023] [Medline: 27085499]
34. Businelle MS, Kendzor DE, Kesh A, Cuate EL, Poonawalla IB, Reitzel LR, et al. Small financial incentives increase smoking cessation in homeless smokers: a pilot study. Addict Behav 2014 Mar;39(3):717-720. [doi: 10.1016/j.addbeh.2013.11.017] [Medline: 24321696]
35. Dranitsaris G, Lacouture ME. Development of prediction tools for diarrhea and rash in breast cancer patients receiving lapatinib in combination with capecitabine. Breast Cancer Res Treat 2014 Oct;147(3):631-638 [FREE Full text] [doi: 10.1007/s10549-014-3126-0] [Medline: 25216762]
36. Borland R, Balmford J, Hunt D. The effectiveness of personally tailored computer-generated advice letters for smoking cessation. Addiction 2004 Mar;99(3):369-377. [doi: 10.1111/j.1360-0443.2003.00623.x] [Medline: 14982550]
37. Strecher VJ, Kreuter M, Den Boer DJ, Kobrin S, Hospers HJ, Skinner CS. The effects of computer-tailored smoking cessation messages in family practice settings. J Fam Pract 1994 Sep;39(3):262-270. [Medline: 8077905]
38. Kreuter MW, Bull FC, Clark EM, Oswald DL. Understanding how people process health information: a comparison of tailored and nontailored weight-loss materials. Health Psychol 1999 Sep;18(5):487-494. [Medline: 10519465]
39. Balmford J, Borland R. How do smokers use a smoking cessation text messaging intervention? Nicotine Tob Res 2014 Dec;16(12):1586-1592. [doi: 10.1093/ntr/ntu111] [Medline: 25031312]
40. Poushter J. Smartphone ownership and internet usage continues to climb in emerging economies. 2016. URL: http://www.pewglobal.org/2016/02/22/smartphone-ownership-and-internet-usage-continues-to-climb-in-emerging-economies/ [accessed 2016-09-29] [WebCite Cache ID 6ktqmfZyI]
41. Pew Research Center. 2015. The smartphone difference URL: http://www.pewinternet.org/2015/04/01/us-smartphone-use-in-2015/ [accessed 2016-09-29] [WebCite Cache ID 6ktqq4bHZ]

42. Copeland A, Businelle M, Stewart D, Patterson S, Rash C, Carney C. Identifying barriers to entering smoking cessation treatment among socioeconomically disadvantaged smokers. Journal of Smoking Cessation 2010 Dec;5(2):164-171. [doi: 10.1375/jsc.5.2.164]
43. Ali A, Hossain S, Hovsepian K, Rahman M, Plarre K, Kumar S. mPuff: Automated detection of cigarette smoking puffs from respiration measurements. 2012 Presented at: ACM/IEEE 11th International Conference on Information Processing in Sensor Networks (IPSN); April 2012; Beijing, China p. 16-20. [doi: 10.1109/IPSN.2012.6920942]
44. Dar R. Smokebeat: A novel smoking cessation app utilizing big data over wearables. In: Society for Research on Nicotine and Tobacco. 2016 Presented at: Society for Research on Nicotine and Tobacco Annual Meeting; March 2-5, 2016; Chicago, IL.
45. US Department of Health and Human Services. The Health Consequences of Smoking: 50 Years of Progress. A Report of the Surgeon General. Atlanta, GA: Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health; 2014. URL: http://www.surgeongeneral.gov/library/reports/50-years-of-progress/full-report.pdf [accessed 2016-06-21]

Abbreviations

EMA: ecological momentary assessment
ROC: receiver operator characteristics

Edited by G Eysenbach; submitted 01.07.16; peer-reviewed by S Shiffman, Y Cui; comments to author 11.08.16; revised version received 23.08.16; accepted 24.09.16; published 17.10.16.

Please cite as:
Businelle MS, Ma P, Kendzor DE, Frank SG, Wetter DW, Vidrine DJ
Using Intensive Longitudinal Data Collected via Mobile Phone to Detect Imminent Lapse in Smokers Undergoing a Scheduled Quit Attempt
J Med Internet Res 2016;18(10):e275
URL: http://www.jmir.org/2016/10/e275/
doi:10.2196/jmir.6307
PMID:27751985

Original Paper

Blood Culture Testing via a Mobile App That Uses a Mobile Phone Camera: A Feasibility Study

Guna Lee[1*], RN, PhD; Yura Lee[2*], MD; Yong Pil Chong[3], MD; Seongsoo Jang[4], MD, PhD; Mi Na Kim[4], MD, PhD; Jeong Hoon Kim[1], MS; Woo Sung Kim[1,2,5], MD, PhD; Jae-Ho Lee[2,6], MD, PhD

[1]Medical Information Office, Asan Medical Center, University of Ulsan College of Medicine, Seoul, Republic of Korea
[2]Department of Biomedical Informatics, Asan Medical Center, University of Ulsan College of Medicine, Seoul, Republic of Korea
[3]Department of Infectious Diseases, Asan Medical Center, University of Ulsan College of Medicine, Seoul, Republic of Korea
[4]Department of Laboratory Medicine, Asan Medical Center, University of Ulsan College of Medicine, Seoul, Republic of Korea
[5]Department of Pulmonary & Critical Care Medicine, Asan Medical Center, University of Ulsan College of Medicine, Seoul, Republic of Korea
[6]Department of Emergency Medicine, Asan Medical Center, University of Ulsan College of Medicine, Seoul, Republic of Korea
[*]these authors contributed equally

Corresponding Author:
Jae-Ho Lee, MD, PhD
Department of Biomedical Informatics
Asan Medical Center
University of Ulsan College of Medicine
88, Olympic-ro 43-gil
Songpa-gu
Seoul, 05505
Republic of Korea
Phone: 82 2 3010 3350
Fax: 82 2 2045 4126
Email: rufiji@gmail.com

Abstract

Background: To evaluate patients with fever of unknown origin or those with suspected bacteremia, the precision of blood culture tests is critical. An inappropriate step in the test process or error in a parameter could lead to a false-positive result, which could then affect the direction of treatment in critical conditions. Mobile health apps can be used to resolve problems with blood culture tests, and such apps can hence ensure that point-of-care guidelines are followed and processes are monitored for blood culture tests.

Objective: In this pilot project, we aimed to investigate the feasibility of using a mobile blood culture app to manage blood culture test quality. We implemented the app at a university hospital in South Korea to assess the potential for its utilization in a clinical environment by reviewing the usage data among a small group of users and by assessing their feedback and the data related to blood culture sampling.

Methods: We used an iOS-based blood culture app that uses an embedded camera to scan the patient identification and sample number bar codes. A total of 4 medical interns working at 2 medical intensive care units (MICUs) participated in this project, which spanned 3 weeks. App usage and blood culture sampling parameters (including sampler, sampling site, sampling time, and sample volume) were analyzed. The compliance of sampling parameter entry was also measured. In addition, the participants' opinions regarding patient safety, timeliness, efficiency, and usability were recorded.

Results: In total, 356/644 (55.3%) of all blood culture samples obtained at the MICUs were examined using the app, including 254/356 (71.3%) with blood collection volumes of 5-7 mL and 256/356 (71.9%) with blood collection from the peripheral veins. The sampling volume differed among the participants. Sampling parameters were completely entered in 354/356 cases (99.4%). All the participants agreed that the app ensured good patient safety, disagreed on its timeliness, and did not believe that it was efficient. Although the bar code scanning speed was acceptable, the Wi-Fi environment required improvement. Moreover, the participants requested feedback regarding their sampling quality.

Conclusions: Although this app could be used in the clinical setting, improvements in the app functions, environment network, and internal policy of blood culture testing are needed to ensure hospital-wide use.

(J Med Internet Res 2016;18(10):e282) doi:10.2196/jmir.6398

KEYWORDS

blood specimen collection; patient safety; mobile applications; mobile phone; user-computer interface; bar codes; patient identification systems

Introduction

Owing to the increase in the widespread use of mobile phones and improvements in wireless networks, the role of mobile health (mHealth) is growing [1-3]. By using this service, patients can be cared for by health care providers at any location and at any time, thus overcoming the limitations of time and space [4,5]. mHealth can help to realize the advantages of health information technology in point-of-care settings [6-8]. In particular, this service can provide information on drugs and diseases and can support clinical decisions [9-11]. Moreover, mHealth—a useful tool for both patients and health care providers—can serve as a tool to overcome the limitations of conventional medical services [3,5]. The services available via mHealth include monitoring of an individual's condition, collection of health data, and prediction of health problems [2,3,5,6,8]. mHealth can also affect the decisions of physicians based on certain algorithms and can provide them with patient data. Thus, this service enables clinicians to make rapid and precise decisions by reducing errors and facilitates convenience in data access [1,8]. Furthermore, mHealth can be used for quality improvement at tertiary hospitals, wherein considerable information and recommendations are exchanged between patients and clinicians [1,8,12].

To evaluate patients with fever of unknown origin or those with suspected bacteremia, the precision of blood culture tests is critical [13-16]. The processes and parameters for blood culturing should strictly adhere to the guidelines of blood culture tests [14,17-20]. Among the parameters for blood cultures, sample volume [14,18], sampling site [12,21], and sampling time [22] are the most important factors affecting the sensitivity and specificity for detecting organisms in the bloodstream. An inappropriate step in the test process or error in a parameter could also lead to a false-positive result, which could then affect the direction of treatment in critical conditions [14,23-27]. As many clinicians are unaware of these guidelines, it is important to monitor the test process for better management and improved quality [28]. mHealth apps can be used to resolve problems with blood culture tests [29], and such apps can hence ensure that the point-of-care guidelines are followed and the processes are monitored for blood culture tests [2,6].

The checking of clinical information, such as the patient's identity or doctor's order, by using a mobile phone has been shown to improve workflow efficiency in clinicians [6]. However, to our knowledge, there is no mobile app that indicates the correct methods for blood sampling, monitors the process of sampling, and accordingly recommends quality improvement measures in blood culture tests. Recently, a mobile phone app for blood culture testing was developed at Asan Medical Center, a tertiary hospital in South Korea [30]. The "Blood Culture" app provides the information of patients who require blood culture tests and monitors the tests by recording the time of sampling, amount of blood sampled, and sampling sites. Before this, such data were not collected in the hospital. In this feasibility study, we implemented the app in medical intensive care units (MICUs) to assess the potential for its utilization in a clinical environment, by reviewing the usage data among a small group of users and by assessing their feedback and the data related to blood culture sampling.

Methods

Introduction to the Blood Culture App

The Blood Culture app was developed for iPod touch and iPhone (iOS version 5.1.1; Apple Inc) from June 2011 to June 2012 by a team of doctors from the departments of laboratory medicine, infectious diseases, emergency medicine, and biomedical informatics; a nurse; and 2 technicians from the medical information office. First, through an analysis of the process of blood culture test sampling, blood culture sampling parameters were defined to guide clinicians in the use of the Blood Culture app. The blood culture sampling parameters were defined based on 2 purposes: to monitor the process of blood culture test sampling (such as blood sampling sites, blood sampling volume, sampling time, and samplers' names) and to support streamlined workflow at the point of care by checking the patient's identity and doctor's order in real time (such as the names of patients who needed blood culture tests, patient identification numbers, and blood culture test numbers). The processes of scanning the bar codes of the blood culture bottle and the patient identification band, as well as the process of entering the sampling parameters, were newly added to the blood culture sampling protocol.

With regard to features, the app enables matching between the prescribed blood culture test and the information of patients who need the test in real time, and it facilitates the entry of blood culture sampling parameters. Using a certified clinician's identification number and password, participants could download the app from the research hospital's app store via the research hospital intranet (Wi-Fi network). The app could be used on 3G (third-generation) and Wi-Fi networks. Using JavaScript Object Notation, the app communicates with the hospital gateway server, which prohibits direct access to the legacy database via device certification and encryption functions. Thereafter, the gateway server communicates with the legacy system (hospital information system; Figure 1).

Figure 1. System architecture of the Blood Culture app service. The app can load patient and specimen data from the legacy system through a gateway server in the hospital, which enforces the security of the clinical data. The gateway server enables data exchange between the app and the legacy system. This gateway server prohibits direct access of the mobile client application to the legacy database via device certification and encryption functions. SEED is a 128-bit encryption algorithm. JSON: JavaScript Object Notation; SSL: Secure Sockets Layer.

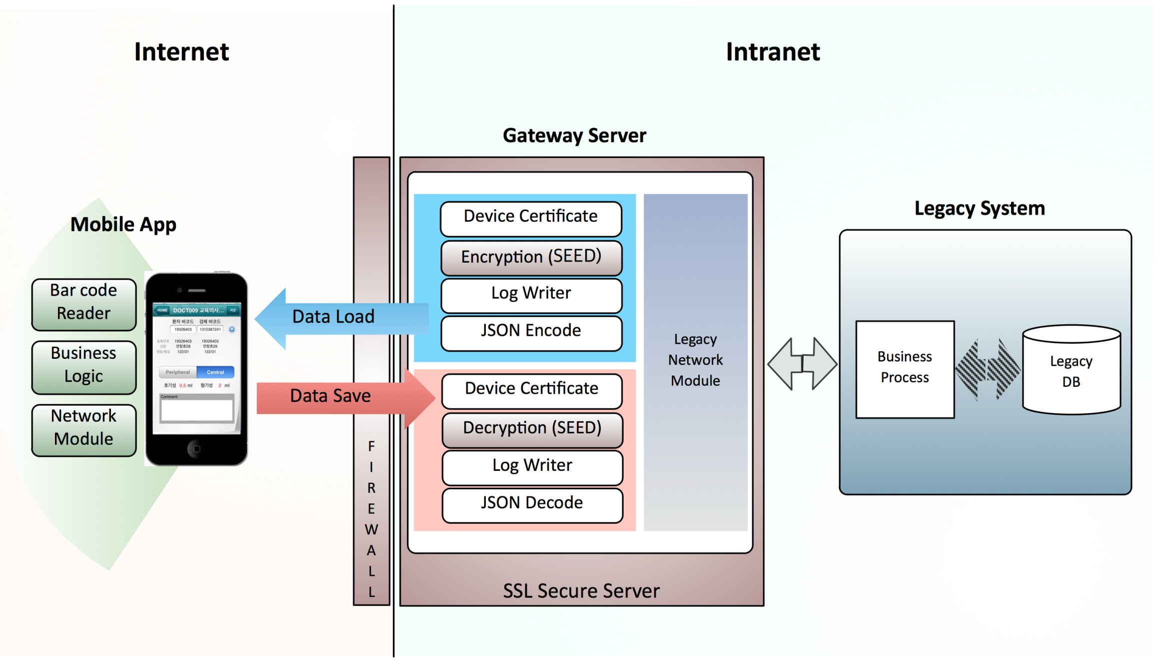
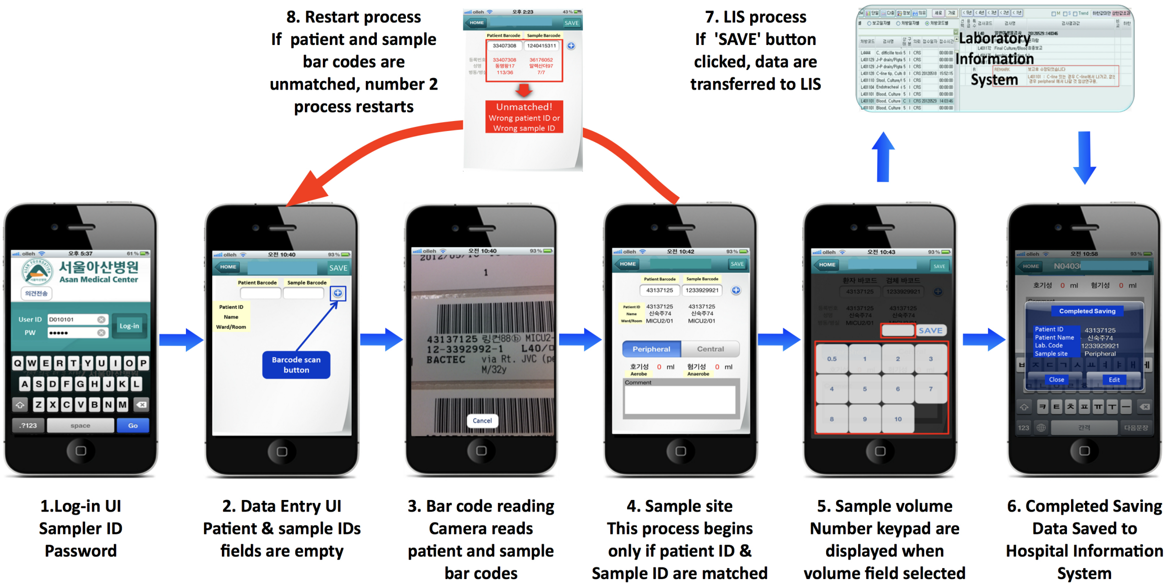


Figure 2. Service description of the Blood culture app. A sampler logs in to the Blood Culture app as a user (step 1). By using the mobile phone camera, the sampler scans the bar code on a patient's wristband and blood culture test specimen, so the app can acquire the patient's name and the patient identification (ID) number (steps 2 and 3). The app shows whether the bar codes match or not on the screen (steps 4 and 8). If not, the sampler is asked to rescan the bar codes (step 8). Once blood culture sampling is completed, the sampler enters and saves the blood culture sampling parameters into the app (step 5). The sampling parameters are stored in the hospital information system in real time (steps 6 and 7). UI: user interface; LIS: laboratory information system.



To ensure that the app functioned in a precise and quick manner in the clinical setting, the performance of bar code scanning with the iPod touch (fourth generation), iPhone 3GS, iPhone 4, and iPad 2 (Apple Inc) was tested by 3 doctors from the departments of laboratory medicine, infectious diseases, and emergency medicine, as well as by a nurse from the medical information office. The bar code scanning performance of the smart devices was found to be acceptable and no errors were noted during the performance test. To prevent sample contamination by a mobile phone, we educated users to match information between the prescribed blood culture test and the patients' identification by scanning the bar code before blood sampling, proceeding with the blood sampling process using an aseptic technique, and then entering the blood culture sampling parameters. The protocol for using the Blood Culture app is illustrated in detail in Figure 2.

Study Design and Setting

This study was conducted at our research hospital located in Seoul, South Korea, which has 2670 beds and a home-grown hospital information system (HIS). A computerized physician order entry method via a laboratory information system (LIS) was adopted in the early 1990s and electronic medical records were established in 2004 [30]. This feasibility study was conducted in 2 MICUs between July 4, 2012, and July 26, 2012, (over 3 weeks) by 4 medical interns with the iPhone 3GS. The 2 MICUs were selected by the app development team based on the frequent blood culture tests conducted and the critical nature of the results at those MICUs. The Wi-Fi protocol used was the IEEE (Institute of Electrical and Electronics Engineers) 802.11a. One of the participants (doctor A) was involved in the study for only 7 days (July 20, 2012, to July 26, 2012) owing to dispatch to other hospitals before enrollment. The study participants who agreed to voluntarily participate in this study were selected and provided informed consent. The study was approved by the institutional review board of the hospital.

Data Analysis

We collected log data from the participants to determine the usage pattern, including compliance and data accuracy, as well as the subjective opinions of the participants to assess the expected effects of the app, such as patient safety, timeliness, and efficiency. The log data were collected and saved from the app and also included blood sampling sites, blood sample volume, sampling time, and samplers' identification numbers. Compliance was determined based on the completeness of the blood culture sampling parameters, whereas data accuracy was determined based on the error reports from users regarding whether a mismatch occurred between the entered data and the data shown in the app. The subjective assessments of the participants were collected primarily via a written survey with an open-ended questionnaire on their satisfaction with and suggestions for the app; moreover, face-to-face or telephone interviews were conducted with the 4 participants individually within 10 minutes to test the accuracy of the survey. The user survey was administered to the doctors only after their MICU rotations to avoid any biased opinions and owing to concerns that the survey could influence their performance records.

The descriptive analyses of the app usage and the blood culture sampling parameters were conducted using SPSS version 18.0 statistical software package (IBM Corporation).

Results

Blood Culture App Data

The Blood Culture app was used to record the blood culture tests in clinical practice a total of 356/644 times (55.3% of all cases) over 3 weeks—an average of 15.5 times per day. A total of 644 blood culture tests were conducted in the MICUs during the study period. The daily use frequency of the app is shown in Figure 3, and the frequency of use gradually increased as the study progressed. The distribution of the entered blood culture sampling parameters is illustrated in Figure 4. In particular, 5-7 mL of blood was collected from 254/356 cases (71.3%), with a mean volume of 4.6 (SD 1.6) mL per bottle (Table 1), and samples were collected via the peripheral veins in 256/356 cases (71.9%). The sample volumes differed among the participants. Although blood sampling by doctor B was sufficient in all cases, blood sampling by doctor A was insufficient in all cases; however, the reason could not be ascertained.

To determine the compliance of entering the blood culture sampling parameters, the entry of all the parameters was carefully assessed. All the parameters were entered in 354/356 cases (99.4%) but not in 2/356 cases (0.6%) where the blood sample volume was recorded as 0 mL (the default value of the volume field). The users were asked if they entered the volume field correctly in order to assess whether there were any errors in the data saving stage for small values, and the users specified whether the data shown accurately reflected the data entered. No differences between the entered data and data shown in the app were reported by the users. In addition, no abnormal values were observed in the LIS.

Table 1. Comparison of blood culture sample volume and sampling site data recorded by 4 medical interns (N=356).

Parameters		Doctor A	Doctor B	Doctor C	Doctor D	Sum
		n (%)	n (%)	n (%)	n (%)	n (%)
Blood culture sample volume per bottle (mL)[a]						
	Mean (SD)	2.4 (0.6)	6.2 (1.4)	4.7 (0.7)	4.3 (1.6)	4.6 (1.6)
	<5	50 (100.0)	4 (4.3)	20 (21.7)	28 (23.0)	102 (28.7)
	≥5	0 (0.0)	88 (95.7)	72 (78.3)	94 (77.9)	254 (71.3)
Blood culture sampling site						
	Peripheral vein	34 (68.0)	68 (73.9)	68 (73.9)	86 (70.5)	256 (71.9)
	Central catheter	16 (32.0)	24 (26.1)	24 (26.1)	36 (29.5)	100 (28.1)

[a] The blood volume fields that were not filled were considered as 0 mL (default value).

Figure 3. Daily usage frequency of the Blood culture app. All participants were on leave on D3, D8, and D19 (asterisk). The Blood Culture app was used for blood culture testing a total of 356 times (356/644 times, 55.3%) over 3 weeks—an average of 15.5 times/day. D represents the days during the study period.

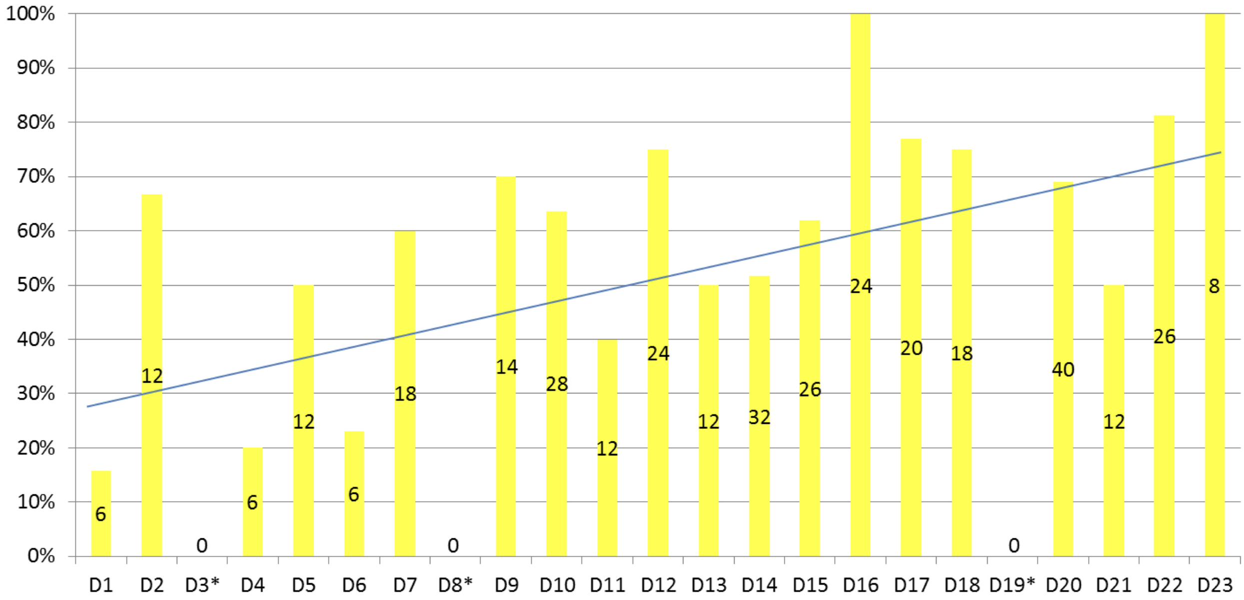
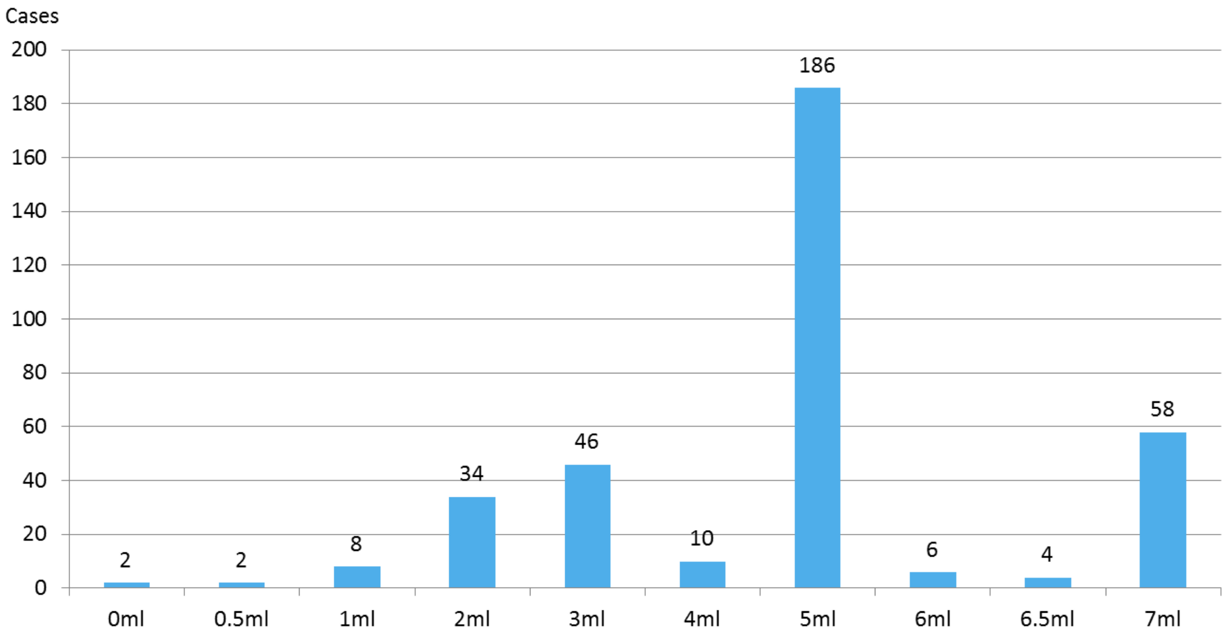


Figure 4. Distribution of blood culture sample volume data recorded by the Blood Culture app. A total of 5-7 mL of blood was collected in 254 cases (254/356 cases, 71.3%), and the mean volume was 4.6 (SD 1.6) mL.



Survey Regarding the Blood Culture App

The participants' opinions of the app, including patient safety, timeliness, and efficiency were assessed. First, with regard to patient safety, all the participants stated that the app had positive effects due to double checking via bar code scanning with the mobile phone camera in real time. Some of the comments made by the users were as follows: "It was great that bar code scanning could confirm that the patient who needed the blood culture test was correct, in addition to checking the patient's name card or calling out patient's name," and "As the app ensured double checking of the patients and specimens, I was able to pay greater attention to the blood sampling."

With regard to timeliness, differing opinions were noted among the participants (2 positive opinions and 2 negative opinions). However, the negative opinions were not related to the app itself but were instead related to the network environments in the hospital. Some of the comments made by the users were as follows: "The speed of bar code scanning of the patient wrist bands and specimens was fine," and "The slow loading time and time for user login into the app due to the Wi-Fi connection were a hindrance."

With regard to the efficiency, no positive comments were noted, possibly because a new process for entry of blood culture sampling parameters was added to the overall protocol. Of the participants, 2 reported that they were unsure whether the app enabled efficiency, whereas the other 2 participants reported negative opinions. Some of the comments made by the users were as follows: “If the work of entering the blood culture sampling parameters is made mandatory, then I would like to use the app. However, I am current not sure about the need for inputting the blood culture sampling parameters,” and “I have many things to do during the day. Do I also need to enter blood culture sampling parameters such as blood sample volumes and sites in addition to my daily tasks?”

The participants also provided suggestions for improvement of the app, including features such as screen layout and input mode, integration of the app with the HIS, and the hospital intranet. Some of the comments made by the users were as follows: “I would like to verify that the entered blood culture sampling parameters are stored correctly in the LIS,” and “I would like to view the blood culture results on the app as well as on the LIS.”

Discussion

Principal Findings

In this feasibility study, we found that the compliance to data entry was satisfactory (354/356, 99.4%) in the clinical setting. No error related to data entry via the app was noted. With regard to the satisfaction level and expectation of effectiveness, all the participants reported positive opinions. However, improvements in the network environment and work process policy were requested for improving timeliness and efficiency.

Although only a small group was tested, the Blood Culture app was found to promote patient safety by the users. Patient identification support and improvement of the blood culture test quality could further enhance patient safety. However, to improve test quality, it is important to educate and guide clinicians as the blood sampling performance could affect the accuracy of the test [18,21,31]. In particular, the volume of sampled blood is the most important factor influencing a correct result [13,15,26]. Mermel and Maki [26] reported that insufficient volume collection often occurs because only a few clinicians and nurses are aware of the vital influence of collection volume on blood culture sensitivity. Hence, increasing the awareness of clinicians regarding this aspect during the point-of-care process and management of test quality represent important solutions. The Blood Culture app was developed for such purposes at the point of sampling. In our study, insufficient collection was noted in 28.7% (102/356) of the cases, although most cases (254/356, 71.3%) showed sufficient blood volume collection (5-7 mL). Accordingly, information on blood volume could be used as an index of reliability. The Blood Culture app can also be used to provide appropriate feedback and to reeducate samplers with relatively frequent errors. In fact, the participants also requested feedback regarding their blood culture quality during the survey.

Comparison With Prior Work

The Blood Culture app described herein differs from other existing medical apps. It directs the actions of clinicians, helps clinicians identify patient information and enter patient-related data in an app connected to the HIS, and monitors the activity of clinicians for quality improvement. Thus, the app can be used to improve patient safety, timeliness, and efficiency for blood culture testing. To guide clinicians more effectively, the app can be upgraded to provide information on the steps for disinfecting hands and disinfecting skin, as well as knowledge about the sterile glove technique. The effective implementation of the app can reduce the gap between the guidelines and actual clinical practice. Consequently, the quality control of the blood culture process could improve patient outcomes, reduce inappropriate antibiotic use and antibiotic resistance, and promote treatment efficiency.

The times for blood culture order, sample submission, and reporting of results have been routinely recorded at our research hospital. However, blood culture sampling parameters—essential data for blood culture quality control—are not collected and managed. The Blood Culture app attempted to collect such information at the point of blood sampling. The speed of the app and ease of data entry were considered to be good, although 2 limitations were cited—weak wireless network environment and the need for data entry. Slow loading time and log-in delay occurred because of the weak wireless network environment or communication with the HIS. These can be overcome by improving the network environment of the hospital and adding an automatic log-in or touch ID feature with the app.

However, the need for recording the blood culture sampling parameters cannot be emphasized without a change in the internal hospital policy regarding the collection of such information to improve test quality. Without such a policy, the app could be considered inefficient and unnecessary. In the departments of laboratory medicine and infectious diseases in the hospital, the policy regarding the recording of blood culture sampling parameters was obligatorily revised, although the change was only recently finalized. Once it is established and appropriately introduced, the app could be widely used to record information correctly and promptly. However, it may be more efficient to record such information via a desktop computer, depending on the sampler’s memory after the procedure. In fact, a desktop version and upgrade versions (for Apple’s iOS and Google’s Android operating systems) of the app were developed and implemented for computerized physician order entry in April 2013.

Lessons Learned

We determined the features that could ensure active use of the app in clinical practice: app functionality for users, high-speed and seamless wireless network, and favorable internal policy. The app can be upgraded to provide more information regarding appropriate blood culture techniques and feedback on the user’s test quality, which could improve the skills of the samplers. A high-speed wireless network and seamless connection to the HIS are essential for its use in the point-of-care settings; the lack of such utilities could cause frustration for users. In addition, an internal policy regarding the recording of blood culture sampling parameters should be established to manage and improve blood culture quality. Strategies to manage such data and guide clinicians could consequently improve the quality of the tests. Our findings may also be useful for individuals developing and implementing mHealth apps in the clinical environment.

Limitations and Future Studies

This study had certain limitations, including the small number of participants, short study period, and single study site. Although the study findings indicated the potential for mobile app implementation in point-of-care settings, the effects of the app on sample volume, patient identification, or contamination rate were not assessed. To control the contamination rate, the app should include aseptic technique guidelines or a program for auditing the data on contaminated blood culture samples; however, it would be conducted in a manner that does not involve apportioning blame. With regard to blood sampling, there is a possibility of overrecording by samplers; however, the participants did not receive any penalty for insufficient sample volume in this study. If an internal policy recommends a penalty for such cases, the samplers may tend to overrecord the sample volume. In those cases, the app cannot be used for quality control. Hence, another solution, such as automatic blood culture volume measurement in the laboratory, is needed. Moreover, we could apply the app's features, including checking the patient's identity and doctor's order in real time, to the sampling processes of other blood tests as well as blood transfusions and the administration of medications.

The data collected from the app, such as sample volume, sampling time, and sampling site of blood culture, could indicate quality improvements in the test, such as the measurement of guideline adherence and evidence of the hospital policy regarding sampling. Further studies that compare the conventional process with the new process (with the app) in terms of impact of contamination, blood volume, or patient identification would be useful for individuals managing hospital infection and implementing mHealth apps in clinical practice.

Conclusions

The Blood Culture app can be applied in the clinic and can be used to provide real-time information, input patient data at the bedside, and manage blood sample quality. If internal policy makes the recording of blood culture sampling parameters an obligation, then clinicians would be more inclined to use the app than a desktop-based program.

Acknowledgments

We thank the Medical Information Office for developing the Blood Culture app. JHL received grant support from the Korea Research Foundation (The Ministry of Education and Human Resources Development; No. NRF-2015R1D1A1A01057091).

Conflicts of Interest

None declared.

References

1. Ozdalga E, Ozdalga A, Ahuja N. The smartphone in medicine: a review of current and potential use among physicians and students. J Med Internet Res 2012;14(5):e128 [FREE Full text] [doi: 10.2196/jmir.1994] [Medline: 23017375]
2. Mosa AS, Yoo I, Sheets L. A systematic review of healthcare applications for smartphones. BMC Med Inform Decis Mak 2012;12:67 [FREE Full text] [doi: 10.1186/1472-6947-12-67] [Medline: 22781312]
3. Camacho E, LoPresti M, Appelboom G, Dumont E, Taylor B. The ubiquitous role of smartphones in mobile health. Biom Biostat Int J 2014;1(1):00004. [doi: 10.15406/bbij.2014.01.00004]
4. Tachakra S, Wang XH, Istepanian RS, Song YH. Mobile e-health: the unwired evolution of telemedicine. Telemed J E Health 2003;9(3):247-257. [doi: 10.1089/153056203322502632] [Medline: 14611692]
5. Silva BM, Rodrigues JJ, de la Torre Díez I, López-Coronado M, Saleem K. Mobile-health: A review of current state in 2015. J Biomed Inform 2015 Aug;56:265-272. [doi: 10.1016/j.jbi.2015.06.003] [Medline: 26071682]
6. Mickan S, Tilson JK, Atherton H, Roberts NW, Heneghan C. Evidence of effectiveness of health care professionals using handheld computers: a scoping review of systematic reviews. J Med Internet Res 2013;15(10):e212 [FREE Full text] [doi: 10.2196/jmir.2530] [Medline: 24165786]
7. O'Neill KM, Holmer H, Greenberg SL, Meara JG. Applying surgical apps: Smartphone and tablet apps prove useful in clinical practice. Bull Am Coll Surg 2013 Nov;98(11):10-18. [Medline: 24313133]
8. Ventola CL. Mobile devices and apps for health care professionals: uses and benefits. P T 2014 May;39(5):356-364 [FREE Full text] [Medline: 24883008]
9. Conroy DE, Yang C, Maher JP. Behavior change techniques in top-ranked mobile apps for physical activity. Am J Prev Med 2014 Jun;46(6):649-652. [doi: 10.1016/j.amepre.2014.01.010] [Medline: 24842742]
10. Zuehlke P, Li J, Talaei-Khoei A, Ray P. A functional specification for mobile eHealth (mHealth) systems. In: 2009 11th International conference on e-Health networking, applications and services (Healthcom 2009); 16-18 Dec. 2009 Presented at: Healthcom 2009; December 16-18, 2009; Sydney.

11. Seabrook HJ, Stromer JN, Shevkenek C, Bharwani A, de GJ, Ghali WA. Medical applications: a database and characterization of apps in Apple iOS and Android platforms. BMC Res Notes 2014;7:573 [FREE Full text] [doi: 10.1186/1756-0500-7-573] [Medline: 25167765]
12. Winokur EJ, Pai D, Rutledge DN, Vogel K, Al-Majid S, Marshall C, et al. Blood culture accuracy: discards from central venous catheters in pediatric oncology patients in the emergency department. J Emerg Nurs 2014 Jul;40(4):323-329. [doi: 10.1016/j.jen.2013.04.007] [Medline: 23816324]
13. Weinstein MP. Current blood culture methods and systems: clinical concepts, technology, and interpretation of results. Clin Infect Dis 1996 Jul;23(1):40-46 [FREE Full text] [Medline: 8816127]
14. Arpi M, Bentzon MW, Jensen J, Frederiksen W. Importance of blood volume cultured in the detection of bacteremia. Eur J Clin Microbiol Infect Dis 1989 Sep;8(9):838-842. [Medline: 2512159]
15. Washington JA, Ilstrup DM. Blood cultures: issues and controversies. Rev Infect Dis 1986;8(5):792-802. [Medline: 3538319]
16. Barenfanger J, Graham DR, Kolluri L, Sangwan G, Lawhorn J, Drake CA, et al. Decreased mortality associated with prompt Gram staining of blood cultures. Am J Clin Pathol 2008 Dec;130(6):870-876 [FREE Full text] [doi: 10.1309/AJCPVMDQU2ZJDPBL] [Medline: 19019762]
17. Hernández-Bou S, Álvarez Álvarez C, Campo Fernández MN, García Herrero MA, Gené Giralt A, Giménez Pérez M, et al. [Blood cultures in the paediatric emergency department. Guidelines and recommendations on their indications, collection, processing and interpretation]. An Pediatr (Barc) 2016 May;84(5):294.e1-294.e9 [FREE Full text] [doi: 10.1016/j.anpedi.2015.06.008] [Medline: 26227314]
18. Towns ML, Jarvis WR, Hsueh P. Guidelines on blood cultures. J Microbiol Immunol Infect 2010 Aug;43(4):347-349 [FREE Full text] [doi: 10.1016/S1684-1182(10)60054-0] [Medline: 20688297]
19. Thomas S, Cheesbrough J, Plumb S, Bolton L, Wilkinson P, Walmsley J, et al. Impact of a blood culture collection kit on the quality of blood culture sampling: fear and the law of unintended consequences. J Hosp Infect 2011 Aug;78(4):256-259. [doi: 10.1016/j.jhin.2011.04.012] [Medline: 21669476]
20. Chew KS, Mohd HF, Jusoh AF, Aziz AA, Nik Hisamuddin NAR, Siti AH. Knowledge of Good Blood Culture Sampling Practice among Healthcare Staffs in An Emergency Department - Are We Getting It Right? Med J Malaysia 2013 Aug;68(4):323-325 [FREE Full text] [Medline: 24145260]
21. Falagas ME, Kazantzi MS, Bliziotis IA. Comparison of utility of blood cultures from intravascular catheters and peripheral veins: a systematic review and decision analysis. J Med Microbiol 2008 Jan;57(Pt 1):1-8. [doi: 10.1099/jmm.0.47432-0] [Medline: 18065660]
22. Schifman RB, Meier FA, Souers RJ. Timeliness and accuracy of reporting preliminary blood culture results: a College of American Pathologists Q-probes study of 65 institutions. Arch Pathol Lab Med 2015 May;139(5):621-626. [doi: 10.5858/arpa.2014-0258-CP] [Medline: 25927146]
23. Ramirez P, Gordón M, Cortes C, Villarreal E, Perez-Belles C, Robles C, et al. Blood culture contamination rate in an intensive care setting: Effectiveness of an education-based intervention. Am J Infect Control 2015 Aug;43(8):844-847. [doi: 10.1016/j.ajic.2015.04.183] [Medline: 26026825]
24. Dawson S. Blood culture contamination rates. J Hosp Infect 2015 Oct;91(2):109-110. [doi: 10.1016/j.jhin.2015.05.007] [Medline: 26122623]
25. Gilligan PH. Blood culture contamination: a clinical and financial burden. Infect Control Hosp Epidemiol 2013 Jan;34(1):22-23. [doi: 10.1086/668771] [Medline: 23221188]
26. Mermel LA, Maki DG. Detection of bacteremia in adults: consequences of culturing an inadequate volume of blood. Ann Intern Med 1993 Aug 15;119(4):270-272. [Medline: 8328734]
27. Snyder SR, Favoretto AM, Baetz RA, Derzon JH, Madison BM, Mass D, et al. Effectiveness of practices to reduce blood culture contamination: a Laboratory Medicine Best Practices systematic review and meta-analysis. Clin Biochem 2012 Sep;45(13-14):999-1011 [FREE Full text] [doi: 10.1016/j.clinbiochem.2012.06.007] [Medline: 22709932]
28. Donnino MW, Goyal N, Terlecki TM, Donnino KF, Miller JB, Otero RM, et al. Inadequate blood volume collected for culture: a survey of health care professionals. Mayo Clin Proc 2007 Sep;82(9):1069-1072. [doi: 10.4065/82.9.1069] [Medline: 17803874]
29. Samson LL, Pape-Haugaard L, Meltzer MC, Fuchs M, Schønheyder HC, Hejlesen O. Design of a Tablet Computer App for Facilitation of a Molecular Blood Culture Test in Clinical Microbiology and Preliminary Usability Evaluation. JMIR Mhealth Uhealth 2016;4(1):e20 [FREE Full text] [doi: 10.2196/mhealth.5041] [Medline: 26993432]
30. Park J, Lee G, Shin S, Kim JH, Han H, Kwon T, et al. Lessons learned from the development of health applications in a tertiary hospital. Telemed J E Health 2014 Mar;20(3):215-222 [FREE Full text] [doi: 10.1089/tmj.2013.0192] [Medline: 23909863]
31. Willems E, Smismans A, Cartuyvels R, Coppens G, Van Vaerenbergh K, Van den Abeele AM, et al. The preanalytical optimization of blood cultures: a review and the clinical importance of benchmarking in 5 Belgian hospitals. Diagn Microbiol Infect Dis 2012 May;73(1):1-8. [doi: 10.1016/j.diagmicrobio.2012.01.009] [Medline: 22578933]

Abbreviations

HIS: hospital information system
IEEE: Institute of Electrical and Electronics Engineers
LIS: laboratory information system
mHealth: mobile health
MICU: medical intensive care unit

Edited by G Eysenbach; submitted 26.07.16; peer-reviewed by L Sheets, S De Rosa, J Rovira Simon; comments to author 11.08.16; revised version received 20.09.16; accepted 07.10.16; published 26.10.16.

Please cite as:
Lee G, Lee Y, Chong YP, Jang S, Kim MN, Kim JH, Kim WS, Lee JH
Blood Culture Testing via a Mobile App That Uses a Mobile Phone Camera: A Feasibility Study
J Med Internet Res 2016;18(10):e282
URL: http://www.jmir.org/2016/10/e282/
doi:10.2196/jmir.6398
PMID:27784649

Original Paper

How Veterans With Post-Traumatic Stress Disorder and Comorbid Health Conditions Utilize eHealth to Manage Their Health Care Needs: A Mixed-Methods Analysis

Julia M Whealin[1,2], PhD; Emily C Jenchura[3], MA; Ava C Wong[4], MPH; Donna M Zulman[4,5], MS, MD

[1]Clinical Informatics Service, VA Pacific Island Health Care System, Honolulu, HI, United States
[2]Department of Psychiatry, John A Burns School of Medicine, University of Hawaii, Honolulu, HI, United States
[3]Department of Psychology, Arizona State University, Tempe, AZ, United States
[4]Center for Innovation to Implementation (Ci2i), VA Palo Alto Health Care System, Menlo Park, CA, United States
[5]Division of General Medical Disciplines, Stanford University School of Medicine, Stanford, CA, United States

Corresponding Author:
Julia M Whealin, PhD
Clinical Informatics Service
VA Pacific Island Health Care System
3375 Koapaka Street, Suite I-150
Honolulu, HI, 96819
United States
Phone: 1 (808) 566 1935
Fax: 1 (808) 566 1885
Email: Julia.Whealin@va.gov

Abstract

Background: Mental health conditions are prevalent among US veterans and pose a number of self-management and health care navigation challenges. Post-Traumatic Stress Disorder (PTSD) with comorbid chronic medical conditions (CMCs) is especially common, in both returning Iraq or Afghanistan and earlier war-era veterans. Patient-facing electronic health (eHealth) technology may offer innovative strategies to support these individuals' needs.

Objective: This study was designed to identify the types of eHealth tools that veterans with PTSD and comorbid CMCs use, understand how they currently use eHealth technology to self-manage their unique health care needs, and identify new eHealth resources that veterans feel would empower them to better manage their health care.

Methods: A total of 119 veterans with PTSD and at least one CMC who have used the electronic personal health record system of the US Department of Veterans Affairs (VA) responded to a mailed survey about their chronic conditions and preferences related to the use of technology. After the survey, 2 focus groups, stratified by sex, were conducted with a subgroup of patients to explore how veterans with PTSD and comorbid CMCs use eHealth technology to support their complex health care needs. Focus groups were transcribed verbatim and analyzed using standard content analysis methods for coding textual data, guided by the "Fit between Individual, Task, and Technology" framework.

Results: Survey respondents had a mean age of 64.0 (SD 12.0) years, 85.1% (97/114) were male, 72.4% (84/116) were white, and 63.1% (70/111) had an annual household income of < US $50,000. Mean score on a measure of eHealth literacy was 27.7 (SD 9.8). Of the respondents, 44.6% (50/112) used health-related technology 1 to 3 times per month and 21.4% (24/112) used technology less than once per month. Veterans reported using technology most often to search for health information (78.9%, 90/114), communicate with providers (71.1%, 81/114), and track medications (64.9%, 74/114). Five major themes emerged that describe how eHealth technology influences veterans with PTSD and comorbid CMCs: (1) interactions with social support, (2) condition management, (3) access to and communication with providers, (4) information access, and (5) coordination of care.

Conclusions: The "Fit between Individual, Task, and Technology" model provided a useful framework to examine the clinical tasks that arose for veterans and their resourceful adoption of eHealth tools. This study suggests that veterans who use the Web are eager to incorporate eHealth technology into their care and self-management activities. Findings illustrate a number of ways in which the VA and eHealth technology developers can refine existing applications, develop new resources, and better promote tools that address challenges experienced by veterans with PTSD and comorbid CMCs.

(J Med Internet Res 2016;18(10):e280) doi:10.2196/jmir.5594

KEYWORDS

stress disorders, post-traumatic; telemedicine; electronic mail; social media; self-care; computer literacy

Introduction

Foremost among the challenges facing the US Department of Veterans Affairs (VA) is providing care for the more than 40% of VA patients who are suffering from mental health disorders [1]. The most commonly diagnosed mental health disorder at VA facilities is Post-Traumatic Stress Disorder (PTSD), occurring in 13% to 21% of veterans [1-5]. The symptoms associated with PTSD—intrusive memories, flashbacks (vivid recollections of the event), avoidance of stimuli associated with a trauma, negative mood, difficulty concentrating, and hyperarousal [6]—can substantially and negatively impact veterans' abilities to cope with stress, function socially, and maintain employment [7-10]. Untreated PTSD is also associated with high rates of domestic violence, homelessness [11], and suicide attempts [12-14]. Not surprisingly, PTSD symptoms can impair veterans' abilities to manage their health care needs [15].

To further complicate matters, PTSD often co-occurs with a number of chronic medical conditions (CMCs) [15,16]. Veterans with PTSD have high rates of circulatory, digestive, musculoskeletal, endocrine-nutritional, respiratory, infectious, and nervous system diseases [17-21]. In a national study of Iraq and Afghanistan veterans, 20% of men and 32% of women with PTSD had 10 or more diagnosed comorbid medical disorders [22]. These veterans can face especially complex self-management and health care navigation challenges associated with symptom control, treatment regimen adherence [23], and engagement in multiple medical services [24].

The potential for electronic health (eHealth) resources to better promote wellness in veterans with PTSD and comorbid CMCs depends on understanding patients' health needs and preferences related to technology [25,26]. Among veterans in general, recent research suggests that about 70% of them access the Web [27], and of those veterans, many also use eHealth technology [28,29]. For example, veterans have been reported to access Web-based medical information [29], communicate with providers over secure messaging [30], access personal health records (PHRs) [31], and use Web-based and mobile apps to manage their symptoms [32]. Additionally, VA patients have been found to use social media to search for others with similar health problems at about the same rate as nonveterans [28].

To date, however, very little research has examined eHealth use among veterans with PTSD. One study that surveyed veterans who attended a VA PTSD outpatient clinic ([32]; N=188) found that 76% reported having access to a mobile phone or tablet device. Among this group, 85% expressed interest in accessing eHealth apps and 28% had accessed such an app. A study of 600 Iraq/Afghanistan era veterans [33] found that, compared with their peers, those who screened positive for PTSD were less willing to use various eHealth modalities, including online computer-based programs (50.6% vs 30.9%), text messaging (35.6% vs 24.3%), clinical telehealth (ie, the use of electronic media to facilitate real-time health care in the home; 52.7% vs 25.4%), and social networking sites (52.5% vs 34.8%). To better understand the needs and challenges facing veterans, Aponte and colleagues [29] recommended conducting follow-up studies on special populations of veterans, such as those suffering from PTSD and comorbid CMCs.

Given the multiple challenges that veterans with PTSD and comorbid CMCs face, it is vital to understand the ways in which the needs of these veterans interface with the types of eHealth resources available, as well as the health-related tasks veterans prefer and desire. The goals of this investigation were threefold: (1) to identify the types of eHealth tools used by veterans with PTSD and comorbid CMCs who use the Internet, (2) to understand how they currently utilize eHealth technology, and (3) to identify new eHealth resources that veterans feel would empower them to better manage their health care.

Methods

Study Design and Participants

We report on secondary data analyses from a sequential, mixed methods study comprising a survey followed by focus groups [34]. In 2012, a survey was mailed to a random sample of 1500 patients who receive care at a VA facility in northern California. Because the goal was to study individuals who use technology for health-related purposes, inclusion criteria for the mailing consisted of all patients who were registered users of the VA's electronic PHR system. Of patients recruited, 479 responded to the survey (response rate of 31.93%, 479/1500). Of these, 119 patients reported having PTSD and at least one CMC and serve as the sample for the analyses reported here. Study procedures were approved by the Stanford University Institutional Review Board.

Survey Design and Administration

For descriptive purposes, the survey asked patients to self-report their current health conditions using a list of 29 conditions that included "Post-Traumatic Stress Disorder." Respondents could also write in additional conditions [34]. Because no validated and reliable item was available to assess comfort with technology when we developed this study, we adapted items from previous assessments of veterans [35] and nonveterans [36]. Respondents were asked: "Please describe how comfortable you are using the following types of technology," with response options including "no experience" and a 5-point scale ranging from "very uncomfortable" to "very comfortable." Participants then indicated whether or not they had experience using any of these technology modalities to help them manage their health care, the frequency of such use, and for what activities (eg, search for health information, buy medications or medical supplies, and communicate with providers).

The 8-item eHEALS (eHealth Literacy Scale) [37] was used to measure eHealth literacy, including respondents' perceived knowledge, comfort, and skill at finding, evaluating, and applying electronic health information to health problems. Items are measured on a 5-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). The summed scores range from 8 to 40 [38]. This measure has been found to consistently capture the concept of eHealth literacy (coefficient alpha = .88; [39]). The scale correlates with consumer comfort and skill in using information technology. Principal components analysis produced a single factor solution (56% of variance).

Focus Group Procedures and Content

Among the 119 individuals with PTSD and at least one CMC who completed the screening survey, 35 met eligibility criteria (29.4%, 35/119) for the focus groups (≥3 chronic conditions and experience using technology to help them care for their health or manage their health care, and having received care at the VA facility). Using purposive sampling, we constructed 2 focus groups of patients with PTSD, stratified by sex to enable a forum for discussing potentially sensitive topics (eg, military sexual assault). Sampling considerations included patients' experiences with PTSD and multimorbidity, their experience with technology, and their availability to participate in a scheduled group. Of the 35 eligible patients with PTSD, 10 (29%, 10/35) participated in one of the focus groups.

The 2 sex-stratified groups consisted of 7 men and 3 women. Written informed consent was obtained from each focus group participant, and each received a US $50 gift card for participation. The focus groups were moderated by a trained research specialist using a semistructured guide [40]. The "Fit between Individual, Task, and Technology" (FITT) framework was used to guide the focus group content. The FITT framework is based on the idea that eHealth adoption depends on the match between the attributes of the user, the attributes of the technology, and the attributes of the clinical tasks and processes that a user needs to complete [41]. Thus, the framework was used to (1) examine the tasks that arise for veterans as a result of having to manage PTSD and comorbid CMCs, (2) determine current eHealth resources that aid patients with PTSD and comorbid CMCs in meeting these challenges, and (3) identify how eHealth resources could be further developed to better serve this population.

Data Analysis

Descriptive summary statistics were computed for demographic and technology variables. Focus groups were transcribed verbatim and analyzed using standard content analysis methods for coding textual data [42]. As described elsewhere [40], transcript coding, supported by ATLAS.ti software (ATLAS.ti Scientific Software Development GmbH), was conducted as part of a larger project with guidance from qualitative research experts. Two research specialists then read through the documents to gain a sense of the data as a whole and then separately coded written responses for the groups with PTSD and comorbid CMCs to identify unique technology practices and needs.

Results

Participant Characteristics

Table 1 presents characteristics of survey respondents and focus group participants, facilitating qualitative comparison of characteristics such as age, sex, race/ethnicity, education, income, and chronic condition number. Survey respondents had a mean age of 64.0 (SD 12.0) years, 85.1% (97/114) were male, 72.4% (84/116) were white, and 63.1% (70/111) had an annual household income of < US $50,000. Focus group participants (n=10) had a mean age of 57.4 (SD 3.8) years, 70% (7/10) were male, 70% (7/10) were white, and 60% (6/10) had an annual household income of < US $50,000. Additionally, the large majority of the survey sample (92.4%, 110/119) and all focus group participants had 3 or more CMCs (Table 1). As shown in Table 2, the most common CMCs were chronic pain, high blood pressure, and arthritis or rheumatism, experienced by 57.1% (68/119), 49.6% (59/119), and 44.5% (53/119) of the entire sample, respectively, with comparable rates among focus group participants.

Table 1. Survey respondent characteristics.

Characteristics	Survey respondents without PTSD[a] (n=347)[b]		Survey respondents with PTSD (n=119)[c]		Focus group participants (n=10)	
	Mean (SD)	n (%)	Mean (SD)	n (%)	Mean (SD)	n (%)
Age, years (N_{SR}[d]=114, N_{NoPTSD}[e]=343)	66.0 (11.3)		64.0 (12.0)		57.4 (3.8)	
Female (N_{SR}=114, N_{NoPTSD}=342)		23 (6.7)		17 (14.9)		3 (30.0)
Race[f] (N_{SR}=116, N_{NoPTSD}=316)						
White, non-Hispanic		289 (91.5)		84 (72.4)		7 (70.0)
Black, non-Hispanic		14 (4.4)		11 (9.6)		0 (0.0)
Hispanic (N_{SR}=115, N_{NoPTSD}=341)		21 (6.2)		12 (10.5)		2 (20.0)
Other, non-Hispanic		28 (8.9)		9 (7.9)		2 (20.0)
Employment[f] (N_{SR}=118, N_{NoPTSD}=343)						
Full-time		58 (16.9)		12 (10.2)		—
Part-time		37 (10.8)		6 (5.1)		—
Retired		207 (60.4)		54 (45.7)		7 (70.0)
Disabled		60 (17.5)		56 (47.5)		6 (60.0)
Unemployed		35 (10.2)		20 (16.9)		2 (20.0)
Student		4 (1.2)		7 (5.9)		2 (20.0)
Education (N_{SR}=118, N_{NoPTSD}=342)						
High school degree or less		39 (11.4)		12 (10.2)		—
Some college		131 (38.3)		62 (52.5)		6 (60.0)
College degree or more		172 (50.3)		44 (37.3)		4 (40.0)
Annual household income, US $ (N_{SR}=111, N_{NoPTSD}=320)						
<$50,000		193 (60.3)		70 (63.1)		6 (60.0)
$50,001-$75,000		53 (16.6)		32 (28.8)		3 (30.0)
>$75,001		74 (23.1)		9 (8.1)		1 (10.0)
Total number of comorbid conditions	3.3 (1.9)		5.3 (2.3)		5.2 (1.3)	
1-2		129 (37.2)		9 (7.6)		—
≥ 3		212 (61.1)		110 (92.4)		10 (100)

[a] PTSD: Post-Traumatic Stress Disorder.

[b] Sample includes 347 individuals unless otherwise indicated.

[c] Sample includes 119 individuals unless otherwise indicated.

[d] N_{SR}: number of survey respondents with PTSD.

[e] N_{NoPTSD}: number of survey respondents without PTSD.

[f] For race and employment, participants could answer more than one.

Table 2. Chronic medical conditions reported by study participants.

Chronic medical condition[a]	Survey respondents without PTSD[b] (n=347), frequency n (%)	Survey respondents with PTSD (n=119), frequency n (%)	Focus group participants (n=10), frequency n (%)
Chronic pain	130 (37.5)	68 (57.1)	6 (60.0)
High blood pressure	211 (60.8)	59 (49.6)	5 (50.0)
Arthritis or rheumatism	127 (36.6)	53 (44.5)	4 (40.0)
Diabetes	102 (29.4)	24 (20.2)	1 (10.0)
Depression	51 (14.7)	73 (61.3)	8 (80.0)
Lung or breathing problem	64 (18.4)	22 (18.5)	2 (20.0)
Prostate problems	64 (18.4)	15 (12.6)	1 (10.0)
Headaches or migraines	29 (8.4)	34 (28.6)	4 (40.0)
Cancer	34 (9.8)	18 (15.1)	2 (20.0)
Heart failure	30 (8.7)	7 (5.9)	2 (20.0)
Kidney problem	26 (7.5)	8 (6.7)	1 (10.0)
Chronic fatigue syndrome	10 (2.9)	10 (8.4)	1 (10.0)
Other	115 (33.1)	30 (25.2)	4 (40.0)

[a] Participants were able to circle more than 1 condition.

[b] PTSD: Post-Traumatic Stress Disorder.

Use of eHealth resources is presented in Table 3. Within the entire sample, 44.6% (50/112) of respondents used health-related technology 1 to 3 times per month and 21.4% (24/112) used technology less than once per month. eHealth technology was most commonly used to search for health information (78.9%, 90/114), communicate with providers (71.1%, 81/114), and track medications (64.9%, 74/114). The survey respondents and focus group participants were similar in that virtually all members of both groups had used and were comfortable using computers, the Web, and email. Similarly, both groups were less comfortable (and had less experience) using eHealth technology to visit support groups, make clinical telehealth calls, or participate in health-related mobile apps or games. Mean score on the eHEALS was 27.7 (SD 9.8) among survey respondents and 31.1 (SD 5.4) among focus group participants.

Table 3. Study participants with post-traumatic stress disorder and their comfort with and experience using technology for health-related purposes.

eHealth Technology Use	Survey respondents n (%)	Focus group participants n (%)
Health-related technology use (N_{SR}[a]=116, N_{FGP}[b]=10)	104 (90.0)	10 (100)
Frequency of health-related technology use (N_{SR}=100, N_{FGP}=10)		
Daily	8 (8.0)	2 (20.0)
1-5 times per week	18 (18.0)	1 (10.0)
1-3 times per month	50 (50.0)	7 (70.0)
Less than once per month	24 (24.0)	—
eHealth activities (N_{SR}=114[c], N_{FGP}=10)		
Searched for health information	90 (78.9)	10 (100)
Communicated with provider	81 (71.1)	10 (100)
Tracked medication list	74 (64.9)	9 (90.0)
Tracked medical information	56 (49.1)	8 (80.0)
Bought medications or supplies	40 (35.1)	5 (50.0)
Made treatment decisions	49 (43.0)	9 (90.0)
Visited online support group	15 (13.2)	3 (30.0)
Used health-related mobile app (N_{SR}=115)	19 (16.5)	4 (40.0)
Participated in health-related competition or game	5 (4.4)	0 (0.0)
Other	13 (11.4)	1 (10.0)
Experience using technology (N_{SR}=113, N_{FGP}=9)[d]		
Computers (N_{SR}=112)	112 (100)	9 (100)
The Web	112 (99.1)	9 (100)
Email (N_{SR}=111)	110 (99.1)	9 (100)
Text messaging (N_{SR}=111, N_{FGP}=8)	94 (84.7)	7 (87.5)
Social media (N_{SR}=111)	81 (73.0)	7 (78.0)
Video calling	76 (67.3)	6 (67.0)
Mobile apps	90 (79.6)	8 (89.0)

[a] N_{SR}: number of survey respondents.

[b] N_{FGP}: number of focus group participants.

[c] N_{SR}=114 for eHealth activity unless otherwise specified.

[d] N_{SR}=113 and N_{FGP}=9 unless otherwise specified.

Focus Group Themes

Five major themes describe how eHealth technology influences veterans with PTSD and comorbid CMCs, including their (1) interactions with social support, (2) condition management, (3) access to and communication with providers, (4) information access, and (5) coordination of care. Quotes from focus groups that represent each theme appear in an abbreviated version in Table 4. See Multimedia Appendix 1 for the complete list of quotes from the focus groups.

Interactions With Social Support

Four subthemes emerged that describe how technology influences veterans’ interactions with their social support.

Receiving Support

Veterans with PTSD and comorbid CMCs reported using technology to overcome difficulties connecting socially with others in person or via the telephone. In particular, texting and social media were seen as useful for connecting with others without the stressors of social interaction, such as becoming “too emotional.”

Providing Mutual Support

Several Veterans described using technology to facilitate mutual support within specific groups of veterans, for example women who attended a retreat together. Others stated that they were still seeking a means to connect with one another via social media. For example, a veteran who is attending a university was "trying to get our own place *(social media site)* to meet so that the veterans can stay together and kind of help each other with the school issues." In other words, technology can allow veterans to connect with peers and maintain supportive relationships when face-to-face support is not feasible.

Obtaining Support to Cope With Symptoms or a Crisis

Veterans also reported using email and text messaging technology to give and receive support in times of crisis. Veterans indicated that they felt more comfortable using technology to connect with a peer or a professional who knew them, rather than someone they did not know, to help them cope with feelings of depression and suicidality. One veteran stated, "...when I got to my point where I was really at my lowest, you know, I called (*my therapist)* in the middle of the night and she arranged for someone to come pick me up...If I hadn't had that, you know, I probably wouldn't have gone to (the) emergency room or called 9-1-1 or called one of those crisis lines where you have to talk to some stranger."

Deterring Social Support

Veterans also recognized that excessive use of technology, including social media, could promote avoidance of face-to-face socialization, which in turn sometimes fueled isolation. One veteran stated, "I think sometimes I feel safe on the computer or Facebook but...sometimes it doesn't really get you out to meet people...Facebook is good but, sometimes, too much is not good."

Condition Management

Three subthemes emerged that describe how technology is used to help veterans manage their medical conditions.

Using Web-Based Tools to Manage Symptoms

Veterans described using technology to access Web-based tools to help them cope with their PTSD and comorbid CMCs. For example, some veterans used mobile apps, such as games, to distract themselves when their anxiety elevated. Others used apps that were specifically designed to manage physical and psychological symptomatology, such as anxiety and high blood pressure. For example, veterans identified the VA "PTSD Coach" app [43] as particularly helpful. One veteran stated, "The (*smartphone*) is glued to my hand all the time and as soon as they got that PTSD app out...I loaded all my little pictures in there and my phone numbers and you can like send a text when you freak out and it will make a phone call (*to the crisis line*) for you." Additionally, veterans used their digital devices to maintain a journal about the problems they encountered. One veteran opened a Web "blog" because he felt a website was a more secure location to write about his symptoms than in a book or on paper.

Providing a Sense of Safety and Security

Veterans stated that their mobile phones, in particular, have become a source of grounding and security and thus function to reduce anxiety when they are in public. One veteran stated, "You know, holding a...smartphone or whatever, you know, like I just have a rock in my pocket or something that will calm me down or focusing on something in the room to like kind of calm my anxiety." Others indicated that following maps or directions was very stressful for them because of memory and concentration difficulties, and so navigation apps were helpful to reduce their anxiety about navigating on the road.

Signaling Reminders

Veterans described using computer programs, email, and mobile apps to keep track of a variety of health-related needs, including medical appointments and medication, as well as non–health-related tasks. Veterans identified the VA's telephone system and Web portal ("My Health *e*Vet") as being helpful for renewing and keeping track of medications. One veteran stated, "I utilize Google mail appointment reminders and I set them all and so they email me and they can message on my phone to tell me to order my medication, to take my medication, to make an appointment, to go to an appointment, and then tell (me) things I have to check off."

Access to and Communication With Providers

Three subthemes emerged that describe how veterans use technology to improve access to and communicate with their providers.

Facilitating Accurate Reports of Pressing or Sensitive Issues

Many veterans reported that they were better able to convey the nature of their problems via digital technology than in person. Some felt that technology enabled them to share about important sensitive and/or stressful topics that were more relevant and accessible to them when they were outside the clinic. For example, veterans felt that being able to email their clinicians helped them share information that was embarrassing for them to talk about in person. Additionally, veterans felt that providing information from their home or natural day-to-day environment provided clinicians with a more accurate measure of their physical and mental health status. One veteran stated, "...when I was on active duty my psychiatrist and psychologist used email and it was good for them when I...could express how I felt at that time; for them to gauge my overall health status and not just what I say when I'm sitting in their chair. And they kept those as records to feed into my medical record so it helped them as much as it helped me."

Promoting Timely Communication Between Veterans and Their Providers

Another theme focused on the convenience of engaging with providers via secure messaging. Veterans felt more connected to their providers and described that they and their providers could resolve problems more quickly using text messaging and email. One veteran stated, "Yeah, I think it's faster for all of us, you know. It kind of frees up (providers') time and they can answer (*my question*) when they can. And sometimes the conversation (*in office-based meetings*) goes a little bit longer because you don’t always think about what you are going to say and it kind of drags on more than what it needs to.”

Increasing Service Access for Disabled Veterans

Similarly, veterans stated that they either used or desired access to home telehealth care services when in-office health care sessions were not feasible. A common theme was the importance of health care sessions provided via technology for veterans disabled by mental and/or physical symptoms. One veteran stated, “For me like sometimes my migraines are really bad and a trigger for me and my migraines is driving so Skyping (*videoconferencing*) would be easier.” Other veterans indicated that technology could be helpful in situations when they are unable to attend health care sessions at the VA facility because of anxiety and hypervigilance secondary to agoraphobia or military sexual assault.

Information Access

Three subthemes emerged that described how veterans use technology to obtain health-related information.

Increasing Access to Trustworthy Health Information

Veterans reported that they often used technology to access “trustworthy” information from reliable websites that better enabled them to understand and manage their symptoms. A veteran stated, “I use the computer a lot. I use...other websites, the VA website. And so when the doctor tells me something then I can go and I can look and find resources or more information.” Another veteran reported using the VA Web portal as a source of information, stating “MyHealth *e*Vet...was a good program in order to find information and...be an advocate for my own health. There was a lot of information that I could use...and I could do it from home.”

Obtaining Information From Peers

Veterans described using the Web to access useful information from peers and/or veteran organizations. Veteran-specific blogs, social media sites, and organizations were particularly helpful. For example, one veteran stated, “...there’s a great blog for PTSD that covers PTSD individual unemployability, so I’m all over that. I don’t know who actually sponsors that blog but, every day there’s probably about 30 or 40 new questions or statements or something so that’s been really helpful.” Another stated, “Sometimes I just Google search a lot. I look for different woman veteran organizations, you know. Just to research and find stuff.”

Identifying Opportunities to Improve Means of Obtaining Health Information

Veterans expressed a need for consolidated health information presented in a way that did not lead to feeling overwhelmed by too much or, at times, conflicting information. Some reported difficulties in navigating information on the Web. For example, one veteran stated, “I went to the National Council for PTSD and got information. That led me off into a bunch of different directions so when you do your search on the Web you can either hit a good spot or a bunch of bad ones...Either way you’re getting a data overload.” To resolve this problem, one veteran suggested he would like to have “an app that would help show...some quick advice for things like PTSD for each of different conditions that you could go to that would help with these things.” Another veteran thought learning modules would be helpful, stating “log in and you could learn about all these different conditions...consolidated in one place and then it tracks what you studied and what you have learned and it gives you little reward points...making yourself feel good...”

Coordination of Care

Two subthemes emerged related to coordination of health care.

Improving Care Coordination Across Providers and Facilities

Instead of waiting for the health care system to create a formal link, veterans used technology to initiate treatment coordination between providers and, at times, across VA and non-VA facilities. One veteran was able to refill a prescription while on vacation. He stated “I ran into a situation where I was on vacation and I realized that I was running out of the medication...I sent my primary doctor an email saying, ‘Hey, I need this renewed.’” Another veteran stated, “So when I was starting to run out of medication, I went in and tried to look for my psychiatrist and I couldn’t. So I sent an email to my primary letting him know what was going on and what had happened. Well, my psychiatrist had forgotten to reissue my medication and they were able to communicate but she and I cannot communicate...but I was happy that it was acted on within a day or two. Good communication there...”

Identifying Opportunities for Improved Care Coordination

Veterans reported circumstances in which care coordination between facilities did not occur, leading to inconvenience. In one situation, for example, a veteran’s son was also enrolled in the VA for PTSD treatment but at a different VA facility than the veteran research participant. The veteran stated, “My son...had forgotten his medication. I took him down...to the VA here...they could not look up his...stuff in (his hometown VA), and be able to access it up here. So what I had to do is we had to sit there for two and a half hours and get him signed up in (my medical center).” Veterans wished for greater access to and coordination of records across VA facilities to expedite access to health care regardless of location and to afford providers knowledge of veteran health care activities across the VA.

Table 4. Focus group themes and sample statements describing eHealth technology's influences for veterans with Post-Traumatic Stress Disorder and comorbid chronic medical conditions.

Themes and subthemes	Sample statements
Interactions with social support	
Receiving support	"The Facebook effect is nice because sometimes you want to connect because you can't pick up the phone and you don't want to see anybody in person but it's that little tangible connection you can put something on and you get instant feedback. But I can be negative, too, if you don't get any feedback."
	"I use Skype all the time. My mother-in-law lives in (*another state)* so she sees the daughters on Skype. And I will Skype with someone."
Providing mutual support	"...my support system is mostly with (*women from a veterans group*). I text them because a lot of us don't like to talk on the phone because sometimes you get too emotional. I just don't feel like talking to people, but I text a lot of my woman vet and we support each other."
	"I'm involved with the vet's center pretty heavily in (*the city)*. I'm there once a week with a group and we all-all of us interact with each other like we're doing right now, be it cell phone or a text or whatever away from the VA kind of, like what are you doing in terms of this, like in terms of mental health, in terms of losing weight. And I am also involved in a group through another added facet of the VA where we are all PTSD guys and we interact with them. So it's all about networking with ourselves. Everybody in this room could be networking away from the VA. I don't know how healthy that is but it's all via communication with our cell phones, primarily."
Obtaining support to cope with symptoms or a crisis	"...when I got to my point where I was really at my lowest, you know, I called (*my therapist*) in the middle of the night and she arranged for someone to come pick me up...if I hadn't had that, you know, I probably wouldn't have gone to emergency room or called 9-1-1 or called one of those crisis lines where you have to talk to some stranger."
	"Because I have one psychologist in (*another city)* when my PTS was worse, I do not like to see anybody. I just-and then she send me an email, a poem, you know, why I should just don't give up because I was suicidal. And she sent me that poem I just-you know, and I-just reading that poem kind of saved my life."
Deterring social support	"I think sometimes I feel safe on the computer or Facebook but...sometimes it doesn't really get you out to meet people so that's why I go on trying to find some social activity to do but I'm doing too much on the computer and I need to push myself out there. Facebook is good but, sometimes, too much is not good."
Condition management	
Using Web-based tools to manage symptoms	"The (*smartphone)* is glued to my hand all the time and as soon as they got that PTSD app out...I loaded all my little pictures in there and my phone numbers and you can like send a text when you freak out and it will make a phone call for you."
	"I...use the PTSD app for my blood pressure because some of the imagery and the progressive relaxation helps me lower my blood pressure."
Providing a sense of safety and security	"...when I come to the VA I get really anxious and I see things that trigger me; men that get me angry and people in uniform. I just-I'm always holding my phone because having the Smartphone...Facebook and games, it has helped [my] mental health a lot..."
	"You know, holding a...smartphone or whatever, you know, like I just have a rock in my pocket or something that will calm me down or focusing on something in the room to like kind of calm my anxiety. Those are just some of the things that I use."
Signaling reminders	"...now that having a smartphone I have a task list. I put it on task so when I have an appointment or, you know, I put stuff on: tomorrow, don't forget to go to MyHealth *e*Vet or reorder."
	"The telephone system for renewing medications works great, you know at least in (*town)* where I go. And like you were saying, if your prescription is expired, they will automatically send a note to your doctor to request a new one, and that happens quickly. I mean it could take three or four days to get a prescription refilled if your prescription is expired and then getting another refill is probably maybe four days. So it's really fast. So I don't have any complaints..."
Access to and communication with providers	
Facilitating accurate reports of pressing or sensitive issues	"...when I was on active duty my psychiatrist and psychologist used email and it was good for them when I would send them an email, I suppose, having like having a difficult time and I could express how I felt at that time; for them to gauge my overall health status and not just what I say when I'm sitting in their chair. And they kept those as records to feed into my medical record so it helped them as much as it helped me."
	"They could make their visual check because there would be a lot of information on how you appear and they could probably learn more about you if they saw you in your home environment and not how you shower and put on clean clothes to come to the VA."

Themes and subthemes	Sample statements
Promoting timely communication between veterans and their providers	"Yeah, I think (using email, secure messaging or texting is) faster for all of us, you know. It kind of frees up their time and they can answer it when they can. And sometimes the (*phone*) conversation goes a little bit longer because you don't always think about what you are going to say and it kind of drags on more than what it needs to." "About the email, the one thing that I really like is that the doctor has always got somebody waiting for him, so the nurses are the ones that were logging in to the email and doing the routing of the-and letting him know what's going on, what the-and I really like that! That's the sort of addresses the issue that you brought up."
Increasing service access for disabled veterans	"When I was on active duty I had the problem like you did. I didn't want to go out of the house. I couldn't get out of bed. I couldn't take a shower. I couldn't do anything. And they expect you, because I was on medical-waiting for my medical board, and they knew you couldn't go to work but how can they expect you to get up and drive 45 miles for a doctor's appointment when you can't even like feed yourself or take a shower?" "So when you have all those things, then it's not making an hour out of your day for an appointment. You have to budget in well, it's going to take me 15 or 20 minutes in the bathroom to clean myself up; it's going to take me an hour, hour and a half before I can drive. Now we are talking, you know, two, three hours out of my day. So when I wake up in the morning do I really want to go? Do I really want to deal with it? I don't want to deal with it. I have other stuff that's more important. I'm just not going to, whereas, if it was just a Skype phone call then, I would be more likely to participate."
Information access	
Increasing access to trustworthy health information	"I use the computer a lot and the research-I use the Mayo Clinic and other websites, the VA website. And so when the doctor tells me something then I can go and I can look and find resources or more information." MyHealth *e*Vet...was a good program in order to find information and...be an advocate for my own health. There was a lot of information that I could use...and I could do it from home."
Obtaining information from peers	"Because there's a great blog for PTSD that covers PTSD individual unemployability, so I'm all over that. I don't know who actually sponsors that blog but, every day there's probably about 30 or 40 new questions or statements or something so that's been really helpful." "Sometimes I just Google search a lot. I look for different woman veteran organizations, you know. Just to research and find stuff.
Opportunities to improve health information access	"I went to the National Council for PTSD and got information. That led me off into a bunch of different directions so when you do your search on the Internet (*Web*) you can either hit a good spot or a bunch of bad ones...Either way you're getting a data overload." "I use the Mayo Clinic and other websites, the VA website...The problem that I have is when I have multiple practitioners with different ideas about conditions as far as how to care for them or solve them or even their own interpretation of what the condition is—especially with PTSD."
Coordination of care	
Improving care coordination across providers and facilities	"I ran into a situation where I was on vacation and I realized that I was running out of the medication and it would take a certain amount of time once I got back to get it refilled. So I got on and I sent my primary doctor an email saying, 'Hey, I need this renewed' and I went in to look and see, no it hadn't. So I had two days later come home, went in to see the pharmacist and she gave me a week's worth of pills and she immediately put in a message to him, and that day he renewed the prescription. So it was really working well!" "So when I was starting to run out of medication, I went in and tried to look for my psychiatrist and I couldn't. So I sent an email to my primary letting him know what was going on and what had happened. Well, my psychiatrist had forgotten to reissue my medication and *they* were able to communicate but she and I cannot communicate through the...but I was happy that it was acted on within a day or two. Good communication there..."
Identifying opportunities for improved care coordination	"I had an experience. My son got out of the Marine Corps about three years ago. He...has PTSD in addition to some other issues. He takes an anti-anxiety medication and so he was up here over Christmas and had forgotten his medication. I took him down...to the VA here. It wasn't that simple. I mean they could not look up his-even though he's down in (*another*) county-he goes to the (*VA)* clinic down there, they could not look up his stuff in [*his hometown VA*], and be able to access it up here. So what I had to do is we had to sit there for two and a half hours and get him signed up in (my medical center)...it got him through it, but it was a pain...you know?"

Discussion

Principal Findings

This investigation used the FITT model [41] to identify how veterans used technology and eHealth resources to better manage their symptoms of PTSD and comorbid CMCs. The model provided a useful framework to examine the clinical tasks that arose for veterans and their resourceful adoption of technology and eHealth tools. Veterans with PTSD often suffer from severe mental health symptoms and multiple CMCs [22] that can substantially and negatively impact their ability to cope with stress, function socially, maintain employment [7-10], and manage their health care [15]. We found that veterans with PTSD who use the Web frequently used technology to creatively and effectively support their health care needs.

The veterans in this study reported moderate levels of perceived knowledge, comfort, and skill at finding, evaluating, and applying electronic health information. Most had searched for health information, communicated with a provider via email, and tracked their medication, but fewer had used online health-related support groups, games, and mobile apps. The average eHEALS (eHealth Literacy Scale) score was comparable to scores reported by similarly aged nonveteran samples, including 283 baby boomers and older adults who use the Web (mean age 67.5 years; mean eHEALS score 29.1, SD 5.8) [44] and 866 adults aged 50 years or older, who use the Web (mean age 62.8 years; mean eHEALS score 30.9, SD 6.0) [39]. The relatively high self-reported eHealth literacy reported in these samples may be due to their high education levels and experience using the Web and, in the case of our study, purposeful sampling of those who had exposure to the VA's electronic patient portal system [44].

Our qualitative findings identified eHealth resources that empowered veterans to better manage their health care for their PTSD and comorbid CMCs. Findings suggest that health care systems should promote technology that addresses 5 themes: (1) interactions with social support, (2) condition management, (3) access to and communication with providers, (4) information access, and (5) coordination of care. Focus group themes aligned with our quantitative findings, which showed that the most common use for technology was to search for health information (consistent with the theme "information access"). Moreover, the second and third most common uses for technology were to communicate with providers and to track medications, respectively. These uses corroborated the focus group themes "access to and communication with providers" and "condition management." As described below, qualitative findings went beyond quantitative results to more comprehensively define how veterans actually used technology to manage their health care needs and to prevent potentially injurious problems from occurring.

Implications of Focus Group Results

Social support is a consistent correlate of positive outcomes in veterans with PTSD [45]. However, PTSD symptoms such as hypervigilance, negative mood, emotional numbing, and avoidance of reminders of the traumatic event make obtaining and maintaining social support difficult. In this study, one attribute of technology that emerged as a potent resource for veterans with PTSD and comorbid CMCs was its ability to facilitate social support. Veterans used email, texting, social media, and blog discussion sites to connect with others for mutual encouragement, informational advice, and tangible support regularly, as well as in times of crisis. Connecting with peers for encouragement helped veterans cope with difficult psychological symptoms that often cause trauma survivors to isolate from others. Our findings support limited empirical data suggesting that peer support may positively impact mental health symptoms [46-48].

Veterans who suffer from PTSD symptoms such as hypervigilance, negative mood, and flashbacks can experience high levels of stress when in public settings. As a result, veterans with PTSD and comorbid CMCs may avoid grocery stores, health care appointments, social gatherings, and other events [49,50]. In this study, mobile phones were found to be an important source of grounding and security that enabled veterans to better function in public settings. In addition to knowing that they could use their phone to access a support person, veterans used specific eHealth tools, such as the VA "PTSD Coach" mobile app [43], to cope with their difficult symptoms. Interestingly, only a minority of participants (16.5% (19/115) of survey respondents and 40.0% (4/10) of focus group members) in this study indicated that they had used a health-related mobile app. Other research on veterans with PTSD who own a mobile phone [32] has found that 28% have heard of or used specific apps related to PTSD (ie, "PTSD Coach"). However, 85% of veterans in that study who owned devices expressed interest in using mobile apps to address health related-issues. Thus, veterans who are not aware of such resources will likely benefit from learning about existing apps.

In addition to directly managing their symptoms, participants used electronic devices to increase communication with providers by mobile phone and by secure email messaging. Veterans felt that communication was more accurate and candid when delivered via digital modalities compared with face-to-face settings. Veterans also described feeling better able to report symptoms more accurately at the time they were occurring, which is consistent with some research on military populations [51,52]. Additionally, because veterans feel more comfortable in their home settings (compared with clinic settings), they also described feeling better able to provide sensitive information, such as thoughts of suicide, more candidly when using technology. Veterans with PTSD are at increased risk for suicide [12-14] and interpersonal violence [11-14], so tools that promote candid and timely communication will be essential to prevent potentially injurious outcomes from occurring.

Another modality embraced by the VA to increase access for veterans is clinical videoconferencing, which directly connects providers to veterans who are located in their homes or in another VA clinic [53,54]. Veterans in our investigation expressed interest in clinical videoconferencing sessions to address active symptoms. However, one symptom of PTSD is avoidance, or the tendency to withdraw and/or disengage from social settings and day-to-day life events [55-58]. It is important to caution that the exclusive use of home-based appointments may not be in the best interest of some veterans with PTSD.

Care must be taken to ensure that virtual services do not prevent veterans from actively engaging in healthy life events.

Moreover, whereas research supports the role of technology in increasing social support and reducing isolation [59], veterans in this study recognized that excessive use of technology, including social media such as Facebook, can promote avoidance of face-to-face socialization among veterans with PTSD. We are not aware of research that has examined the effect of technology on social support in those with PTSD and comorbid CMCs, but our results support our clinical experience suggesting that technology can be used by those with PTSD and comorbid CMCs to promote isolation ([60, page 49]; [61]). Clinical intervention may be necessary to encourage veterans with PTSD and comorbid CMCs to approach technology in a manner conducive to recovery.

Veterans used technology to access health information, but some indicated that they have become overwhelmed by the amount of resources available and, at times, by conflicting information. Materials designed for veterans with PTSD and comorbid CMCs should take into consideration the mild to moderate cognitive impairment that can be associated with their symptoms. There additionally appeared to be a desire for a trusted service that distinguishes high-quality consumer information from biased or lower-quality materials. Veterans need information presented in a format and at an educational level that engages them [54], and they may benefit from guidance when sifting through seemingly disparate and/or conflicting materials.

Finally, veterans used technology to initiate treatment coordination between providers and, at times, across facilities. This care coordination was particularly important because study participants were often tasked with coordinating care for different health issues from multiple providers [40]. Veterans in this study also reported instances when technology was not available to promote care coordination between facilities. Thus, providing veterans with greater access to records across health care institutions via patient-facing apps and/or Web portals will better empower veterans to quickly access health resources regardless of their location, improving the VA records system and facilitating communication across systems of care.

Limitations

The purpose of this research was to understand veterans' experiences using eHealth technology to help manage their unique PTSD and comorbid CMC symptoms. Because our goal was to identify how veterans use eHealth, we purposefully selected from users of the VA's patient portal system (My Health *e*Vet) in order to restrict the sample to veterans who have had Web exposure, which limits the generalizability of the results. Results are also limited by our survey response rate of 31.93% (479/1500). Survey respondents may be predisposed to view eHealth positively. We attempted to minimize this bias by offering veterans remuneration for their efforts filling out the survey. Additionally, participants in this study were primarily Caucasian veterans selected from a relatively computer-literate region in northern California. Their perspectives may be different from veterans who do not have access to or prefer not to use the Web, reside in other regions, or are of minority status. Finally, focus group members consisted of a small subgroup of veterans whose attitudes may not represent all veterans with PTSD and comorbid CMCs who use the Web. However, focus group members were similar to other study participants in that virtually all members of both groups had used and were comfortable using computers, the Web, and email but had less experience using online health-related support groups, games, and mobile apps. Additionally, eHealth literacy scores of veterans in the survey sample and focus group subsample were similar to those found in other samples of similarly aged adults who use the Web [41].

Recommendations and Summary

Our study suggests a number of opportunities to support veterans with PTSD and CMCs through eHealth technology. First, study participants expressed interest in increasing contact with peers through technology, for example, through social media groups for veterans in college or clinician-monitored chat rooms for group therapy patients to support one another between visits. Second, eHealth technology can provide symptom management support, for example, through mobile apps [62] or live Web-based classes. The VA continues to develop its mobile apps patient portal system, and individual staff members are in an ideal position to help disseminate effective tools [63,64]. Third, providers can capitalize on veterans' desire to use eHealth to access help when they need it. In addition to mobile apps, modalities for development might include texting, email, and/or blog sites. Fourth, using digital technology, veterans can consolidate new life skills by completing "homework" assignments between therapy sessions. Timely feedback from remote clinicians can help maximize the relevance and effectiveness of such tools. Fifth, veterans expressed a need for consolidated health information. It is clear that veterans need educational materials presented at an appropriate level and in an engaging format [54]. To this end, the VA has adopted a patient-centered model of care with a focus on coordination of information technology [40,64] and is leading efforts to understand how technology may be adapted to meet individuals' needs [25,64].

In summary, the results of this investigation help establish that veterans with PTSD and CMCs who use the Web are eager to incorporate eHealth technology into their care and self-management activities. Furthermore, study findings suggest opportunities to augment the potential power of eHealth as an adjunct to care, particularly with regard to preventive care. The themes that emerged from this investigation help characterize approaches the VA and eHealth technology developers can take to refine existing resources and develop new tools to better serve veterans with PTSD and CMCs. Future research should evaluate whether such patient-centered endeavors facilitate the appropriate use of health care services and improve clinical outcomes.

Acknowledgments

This study was funded by a grant from the Gordon and Betty Moore Foundation (#3432). DMZ is supported by a VA Health Services Research and Development Career Development Award (CDA 12–173). The funding sources had no role in study design, data analysis, or reporting of results. Views expressed are those of the authors and not necessarily those of the US Department of Veterans Affairs. The authors thank Danielle Cohen, MPH, for her contribution to the study.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Focus group themes describing eHealth technology's influences for veterans with Post-Traumatic Stress disorder and comorbid chronic medical conditions.

[PDF File (Adobe PDF File), 79KB - jmir_v18i10e280_app1.pdf]

References

1. National Alliance on Mental Illness. Arlington, VA: National Alliance on Mental Illness; 2009. Depression and veterans: Fact sheet URL: http://www2.nami.org/Template.cfm?Section=Depression&Template=/ContentManagement/ContentDisplay.cfm&ContentID=88939 [accessed 2015-10-20] [WebCite Cache ID 6Za2LC8S8]
2. Cohen BE, Gima K, Bertenthal D, Kim S, Marmar CR, Seal KH. Mental health diagnoses and utilization of VA non-mental health medical services among returning Iraq and Afghanistan veterans. J Gen Intern Med 2010 Jan;25(1):18-24 [FREE Full text] [doi: 10.1007/s11606-009-1117-3] [Medline: 19787409]
3. Seal KH, Bertenthal D, Miner CR, Sen S, Marmar C. Bringing the war back home: mental health disorders among 103,788 US veterans returning from Iraq and Afghanistan seen at Department of Veterans Affairs facilities. Arch Intern Med 2007 Mar 12;167(5):476-482. [doi: 10.1001/archinte.167.5.476] [Medline: 17353495]
4. Barrera TL, Mott JM, Hundt NE, Mignogna J, Yu H, Stanley MA, et al. Diagnostic specificity and mental health service utilization among veterans with newly diagnosed anxiety disorders. Gen Hosp Psychiatry 2014;36(2):192-198. [doi: 10.1016/j.genhosppsych.2013.10.013] [Medline: 24268573]
5. Seal KH, Maguen S, Cohen B, Gima KS, Metzler TJ, Ren L, et al. VA mental health services utilization in Iraq and Afghanistan veterans in the first year of receiving new mental health diagnoses. J Trauma Stress 2010 Feb;23(1):5-16. [doi: 10.1002/jts.20493] [Medline: 20146392]
6. Psychiatry. Help With Posttraumatic Stress Disorder (PTSD) URL: http://www.psychiatry.org/ptsd [accessed 2015-07-14] [WebCite Cache ID 6a1K9FFVJ]
7. Kaniasty K, Norris FH. Longitudinal linkages between perceived social support and posttraumatic stress symptoms: sequential roles of social causation and social selection. J Trauma Stress 2008 Jun;21(3):274-281. [doi: 10.1002/jts.20334] [Medline: 18553415]
8. Jakupcak M, Hoerster KD, Varra A, Vannoy S, Felker B, Hunt S. Hopelessness and suicidal ideation in Iraq and Afghanistan War Veterans reporting subthreshold and threshold posttraumatic stress disorder. J Nerv Ment Dis 2011 Apr;199(4):272-275. [doi: 10.1097/NMD.0b013e3182124604] [Medline: 21451353]
9. Magruder KM, Frueh BC, Knapp RG, Johnson MR, Vaughan JA, Carson TC, et al. PTSD symptoms, demographic characteristics, and functional status among veterans treated in VA primary care clinics. J Trauma Stress 2004 Aug;17(4):293-301. [doi: 10.1023/B:JOTS.0000038477.47249.c8] [Medline: 15462536]
10. Schnurr PP, Lunney CA, Bovin MJ, Marx BP. Posttraumatic stress disorder and quality of life: extension of findings to veterans of the wars in Iraq and Afghanistan. Clin Psychol Rev 2009 Dec;29(8):727-735. [doi: 10.1016/j.cpr.2009.08.006] [Medline: 19744758]
11. Shalev AY. Treatment failure in acute PTSD. Lessons learned about the complexity of the disorder. Ann N Y Acad Sci 1997 Jun 21;821:372-387. [Medline: 9238218]
12. Kessler RC. Posttraumatic stress disorder: the burden to the individual and to society. J Clin Psychiatry 2000;61(Suppl 5):4-12; discussion 13. [Medline: 10761674]
13. Kang HK, Bullman TA. Risk of suicide among US veterans after returning from the Iraq or Afghanistan war zones. JAMA 2008 Aug 13;300(6):652-653. [doi: 10.1001/jama.300.6.652] [Medline: 18698062]
14. Kang HK, Bullman TA. Is there an epidemic of suicides among current and former U.S. military personnel? Ann Epidemiol 2009 Oct;19(10):757-760. [doi: 10.1016/j.annepidem.2009.05.004] [Medline: 19628411]
15. Sledjeski EM, Speisman B, Dierker LC. Does number of lifetime traumas explain the relationship between PTSD and chronic medical conditions? Answers from the National Comorbidity Survey-Replication (NCS-R). J Behav Med 2008 Aug;31(4):341-349 [FREE Full text] [doi: 10.1007/s10865-008-9158-3] [Medline: 18553129]

16. Taylor-Clift A, Hobfoll SE, Gerhart JI, Richardson D, Calvin JE, Powell LH. Posttraumatic stress and depression: potential pathways to disease burden among heart failure patients. Anxiety Stress Coping 2016 Mar;29(2):139-152. [doi: 10.1080/10615806.2015.1006206] [Medline: 25599115]
17. Beckham JC, Moore SD, Feldman ME, Hertzberg MA, Kirby AC, Fairbank JA. Health status, somatization, and severity of posttraumatic stress disorder in Vietnam combat veterans with posttraumatic stress disorder. Am J Psychiatry 1998 Nov;155(11):1565-1569. [doi: 10.1176/ajp.155.11.1565] [Medline: 9812119]
18. Annest JL, Barrett DH, Baughman AL, Boyle CA, Brann EA, Decoufle P, et al. Health status of Vietnam veterans. II. Physical Health. The Centers for Disease Control Vietnam Experience Study. JAMA 1988 May 13;259(18):2708-2714. [Medline: 2833631]
19. Asnaani A, Reddy MK, Shea MT. The impact of PTSD symptoms on physical and mental health functioning in returning veterans. J Anxiety Disord 2014 Apr;28(3):310-317. [doi: 10.1016/j.janxdis.2014.01.005] [Medline: 24647406]
20. David D, Woodward C, Esquenazi J, Mellman TA. Comparison of comorbid physical illnesses among veterans with PTSD and veterans with alcohol dependence. Psychiatr Serv 2004 Jan;55(1):82-85. [doi: 10.1176/appi.ps.55.1.82] [Medline: 14699207]
21. Kang HK, Natelson BH, Mahan CM, Lee KY, Murphy FM. Post-traumatic stress disorder and chronic fatigue syndrome-like illness among Gulf War veterans: a population-based survey of 30,000 veterans. Am J Epidemiol 2003 Jan 15;157(2):141-148 [FREE Full text] [Medline: 12522021]
22. Frayne SM, Chiu VY, Iqbal S, Berg EA, Laungani KJ, Cronkite RC, et al. Medical care needs of returning veterans with PTSD: their other burden. J Gen Intern Med 2011 Jan;26(1):33-39 [FREE Full text] [doi: 10.1007/s11606-010-1497-4] [Medline: 20853066]
23. Reeves RR. Diagnosis and management of posttraumatic stress disorder in returning veterans. J Am Osteopath Assoc 2007 May;107(5):181-189. [Medline: 17596586]
24. Shiner B. Health services use in the Department of Veterans Affairs among returning Iraq war and Afghan war veterans with PTSD. PTSD Research Quarterly. 2011. (2) p. 1-10 Help With Posttraumatic Stress Disorder (PTSD) URL: http://www.ptsd.va.gov/professional/newsletters/research-quarterly/v22n2.pdf [WebCite Cache ID 6lWwcHkU3]
25. Nazi KM. The journey to e-Health: VA Healthcare Network Upstate New York (VISN 2). J Med Syst 2003 Feb;27(1):35-45. [Medline: 12617196]
26. Snowdon AW, Alessi C, Bassi H, DeForge RT, Schnarr K. Enhancing patient experience through personalization of health services. Healthc Manage Forum 2015 Sep;28(5):182-185. [doi: 10.1177/0840470415588656] [Medline: 26135292]
27. Tsai J, Rosenheck RA. Use of the internet and an online personal health record system by US veterans: comparison of Veterans Affairs mental health service users and other veterans nationally. J Am Med Inform Assoc 2012;19(6):1089-1094 [FREE Full text] [doi: 10.1136/amiajnl-2012-000971] [Medline: 22847305]
28. Houston TK, Volkman JE, Feng H, Nazi KM, Shimada SL, Fox S. Veteran internet use and engagement with health information online. Mil Med 2013 Apr;178(4):394-400. [doi: 10.7205/MILMED-D-12-00377] [Medline: 23707823]
29. Aponte M, Giambo P, Helmick J, Hintze W, Sigman R, Winglee M, et al. National survey of Veterans, active duty service members, demobilized national guard and reserve members, family members, and surviving spouses. National Center for Veterans Analysis and Statistics, United States Department of Veterans Affairs 2010:1-317.
30. Haun JN, Lind JD, Shimada SL, Martin TL, Gosline RM, Antinori N, et al. Evaluating user experiences of the secure messaging tool on the Veterans Affairs' patient portal system. J Med Internet Res 2014;16(3):e75 [FREE Full text] [doi: 10.2196/jmir.2976] [Medline: 24610454]
31. Turvey C, Klein D, Fix G, Hogan TP, Woods S, Simon SR, et al. Blue Button use by patients to access and share health record information using the Department of Veterans Affairs' online patient portal. J Am Med Inform Assoc 2014;21(4):657-663. [doi: 10.1136/amiajnl-2014-002723] [Medline: 24740865]
32. Erbes CR, Stinson R, Kuhn E, Polusny M, Urban J, Hoffman J, et al. Access, utilization, and interest in mHealth applications among veterans receiving outpatient care for PTSD. Mil Med 2014 Nov;179(11):1218-1222. [doi: 10.7205/MILMED-D-14-00014] [Medline: 25373044]
33. Whealin J, Seibert-Hatalsky L, Howell J, Tsai J. Telehealth preferences in ethno-racially diverse veterans and national guard members. J. Rehabil. Res. Dev. 2015;52:725-738.
34. Creswell JW, Zhang W. The application of mixed methods designs to trauma research. J Trauma Stress 2009 Dec;22(6):612-621. [doi: 10.1002/jts.20479] [Medline: 19960518]
35. Falan S, Han M, Rea A. A Smart Consumer-empowered Diabetes Education System (SCEDES): Integrating Human Wellbeing and Health Care in the Community Environment. 2011 Presented at: AMCIS 2011 Proceedings - All Submissions; 2011; Detriot, MI.
36. Zulman DM, Schafenacker A, Barr KL, Moore IT, Fisher J, McCurdy K, et al. Adapting an in-person patient-caregiver communication intervention to a tailored web-based format. Psychooncology 2012 Mar;21(3):336-341 [FREE Full text] [doi: 10.1002/pon.1900] [Medline: 21830255]
37. Dominick GM, Friedman DB, Hoffman-Goetz L. Do we need to understand the technology to get to the science? A systematic review of the concept of computer literacy in preventive health programs. Health Education Journal 2010 Mar 15;68(4):296-313. [doi: 10.1177/0017896909349289]

38. Norman CD, Skinner HA. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res 2006 Jun;8(2):e9 [FREE Full text] [doi: 10.2196/jmir.8.2.e9] [Medline: 16867972]
39. Chung S, Nahm E. Testing reliability and validity of the eHealth Literacy Scale (eHEALS) for older adults recruited online. Comput Inform Nurs 2015 Apr;33(4):150-156. [doi: 10.1097/CIN.0000000000000146] [Medline: 25783223]
40. Zulman DM, Jenchura EC, Cohen DM, Lewis ET, Houston TK, Asch SM. How Can eHealth Technology Address Challenges Related to Multimorbidity? Perspectives from Patients with Multiple Chronic Conditions. J Gen Intern Med 2015 Feb 18;30(8):1063-1070. [doi: 10.1007/s11606-015-3222-9] [Medline: 25691239]
41. Ammenwerth E, Iller C, Mahler C. IT-adoption and the interaction of task, technology and individuals: a fit framework and a case study. BMC Med Inform Decis Mak 2006;6:3 [FREE Full text] [doi: 10.1186/1472-6947-6-3] [Medline: 16401336]
42. Forman J, Damschroder L. Qualitative Content Analysis. In: Jacoby L, Siminoff L, editors. Empirical Methods for Bioethics: A Primer (Advances in Bioethics, Volume 11). Oxford, UK: Emerald Group Publishing Limited; 2007:39-62.
43. Kuhn E, Greene C, Hoffman J, Nguyen T, Wald L, Schmidt J, et al. Preliminary evaluation of PTSD Coach, a smartphone app for post-traumatic stress symptoms. Mil Med 2014 Jan;179(1):12-18. [doi: 10.7205/MILMED-D-13-00271] [Medline: 24402979]
44. Tennant B, Stellefson M, Dodd V, Chaney B, Chaney D, Paige S, et al. eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. J Med Internet Res 2015;17(3):e70 [FREE Full text] [doi: 10.2196/jmir.3992] [Medline: 25783036]
45. Brewin CR, Andrews B, Valentine JD. Meta-analysis of risk factors for posttraumatic stress disorder in trauma-exposed adults. J Consult Clin Psychol 2000 Oct;68(5):748-766. [Medline: 11068961]
46. Ali K, Farrer L, Gulliver A, Griffiths KM. Online Peer-to-Peer Support for Young People With Mental Health Problems: A Systematic Review. JMIR Ment Health 2015;2(2):e19 [FREE Full text] [doi: 10.2196/mental.4418] [Medline: 26543923]
47. Pfeiffer PN, Heisler M, Piette JD, Rogers MA, Valenstein M. Efficacy of peer support interventions for depression: a meta-analysis. Gen Hosp Psychiatry 2011;33(1):29-36 [FREE Full text] [doi: 10.1016/j.genhosppsych.2010.10.002] [Medline: 21353125]
48. Griffiths KM, Calear AL, Banfield M. Systematic review on Internet Support Groups (ISGs) and depression (1): Do ISGs reduce depressive symptoms? J Med Internet Res 2009;11(3):e40 [FREE Full text] [doi: 10.2196/jmir.1270] [Medline: 19793719]
49. Hayes JP, Vanelzakker MB, Shin LM. Emotion and cognition interactions in PTSD: a review of neurocognitive and neuroimaging studies. Front Integr Neurosci 2012;6:89 [FREE Full text] [doi: 10.3389/fnint.2012.00089] [Medline: 23087624]
50. McMillan KA, Sareen J, Asmundson GJ. Social anxiety disorder is associated with PTSD symptom presentation: an exploratory study within a nationally representative sample. J Trauma Stress 2014 Oct;27(5):602-609. [doi: 10.1002/jts.21952] [Medline: 25322889]
51. Wilson JA, Onorati K, Mishkind M, Reger MA, Gahm GA. Soldier attitudes about technology-based approaches to mental health care. Cyberpsychol Behav 2008 Dec;11(6):767-769. [doi: 10.1089/cpb.2008.0071] [Medline: 18991533]
52. Cook JE, Doyle C. Working alliance in online therapy as compared to face-to-face therapy: preliminary results. Cyberpsychol Behav 2002 Apr;5(2):95-105. [Medline: 12025884]
53. Whealin JM, Seibert-Hatalsky LA, Howell JW, Tsai J. E-mental health preferences of Veterans with and without probable posttraumatic stress disorder. J Rehabil Res Dev 2015;52(6):725-738 [FREE Full text] [doi: 10.1682/JRRD.2014.04.0113] [Medline: 26562090]
54. Hogan TP, Wakefield B, Nazi KM, Houston TK, Weaver FM. Promoting access through complementary eHealth technologies: recommendations for VA's Home Telehealth and personal health record programs. J Gen Intern Med 2011 Nov;26 Suppl 2:628-635 [FREE Full text] [doi: 10.1007/s11606-011-1765-y] [Medline: 21989614]
55. Benotsch EG, Brailey K, Vasterling JJ, Uddo M, Constans JI, Sutker PB. War zone stress, personal and environmental resources, and PTSD symptoms in Gulf War veterans: a longitudinal perspective. J Abnorm Psychol 2000 May;109(2):205-213. [Medline: 10895558]
56. Sharkansky EJ, King DW, King LA, Wolfe J, Erickson DJ, Stokes LR. Coping with Gulf War combat stress: mediating and moderating effects. J Abnorm Psychol 2000 May;109(2):188-197. [Medline: 10895556]
57. Thompson BL, Waltz J. Mindfulness and experiential avoidance as predictors of posttraumatic stress disorder avoidance symptom severity. J Anxiety Disord 2010 May;24(4):409-415. [doi: 10.1016/j.janxdis.2010.02.005] [Medline: 20304602]
58. Pietrzak RH, Harpaz-Rotem I, Southwick SM. Cognitive-behavioral coping strategies associated with combat-related PTSD in treatment-seeking OEF-OIF Veterans. Psychiatry Res 2011 Sep 30;189(2):251-258. [doi: 10.1016/j.psychres.2011.07.019] [Medline: 21813184]
59. Cho J. Roles of Smartphone App Use in Improving Social Capital and Reducing Social Isolation. Cyberpsychol Behav Soc Netw 2015 Jun;18(6):350-355. [doi: 10.1089/cyber.2014.0657] [Medline: 26075923]
60. DeCarvalho L, Whealin J. Healing stress in military families: eight steps to wellness. Hoboken, NJ: John Wiley & Sons; 2012.
61. Laffaye C, Cavella S, Drescher K, Rosen C. Relationships among PTSD symptoms, social support, and support source in veterans with chronic PTSD. J Trauma Stress 2008 Aug;21(4):394-401. [doi: 10.1002/jts.20348] [Medline: 18720391]

62. Kuhn E, Hoffman J, Ruzek J. Telemental Health Approaches for Trauma Survivors. In: Schnyder U, Cloitre M, editors. Evidence Based Treatments for Trauma-Related Psychological Disorders: A Practical Guide for Clinicians. New York, NY: Springer International Publishing; 2015:461-476.
63. Mishuris RG, Stewart M, Fix GM, Marcello T, McInnes DK, Hogan TP, et al. Barriers to patient portal access among veterans receiving home-based primary care: a qualitative study. Health Expect 2015;18(6):2296-2305. [doi: 10.1111/hex.12199] [Medline: 24816246]
64. Evens NC, Frisbee KL. Hsrd.research.: VA Connected Health; 2014. Director's Letter URL: http://www.hsrd.research.va.gov/publications/forum/may14/default.cfm?ForumMenu=may14-1 [accessed 2016-01-06] [WebCite Cache ID 6eMs5yo15]

Abbreviations

CMC: chronic medical condition
eHEALS: eHealth Literacy Scale
eHealth: electronic health
FITT: Fit between Individual, Task, and Technology
PHR: personal health record
PTSD: Post-Traumatic Stress Disorder
VA: US Department of Veterans Affairs

Edited by G Eysenbach; submitted 02.02.16; peer-reviewed by D McInnes, H Kim; comments to author 25.02.16; revised version received 29.03.16; accepted 13.04.16; published 26.10.16.

Please cite as:
Whealin JM, Jenchura EC, Wong AC, Zulman DM
How Veterans With Post-Traumatic Stress Disorder and Comorbid Health Conditions Utilize eHealth to Manage Their Health Care Needs: A Mixed-Methods Analysis
J Med Internet Res 2016;18(10):e280
URL: http://www.jmir.org/2016/10/e280/
doi:10.2196/jmir.5594
PMID:27784650

Original Paper

Developing a Health Information Technology Systems Matrix: A Qualitative Participatory Approach

Jolie N Haun[1,2], EdS, PhD; Margeaux Chavez[1], MA, MPH; Kim M Nazi[3], MA, PhD; Nicole Antinori[1], MBA

[1]HSR&D Center of Innovation on Disability and Rehabilitation Research, James A. Haley VA Hospital, US Department of Veterans Affairs, Tampa, FL, United States

[2]Department of Community & Family Health, College of Public Health, University of South Florida, Tampa, FL, United States

[3]Veterans and Consumers Health Informatics Office, Veterans Health Administration, Department of Veterans Affairs, Albany, NY, United States

Corresponding Author:
Jolie N Haun, EdS, PhD
HSR&D Center of Innovation on Disability and Rehabilitation Research
James A. Haley VA Hospital
US Department of Veterans Affairs
8900 Grand Oak Circle (118M)
Tampa, FL, 33637-1022
United States
Phone: 1 813 558 7622
Fax: 1 813 558 7616
Email: joliehaun@gmail.com

Abstract

Background: The US Department of Veterans Affairs (VA) has developed various health information technology (HIT) resources to provide accessible veteran-centered health care. Currently, the VA is undergoing a major reorganization of VA HIT to develop a fully integrated system to meet consumer needs. Although extensive system documentation exists for various VA HIT systems, a more centralized and integrated perspective with clear documentation is needed in order to support effective analysis, strategy, planning, and use. Such a tool would enable a novel view of what is currently available and support identifying and effectively capturing the consumer's vision for the future.

Objective: The objective of this study was to develop the VA HIT Systems Matrix, a novel tool designed to describe the existing VA HIT system and identify consumers' vision for the future of an integrated VA HIT system.

Methods: This study utilized an expert panel and veteran informant focus groups with self-administered surveys. The study employed participatory research methods to define the current system and understand how stakeholders and veterans envision the future of VA HIT and interface design (eg, look, feel, and function). Directed content analysis was used to analyze focus group data.

Results: The HIT Systems Matrix was developed with input from 47 veterans, an informal caregiver, and an expert panel to provide a descriptive inventory of existing and emerging VA HIT in four worksheets: (1) access and function, (2) benefits and barriers, (3) system preferences, and (4) tasks. Within each worksheet is a two-axis inventory. The VA's existing and emerging HIT platforms (eg, My HealtheVet, Mobile Health, VetLink Kiosks, Telehealth), My HealtheVet features (eg, Blue Button, secure messaging, appointment reminders, prescription refill, vet library, spotlight, vitals tracker), and non-VA platforms (eg, phone/mobile phone, texting, non-VA mobile apps, non-VA mobile electronic devices, non-VA websites) are organized by row. Columns are titled with thematic and functional domains (eg, access, function, benefits, barriers, authentication, delegation, user tasks). Cells for each sheet include descriptions and details that reflect factors relevant to domains and the topic of each worksheet.

Conclusions: This study provides documentation of the current VA HIT system and efforts for consumers' vision of an integrated system redesign. The HIT Systems Matrix provides a consumer preference blueprint to inform the current VA HIT system and the vision for future development to integrate electronic resources within VA and beyond with non-VA resources. The data presented in the HIT Systems Matrix are relevant for VA administrators and developers as well as other large health care organizations seeking to document and organize their consumer-facing HIT resources.

(J Med Internet Res 2016;18(10):e266) doi:10.2196/jmir.6499

KEYWORDS

veterans; patient-centered care; information resources; patient preferences; integrated delivery system; health information technology

Introduction

The strategic plan of the US Department of Veterans Affairs (VA) aims to provide a modern, consistent health service experience to put veterans in control of how, when, and where they wish to be served [1,2]. The VA's health information technology (HIT) apps and systems, such as VetLink Kiosks, the My HealtheVet patient and provider portal, and Web and mobile solutions, are central to the realization of the VA strategic plan because these services support an integrated patient experience across multiple technology platforms [3]. Comprehensive and integrated HIT that is based on patient preferences in various contexts is shown to have meaningful effects on patient engagement, empowerment, quality of care, and health outcomes [4,5]. Although the VA's investment in HIT supports patient self-care management, improved patient-provider communication, and better patient health outcomes, the adoption and sustained use of these technologies varies widely among veteran patients and VA providers. Reasons for this variance in use include lack of awareness of available resources; lack of skills, experience, and/or motivation to use technology effectively; and discrepancies in how these technologies meet the specific needs of targeted users [6,7].

An aim of this VA-funded research was to develop a novel multiaxis Health Information Technology (HIT) Systems Matrix including currently available and desired future VA patient-facing platforms, their features, availability, and conditions for appropriate use. Although extensive system documentation exists for various VA HIT systems, a more centralized and integrated perspective with clear documentation is needed in order to support effective analysis, strategy, planning, and use. Such a tool would enable a novel view of what is currently available and support identifying and effectively capturing consumers' vision for the future. The HIT Systems Matrix was developed with input from participants and expert panel members to represent relevant topics, such as access, function, preferences, barriers to use, and relevant user tasks. Topic-related data were organized using a matrix because, although it is treated as a single entity, diverse content can be documented and presented in a systematic way using rows and columns for ease of readability and matrix use.

In this paper, we describe our protocol and product development process that leveraged a participatory approach to cultivating an inventory of the current HIT system used by the VA. Stakeholder groups and veteran informants were encouraged to include their vision for the future of VA's tethered system of electronic resources.

Methods

The HIT Systems Matrix is the first inclusive inventory of VA's electronic health resources. It was developed in partnership with a panel of subject matter experts, operational and clinical stakeholders, and veteran/caregiver focus group participants. To develop the HIT Systems Matrix, expert panel members and veteran focus group participants provided initial descriptive information about VA and non-VA electronic health resources veterans may utilize for health care management. The protocol for this study has been previously published and can be referenced for a detailed description of the methods [8].

Sample and Sampling

Veteran Sample

In qualitative research such as this, sample size relies on the quality and richness of information obtained [9,10]. We purposively recruited 47 veterans and one caregiver as "informants" who were English speaking, aged 35 years and older, had at least two chronic comorbid conditions (eg, diabetes and high blood pressure), and were invested in using HIT, measured by use of two or more electronic resources or VA HIT more than once a month. Exclusion criteria included veterans with visual, hearing, or cognitive impairments that would prevent consent and full study participation. Participants were recruited for study participation until domain and theme saturation was reached. Veterans received up to US $50 for their participation (US $25 for participating in each focus group). This study was approved and regulated by the VA Central Institutional Review Board.

Expert Panel

Snowball sampling was used to identify providers, key operational representatives, and subject matter experts who could serve as expert panel members. Initial invitations were sent via email to operational partners who were asked to assess gaps in representation and nominate other experts or stakeholders to participate. Over the course of 6 months, expert panel members were asked to participate in monthly HIT Systems Matrix development meetings, which culminated in the pairwise comparison activity [11]. As indicated by VA regulations, panel members participated as employees during their regular work schedule and were not compensated by the study.

Data Collection

Researchers used teleconference technology to collect initial descriptive data about VA electronic resources from expert panel members (n=34) to inform the development of the HIT Systems Matrix. Electronic mail was used to obtain individual panel member's responses to the structured pairwise comparison activity. A total of 13 expert panel members completed the pairwise comparison activity. A total of 48 participants provided initial descriptive data about VA and non-VA HIT during the first round of focus groups and a total of 21 completed the pairwise comparison activity.

Expert panel members and veterans were asked to provide information about each VA HIT system, including accessibility, function, and the perceived benefits and barriers related to using VA HIT. Participants were asked to supply additional descriptive information regarding their preferences for using VA HIT in general and complete specific health care management tasks. Additionally, veterans were also asked to provide information about the accessibility, function, and use of commonly used non-VA electronic health resources. Focus groups were conducted with veteran participants to complete the pairwise comparison process.

Data Management and Analysis

The VA HIT Systems Matrix was developed iteratively. The first step was identifying the patient-facing HIT available to veterans, their features, and elements for prioritization. The research study team identified relevant VA HIT platforms (eg, My HealtheVet, Mobile Health, VetLink Kiosks, Telehealth), features (eg, secure messaging, Blue Button, prescription refill), and elements for prioritization (eg, access/availability, specific resources, user groups, and context). This initial activity facilitated a focus on available HIT and their functions and features; the tool was revised throughout this process, particularly as data were collected from expert panel members and veterans in subsequent steps of the process. Table 1 provides a draft sample of the VA HIT Systems Matrix on completion of the first step of the development process.

The second step focused on expanding content developed in the first step through an information gathering process with expert panel members. To complete this second step, we developed the initial model representing a detailed inventory of platforms, their features, characteristics, and contexts for use. The multiaxis HIT Systems Matrix included both existing and future (planned or desired) VA patient-facing platforms, their features, availability, and conditions for appropriate use. Due to the complexity of VA HIT and the elements of interest, the HIT Systems Matrix was developed using an Excel workbook with several worksheets representing relevant topics, such as access, function, preferences, barriers to use, and relevant user tasks.

In the third step, we integrated data collected during veteran/caregiver focus groups to represent this user perspective. Focus group data was analyzed using content analysis. Directed content analysis allowed the team to focus on the core elements addressed in the focus group script items to identify patterns in descriptions of experience, behavior, and beliefs so that the phenomena could be understood within context [12]. Focus group notes were cleaned and expanded into comprehensive write-ups, which were uploaded into the qualitative data analysis software program ATLAS.ti version 7.1 (ATLAS.ti Scientific Software Development GmbH) along with the transcribed audio-recorded focus groups. Data were analyzed in two stages [13]. First-cycle coding allowed team members to summarize and reduce data from the notes and transcripts into broad, preliminary domains. Methods included deductive, structural coding with codes derived from the interview guide and inductive, descriptive coding using single word codes to describe the topic of a passage. Second-cycle coding allowed researchers to further reduce coded data into meaningful domains and themes. Team members established an interrater reliability rate of 80%.

Results

Veteran Participants

The majority of participants were older, white, non-Hispanic/non-Latino males, with a mean age of 63.5 years (SD 8.4), ranging from 43 to 83 years of age (data not shown). Most participants had at least a high school education with an annual income of US $25,001 or more (30/48, 63%); more than half (28/48, 58%) were married. Veterans were asked to list up to 10 of their chronic health conditions. Participants reported a mean of 6.5 (SD 1.89) conditions, ranging from 2 to 10 conditions (data not shown). Demographic data are presented in Table 1.

Expert Panel

The expert panel included 34 representatives from 16 key VA operational offices and clinical disciplines including the VA's Office of Mental Health; Office of Patient Centered Care and Cultural Transformation; Office of Rural Health; Office of Connected Health; Telehealth; My HealtheVet; VetLink Kiosks; Mobile Health; Human Factors; Pharmacy Informatics; Patient Education; and clinical disciplines such as primary care, specialty care, nursing, psychology, women's health, and polytrauma.

Overview of the VA Health Information Technology Systems Matrix

The VA HIT Systems Matrix is presented in Excel workbook spreadsheet format in Multimedia Appendix 1. There are four worksheets that present data: (1) access and function, (2) benefits and barriers, (3) system preferences, and (4) tasks. Within each worksheet, there is a two-axis inventory. The VA's existing and emerging HIT platforms (eg, My HealtheVet, Mobile Health, VetLink Kiosks, Telehealth), My HealtheVet features (eg, Blue Button, secure messaging, appointment reminders, prescription refill, Veterans Health Library, spotlight, vitals tracker), and non-VA platforms (eg, phone/mobile phone, texting, non-VA mobile apps, non-VA mobile electronic devices, non-VA websites) are organized by row. Columns are titled with thematic and functional domains (eg, access, function, benefits, barriers, authentication, delegation, user tasks). Thematic and functional domains are presented in Textbox 1. Cells for each sheet include descriptions and details that reflect factors relevant to domains and the topic of each worksheet.

Table 1. Participant characteristics (N=48).

Characteristic	n (%)
Gender	
Female	4 (8)
Male	44 (92)
Status	
Veteran	47 (98)
Caregiver	1 (2)
Education	
High school	7 (15)
Some college/vocational	20 (42)
Associate's degree	7 (15)
College degree	7 (15)
Graduate degree	7 (15)
Race	
Caucasian/White	40 (83)
African American/Black	5 (10)
Native Hawaiian/other Pacific Islander	1 (2)
American Indian/Alaskan Native	1 (2)
Other American	1 (2)
Ethnicity	
Hispanic or Latino	2 (4)
Not Hispanic or Latino	45 (94)
Declined to respond	1(2)
Marital status	
Married	28 (58)
Divorced	17 (35)
Single/never married	3 (6)
Annual income (US $)	
≤4999	3 (6)
5000-10,000	1 (2)
10,001-15,000	2 (4)
15,001-25,000	7 (15)
25,001-35,000	7 (15)
35,001-45,001	6 (13)
>45,001	17 (35)
Declined to respond	5 (10)

Textbox 1. US Department of Veterans Affairs (VA) Health Information Technology Systems Matrix worksheet topics by column.

Access and function

- Service availability
- Access
- Function

Benefits and barriers

- Benefits-expert panel members
- Barriers-expert panel members
- Benefits-veteran focus group participants
- Barriers-veteran focus group participants

System preferences

- Authentication
- Delegation
- Real-time synchronization
- Integration across platforms and with non-VA electronic resources
- Single sign-on
- Security
- Design

Tasks

- General tasks
- Communication with care team
- Laboratory test results
- Researching medical information
- Tracking health vitals
- Appointments
- Managing prescriptions

Access and Function

This worksheet of the VA HIT Systems Matrix provides validated information from panel members about service availability, access requirements (eg, user group eligibility for different account types), and the function of each resource and feature. For example, eligibility and access requirements for the VA's three My HealtheVet account types (basic, advanced, and premium) were not well understood by contributors and were often cited as barriers to use. Account types offer three different levels of access to patients' health records, so understanding requirements can significantly impact a patient's experience. These findings suggested that veterans required more comprehensive information about VA HIT function in order to appropriately utilize these tools to meet their self-care management needs.

Benefits and Barriers

This worksheet provides an overview of perceived VA HIT benefits and barriers from the panel and veterans' perspectives. Benefits included 24-hour remote accessibility of appointment and prescription services, medical records, providers, and their ability to determine personal communication preferences. Panel members emphasized the efficiency and convenience of the resources and their benefit to patients. Barriers were related to accessibility, including limited access to requisite technologies or Internet connection and lack of available mobile technologies, lack of awareness of resources and how to use these resources, lack of accessibility to education, and navigation and system difficulties.

System Preferences

This worksheet addresses VA HIT system design preferences for authentication, delegation, synchronization, integration, sign-on, security, and interface design identified by panel and veterans' groups. *Authentication* refers to the one-time identity authorization process required to obtain a premium-use My HealtheVet account for full system access. Many participants recommended a secure, online authentication process as opposed to the existing in-person requirement, which was perceived as inconvenient. The VA subsequently added an online option for authentication. Veterans also noted preference for mobile options, such as a My HealtheVet mobile app. *Delegation* refers to regulatory requirements, policy issues, and veteran preferences about surrogate account access (eg, who, timeframe, access level). Although unavailable at the time of the study, veterans felt that delegation represented a vital feature to the VA HIT system to better manage veterans' care in partnership with informal caregivers and non-VA providers. *Real-time synchronization* and *integration across platforms and with non-VA electronic resources* details illustrate veterans' preferences for an integrated, standardized, synchronized, and secure HIT system that integrates non-VA HIT across platforms such as kiosks and mobile apps. *Single sign-on* details addressed regulatory issues and veterans' perceptions and concerns about the security and utility of federated credentialing, more commonly known as single sign-on. *Security* details provided by veteran participants indicate their clear concern for data privacy on VetLink Kiosks and mobile apps. Lastly, *design* details provided veteran input about the front-end user interface and experience when using VA HIT; most commonly, veteran participants stated a preference for simple "dashboard" designs that facilitated ease of use and continuity across resources and platforms.

Tasks

Veteran data clearly indicated that consumers used VA HIT to complete primary categories of tasks, including: (1) general tasks, (2) communication with care team, (3) laboratory test results/tests, (4) researching medical information, (5) tracking health vitals, (6) appointments, and (7) managing prescriptions. Data entries for these tasks provided veterans' perspectives of the usefulness for utilizing each VA HIT resource and/or feature to complete the given task within different contexts. Due to the length and breadth of detail contained within the VA HIT Systems Matrix, the matrix document was structured to allow review and prioritization of content. The VA HIT Systems Matrix has search, filtering, and categorization options so content could be easily selected and compared (eg, to compare two or more resources).

Veteran Recommendations for Educating Consumers About the VA Health Information Technology System

As previously stated, investments in education and marketing are necessary to promote veteran and provider access and sustained use of VA HIT. Thus, HIT Systems Matrix participants were asked to make consumer marketing and education recommendations for all VA HIT resources in order to address consumer confusion about resource access and function. Categories and recommendations are illustrated in Textbox 2.

Textbox 2. Veteran recommendations and strategies for educating consumers about US Department of Veterans Affairs (VA) health information technology (HIT).

Delivery

- Involve veteran service organizations (eg, veterans of foreign wars) in educating veterans about VA HIT
- Target user groups who may require more assistance (eg, elders, traumatic brain injury)
- Provide peer-to-peer mentoring for sign-up instructions and updates
- Allow an educator to access veteran's computer to help set up My HealtheVet, create icons, and teach veterans about My HealtheVet
- Have providers' market services in person; provide brochures at the time of appointments with providers that explain key elements of VA resources

Format

- Provide multiple types of education to fit all learning styles (eg, paper-based, electronic, in person)
- Use graphics and pictures to augment text
- Provide a VA welcome package or mail a digital video transmitter (DVD/YouTube) when veterans request their ID cards.

Communication

- Send notifications about available technologies or changes to technologies (eg, secure messaging)
- Provide large print and display so veterans can read instructions easily in presentations (eg, PowerPoint)

My Health *e* Vet specific

- Advertise tutorials/updates on VA sign-in page
- Integrate education on the My HealtheVet website
- Provide tutorials to learn more about My HealtheVet

Troubleshooting

- Establish a call desk to help veterans who are having trouble with aspects of VA HIT
- Inform veterans of the name and contact information for their My HealtheVet coordinator

Discussion

Integrated HIT systems improve health care delivery and help veterans become active participants in their care and self-care management; HIT is essential to adequately address veterans' health care needs [3]. Development and redesign in the VA must focus on the interactions and processes among patients, providers, administrators, organizational structures, and the technology itself to develop HIT resources that optimally meet consumer needs [3,14,15]. The data presented in the HIT Systems Matrix is relevant for VA administrators and developers as well as other large health care organizations seeking to document and organize their consumer-facing HIT resources.

The goal of this participatory study was to inform the VA's vision of an integrated HIT system from the shared perspective of veterans, providers, and key stakeholders (eg, VA operational partners, clinicians). In alignment with the goals of the VA, the HIT Systems Matrix provides a descriptive blueprint for decision making and supports the ongoing development of a user-friendly HIT system that prioritizes increased access to personalized, proactive, and patient-driven virtual care. The utility of organizing and presenting information in the HIT Systems Matrix was threefold: (1) it allows users (eg, administrators and developers within and outside the VA) to view and interpret direct stakeholder and veteran input despite its organizing structure because it was designed to allow sorting and manipulation of data; (2) it provides a living, evolving document that can be shared at any stage of development and that can be updated as HIT systems evolve; and (3) it allows users of the tool to easily compare and contrast the characteristics of different HIT technologies and platforms as well as understand the VA HIT system as a single entity.

Although this study protocol and its HIT Systems Matrix product are useful in developing valuable knowledge to inform system improvements, this study has limitations. First, this study represented findings only relevant to the VA HIT systems and technologies; however, this study and its product may be useful for development and redesign of other tethered HIT systems in health care delivery. Second, current technological infrastructure capacity was not a primary focus and thus may have limited use of some findings although it should not limit the VA HIT vision of the future. Third, although our sample represented multiple stakeholder groups and was relatively small, it should be noted that participants were a representative, purposively sampled group and were comparable to sample sizes used in other qualitative mixed-methods studies [16]. As such, data presented in the matrix represent expert panel member and focus group participant reports only and in some instances may be incomplete. Fourth, we purposively recruited participants who were invested users of two or more platforms as we felt they could provide salient in-depth feedback. As such, we may have missed valuable data that may have represented noninvested users. Fifth, we purposefully included veterans with comorbid conditions because these individuals are more likely to leverage the use of electronic resources to manage their health care. As such, we may have missed valuable data that may represent healthier participants.

Future research should inform the ongoing development of VA's vision for an integrated HIT system to include front-end patient user experiences and outcomes. Specifically, research should evaluate best practices for supporting consumers' proactive and integrated use of VA HIT systems. Ongoing investigation in this area of research is also warranted to address identified barriers in the existing system and solutions to eliminating those barriers in the evolving VA HIT system. Issues for VA employees, including workload and workflow data, and organization-level research is needed to identify largescale infrastructural consequences and outcomes relevant to the supply and demand of the growing VA patient population. Finally, system preferences, such as single sign-on and delegation, merit further investigation to better understand the feasibility, acceptability, and usefulness of these features within the current and evolving VA HIT system across traditional (eg, personal computers) and emerging (eg, mobile technology) technologies. Delegation in particular has become increasingly important because the VA places more emphasis on engaging with community care providers and informal caregivers. The provision of comprehensive and consistent veteran health care rests on the veteran's ability to securely and easily delegate access to medical records and virtual health services.

To our knowledge, this is one of the few published studies to aid in the development of an integrated system of HIT resources within a large health care system with nearly 4 million users (Veterans and Consumers Health Informatics Office, US Department of Veterans Affairs, 2016). Future research should inform the ongoing development of VA's vision for an integrated HIT system to include front-end patient user experiences and outcomes. Specifically, research should evaluate best practices for supporting consumers' proactive and integrated use of VA HIT systems.

Although this research lends itself to recommendations for future research, the authors' aim in completing this work was to produce a useful resource to assist ongoing development, redesign, and research efforts. The VA is currently utilizing this tool to support multiple initiatives including the redesign of the patient portal, the design of an enterprise-wide delegation service, and has strategic communication plans to increase awareness and use of VA HIT. Beyond VA, other organizations can benefit from using a similar approach and may also find the matrix model useful as a template to enhance HIT analysis, strategy, planning, and use.

Acknowledgments

The Department of Veterans Affairs, Veterans Health Administration, Office of Research and Development, Health Services Research and Development Service, and National eHealth Quality Enhancement Research Initiative (QUERI) Coordinating Center (RRP 12-495) supported this study. This study was also supported in part by the Center of Innovation for Disability and

Rehabilitation Research at the James A. Haley Veterans Hospital. The contents of this paper do not represent the views of the Department of Veterans Affairs or the US Government. The authors would like to acknowledge the efforts of the VA Human Factors team, including Nancy Wilck, Abigail Noonan, and Ashley Cook, for their significant contribution to the success of this project. We would also like to thank Susan Woods and Jeffrey Sartori for their generosity of time and consultation throughout the conceptualization and implementation of this project.

Authors' Contributions

The corresponding author, as a US government employee, has the right to grant on behalf of all authors and does grant on behalf of all authors, a nonexclusive worldwide license to the publishers and its licensees in perpetuity, in all forms, formats, and media (whether known now or created in the future) to (1) publish, reproduce, distribute, display, and store the contribution, (2) translate the contribution into other languages, create adaptations, reprints, include within collections and create summaries, extracts and/or, abstracts of the contribution, (3) create any other derivative work(s) based on the contribution, (4) to exploit all subsidiary rights in the contribution, (5) the inclusion of electronic links from the contribution to third-party material wherever it may be located, and (6) licensee any third party to do any or all of the above.

Multimedia Appendix 1

Department of Veterans Affairs Health Information Technology Systems Matrix.

[XLSX File (Microsoft Excel File), 44KB - jmir_v18i10e266_app1.xlsx]

References

1. MyVA Integrated Health Plan (MIP) Overview Veterans Health Administration. 2015 Jul 30. URL: http://www.va.gov/opa/myva/docs/myva_integrated_plan_overview.pdf [accessed 2016-09-26] [WebCite Cache ID 6kp58Q0A1]
2. US Department of Veterans Affairs. Connected Health URL: http://www.va.gov/health/ConnectedHealth/index.asp [accessed 2016-09-26] [WebCite Cache ID 6kp59Y97D]
3. Nazi KM. Structures and processes in health care systems. In: Duffy VG, editor. Advances in Human Aspects of Healthcare. Boca Raton, FL: CRC Press; 2012:165-178.
4. Hogan TP, Wakefield B, Nazi KM, Houston TK, Weaver FM. Promoting access through complementary eHealth technologies: recommendations for VA's Home Telehealth and personal health record programs. J Gen Intern Med 2011 Nov;26 Suppl 2:628-635 [FREE Full text] [doi: 10.1007/s11606-011-1765-y] [Medline: 21989614]
5. Nazi KM. The personal health record paradox: health care professionals' perspectives and the information ecology of personal health record systems in organizational and clinical settings. J Med Internet Res 2013 Apr;15(4):e70 [FREE Full text] [doi: 10.2196/jmir.2443] [Medline: 23557596]
6. Haun JN, Lind JD, Shimada SL, Martin TL, Gosline RM, Antinori N, et al. Evaluating user experiences of the secure messaging tool on the Veterans Affairs' patient portal system. J Med Internet Res 2014;16(3):e75 [FREE Full text] [doi: 10.2196/jmir.2976] [Medline: 24610454]
7. Nazi KM. The personal health record paradox: health care professionals' perspectives and the information ecology of personal health record systems in organizational and clinical settings. J Med Internet Res 2013;15(4):e70 [FREE Full text] [doi: 10.2196/jmir.2443] [Medline: 23557596]
8. Haun JN, Nazi KM, Chavez M, Lind JD, Antinori N, Gosline RM, et al. A participatory approach to designing and enhancing integrated health information technology systems for veterans: protocol. JMIR Res Protoc 2015;4(1):e28 [FREE Full text] [doi: 10.2196/resprot.3815] [Medline: 25803324]
9. Strauss A, Corbin J. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. Thousand Oaks, CA: Sage Publications; 1998.
10. Sandelowski M. Sample size in qualitative research. Res Nurs Health 1995 Apr;18(2):179-183 [FREE Full text] [doi: 10.1002/nur.4770180211]
11. Saaty T. Decision making with the analytic hierarchy process. Int J Services Sciences 2008;1(1):83-98 [FREE Full text] [doi: 10.1504/IJSSci.2008.01759]
12. Hsieh H, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res 2005 Nov;15(9):1277-1288. [doi: 10.1177/1049732305276687] [Medline: 16204405]
13. Miles MB, Huberman AM, Saldana J. Qualitative Data Analysis A Methods Sourcebook. Thousand Oaks, CA: Sage Publishing; 2014.
14. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: systematic review and recommendations. Milbank Q 2004;82(4):581-629 [FREE Full text] [doi: 10.1111/j.0887-378X.2004.00325.x] [Medline: 15595944]
15. Orlikowski W. Using technology and constituting structures: a practice lens for studying technology in organizations. Organ Sci 2000 Aug;11(4):404-428 [FREE Full text] [doi: 10.1287/orsc.11.4.404.14600]

16. Guest G. How many interviews are enough?: An experiment with data saturation and variability. Field Methods 2006 Feb 01;18(1):59-82 [FREE Full text] [doi: 10.1177/1525822X05279903]

Abbreviations

HIT: health information technology
VA: Department of Veterans Affairs

Edited by G Eysenbach; submitted 24.08.16; peer-reviewed by C Turvey, T Irizarry; comments to author 14.09.16; revised version received 15.09.16; accepted 17.09.16; published 06.10.16.

Please cite as:
Haun JN, Chavez M, Nazi KM, Antinori N
Developing a Health Information Technology Systems Matrix: A Qualitative Participatory Approach
J Med Internet Res 2016;18(10):e266
URL: http://www.jmir.org/2016/10/e266/
doi:10.2196/jmir.6499
PMID:27713112

Original Paper

The Relationship Between Health Management and Information Behavior Over Time: A Study of the Illness Journeys of People Living With Fibromyalgia

Annie T Chen[1], MSIS, PhD

[1]University of Washington School of Medicine, Department of Biomedical Informatics and Medical Education, Seattle, WA, United States

Corresponding Author:
Annie T Chen, MSIS, PhD
University of Washington School of Medicine
Department of Biomedical Informatics and Medical Education
850 Republican St., Box 358047, C238
Seattle, WA, 98109
United States
Phone: 1 206 221 9218
Fax: 1 206 221 2671
Email: atchen@uw.edu

Related Article:

This is a corrected version. See correction statement: https://www.jmir.org/2020/8/e23597/

Abstract

Background: Over the course of a chronic illness, patients face many challenges, including understanding what is happening to them and developing an effective strategy for managing illness. While there is existing literature concerning how people seek health-related information and cope with chronic illnesses, there is a need for additional research on how information affects patients' understandings of their illness, and how changes in this understanding affect their health management strategies over time.

Objective: This study examined how health management, information seeking, and information consumption and use processes are related throughout an illness.

Methods: A diversified recruitment strategy involving multiple media channels was used to recruit participants for an interview study. During the interviews, participants were asked to draw an "illness journey" timeline. The data were analyzed using a qualitative approach drawn from Interpretative Phenomenological Analysis and Grounded Theory.

Results: The study identified four main health management features of illness journeys: onset, progression toward diagnosis, acceptance, and development of an effective management strategy. The study then focused on how information seeking changes over illness journeys, particularly in terms of a transition from active information seeking to monitoring with intermittent focused searching. Last, the paper describes the information consumption and use processes that patients engaged in throughout their journey.

Conclusions: This study makes three important contributions to the field. First, it presents an integrated conceptualization of how health management and information behaviors are related on illness journeys. Second, it adds to our existing knowledge on health literacy and self-management of chronic illness. Third, the study has implications for health interface design.

(J Med Internet Res 2016;18(10):e269) doi:10.2196/jmir.5309

KEYWORDS

health knowledge, attitudes, practice; information seeking behavior; information use; consumer health information; chronic disease; fibromyalgia

Introduction

Over the course of a chronic illness, patients face challenges on many fronts. On a basic level, they endeavor to understand what is happening to them and deal with their illness. This may include navigating the health care system and understanding their medication regimen. They interact with information that may change their abilities to engage in these behaviors and make health decisions. While existing literature has investigated how people seek health-related information, there is a need for additional research on how information facilitates changes in patients' understanding of their health, which may in turn lead to long-term changes in health management.

This study investigated the relationship between information and health management of those with a chronic condition—fibromyalgia. Fibromyalgia is a complex, poorly understood condition characterized by chronic widespread pain, joint stiffness, and systemic symptoms (eg, mood disorders, fatigue, cognitive dysfunction, and insomnia) [1-3]. Due to the diversity of symptoms and problems that patients experience, fibromyalgia has an impact on multiple facets of patients' lives [4-6].

Because fibromyalgia patients often appear healthy and their symptoms are invisible, patients continually struggle with stigma, social isolation, and a search for legitimacy [7-10]. In addition, patients struggle with the medically unexplained nature of the syndrome [6,7]. In the case of many illnesses, diagnosis can serve to give meaning to an illness experience, but with fibromyalgia, initial relief is replaced with the realization that the diagnosis does not lead to increased understanding, treatment options, or respect from others [11-13].

This is where information might potentially play a role. Though patients with fibromyalgia have shown little long-term improvement [14], previous research has shown that becoming knowledgeable about one's condition is an important factor in acceptance or coming to terms with pain [15], and pain acceptance is associated with less pain, disability, symptoms, mood disturbance, as well as better general health, functioning, and greater well-being (eg, [16,17]). Because fibromyalgia is a condition for which there are limited treatment options, self-management is increasingly being recommended [18].

Fibromyalgia patients consult many sources to try to understand their condition and possible treatments, including health care professionals, the Internet, health organizations, magazines, television, radio, support groups, and other people [19,20]. Fibromyalgia patients and other patients with chronic conditions may use online resources such as online discussion forums and blogs to exchange information, understand their illness, and offer social support [21-23]. Online participation may lead to benefits such as reduction of social isolation [22], patient empowerment [24], and improved psychological, social, and cognitive health [25].

Previous research has also reported that fibromyalgia patients' information needs change over the course of the illness [26]. At first, individuals may be preoccupied with finding a cure. Searches for information on exercise, medications, and research increase over time. However, it is unclear what drives this evolution in information behavior, and moreover, what information behaviors may lead to successful self-management. The motivation for the current study was to provide insight concerning this gap. This paper explores three aspects of fibromyalgia patients' illness journeys: (1) health management, (2) information seeking, and (3) information consumption and use processes.

Methods

Sample and Recruitment

Multiple mechanisms were used to recruit a convenience sample that self-identified as having fibromyalgia (N=23). A recruitment goal was established to recruit a sample that was diverse in terms of three characteristics: age (47 years and ≥47 years), illness duration (≤4 years and 4 years), and social media participation style (non-user/lurker, infrequent participator, active participator), with substantive representation in each of the subcategories per category. A lurker was defined as someone who read social media content but did not author content themselves, an infrequent participator was someone who authored social media, but infrequently, and a frequent participator was someone who authored social media content quite often. These definitions are based on those in previous studies, with modifications to account for participation on other types of social media [27,28].

The decision to focus on these dimensions was based on previous work that showed there was great variation in the age and illness duration of fibromyalgia patients and that social media participation style was significantly associated with other aspects of illness adjustment [29]. The age threshold was based on the mean age in prior studies [19,26], and the illness duration threshold was set in order to emphasize the first several years after onset.

The recruitment mechanisms included an email contact list from a previous survey [26], a university staff and student listserv, face-to-face support groups, health-related discussion forums, and Twitter (Table 1). In the case of face-to-face support groups, the leaders of support groups for fibromyalgia, chronic pain, and chronic fatigue syndrome were contacted, and permission was sought to visit the support groups to introduce the study and invite members to participate. The health-related discussion forums included websites such as Reddit, HealingWell, and ProHealth, which feature forums dedicated to fibromyalgia and other conditions that are often co-morbid with fibromyalgia, such as chronic fatigue syndrome. In each case, a description of the study and an invitation to participate was posted in relevant forums. In the case of Twitter, users who self-identified as having fibromyalgia were contacted and invited to participate.

Table 1. Recruitment mechanisms and participants recruited.

Recruitment mechanism	Participants, n
Participant pool from previous survey	4
Listserv[a]	7
Social networking sites	5
Face-to-face support groups	6
Twitter	1

[a] Includes those referred by someone on the listserv.

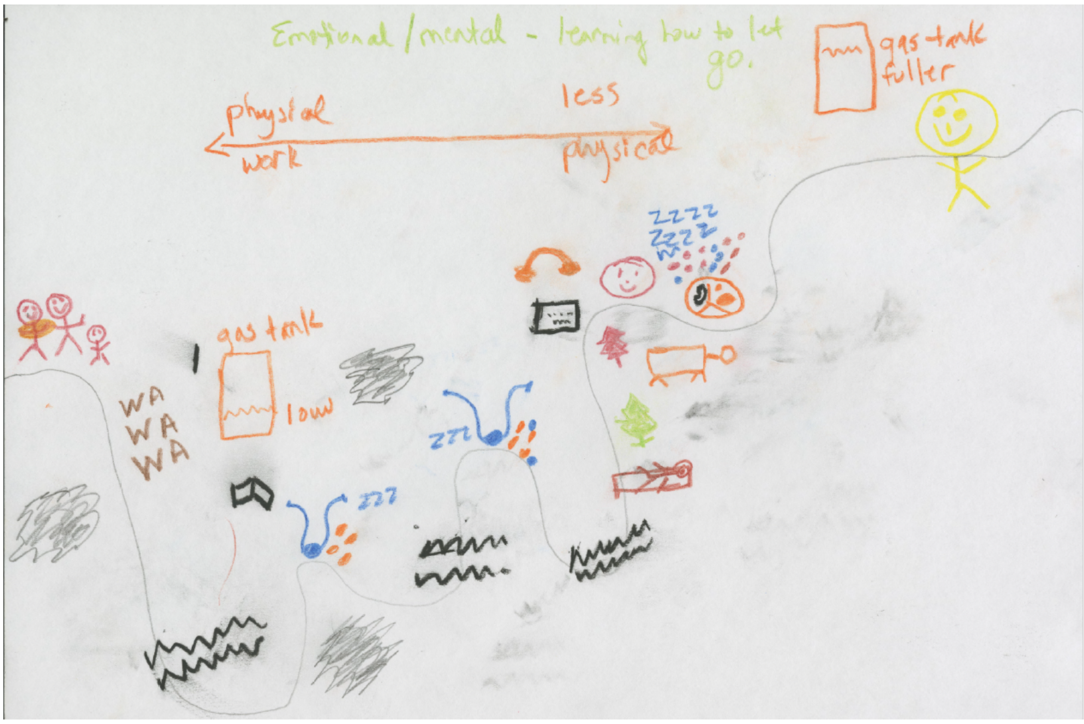
Interviews

The first interview focused on participants' health history and information seeking and use. Participants were also asked to draw a timeline representing their illness journey (Figure 1). Timelines have been used in previous health-related research (eg, [30-32]). When the exercise was introduced, participants were asked to think about their illness journey and "to draw something that represent[ed] it." They were told there were no rules as to what they drew and that the timeline need not be a line. The aim of the prompt was to leave the activity as open as possible, so that participants would feel free to depict the journey as they experienced it. The purpose of this activity was to help participants access their memories of their illness history.

The second interview was used to explore participants' social media participation histories, using an interface called the Online Scrapbook that was designed for the study. This interface enabled participants to view their social media participation over time. There were multiple reasons to incorporate the interface, including reminding participants of what they had previously authored, as well as providing them a fresh look at it through an interactive visualization. As this paper focuses on thematic analysis of the interview content, the interface will not be discussed in further depth. The interview guides for the two interviews have been included in the Multimedia Appendices 1 and 2.

Participants were interviewed either once or twice, depending on the extent to which they participated in social media and their geographic proximity. If participants participated only minimally in social media or lived far away, they were usually interviewed once, and the questions from the second interview were integrated into the first interview. Three interviews were conducted via Skype or phone due to issues of geographic proximity. All other interviews were conducted in person. To ensure that participants were comfortable during the interview, the location for the interview was left up to the participant, and almost all interviews occurred either in participants' homes or in coffee shops. Altogether, the study involved 37 interviews with 23 participants, and the mean total interview time per participant was 2 hours and 26 minutes.

Figure 1. P21's illness journey timeline.



Data Analysis

The analysis method was derived from two approaches: interpretative phenomenological analysis and constructivist grounded theory. The primary aim of interpretative phenomenological analysis is to explore how participants make sense of their world and focuses on participants' interpretations of the object or event [33,34]. Grounded theory focuses on how social and psychological processes occur in a given environment or situation [35,36]. These two foci facilitated a study that investigated lived experience as well as social interactions and context.

The interview transcripts and a purposively sampled subset of posts authored by participants who engaged in online discussion forums such as Reddit served as the basis for the analysis. Because some participants were extremely prolific in their social media content production and it was not possible to manually analyze all of the posts, it was necessary to select a subset of posts that provided a sense of the diversity of each participant's social media production. The posts that participants authored were analyzed in the context of the threads, or dialogues, in which the posts were embedded.

The content was analyzed using Atlas.ti Version 1.0.1. In order to protect the identities of the participants, each participant was assigned an identification number. There were four pilot participants; thus, the 23 participants in the study will be referred to as P05-P27.

The analytic procedure involved initial line-by-line coding, followed by conceptualization of codes as a nested hierarchy, as is customary in grounded theory [37]. In interpretative phenomenological analysis, a similar process is performed in which the codes are thought of as belonging to themes and subthemes [33]. The themes and subthemes relating to health management and information behaviors are reported in this paper.

Exact prevalence of themes has not been reported in this study for two reasons. First, due to the sample size and recruitment strategy, the sample is not necessarily representative of fibromyalgia patients as a whole. Second, though prevalence of a theme may be an indicator of its significance, simply because a behavior occurs often does not immediately render it important [38]. However, it is understandable that a reader would like to acquire a sense of how common a behavior is from the reading, and thus, consistent conventions of "a few," "some," "many," "almost all," and "all" have been used, as in previous research [38].

The study protocol was approved by the Institutional Review Board at the University of North Carolina, Chapel Hill. All participants gave written informed consent for their data to be used in publications.

Results

Participants

The sample included 23 individuals who self-reported that they had fibromyalgia. The majority of the sample was white women (Table 2). The participants resided in nine different states; Washington, DC; and Australia. Because recruitment occurred using multiple mechanisms including several social media channels, the sample was naturally geographically diverse. The use of multiple recruitment methods also led to a sample that varied in terms of age (range 21-79 years), illness duration (1-58 years), and social media participation style. Though diversity was achieved in all three target categories, those with short illness durations were underrepresented.

The sample was highly educated, with the majority holding at least a 2-year or 4-year degree, and approximately half holding graduate degrees. Potential reasons for this bias were that a university listserv was used for recruitment and that those who had graduate degrees might have had a greater appreciation for the contribution of research to health care and thus volunteered for the study.

Health Management Features of the Illness Journey

This section focuses on the health management aspects of the journey in three parts: (1) moving from onset to diagnosis, (2) acceptance, and (3) development of an acceptable level of self-management.

Moving From Onset to Diagnosis

Though for some participants, fibromyalgia onset coincided with an event such as a surgery or immunization, a more common pattern was experiencing symptoms for some time, before recognizing that the symptoms were not to be ignored. Most participants were diagnosed years after onset. There were various reasons. In many cases, participants did not seek medical assistance right away. P09 experienced fatigue for years, but she did not seek help because she thought she was just being lazy. It was not until she started experiencing pain that she sought the opinion of a physician. P27 had a fast-paced lifestyle full of events that she was committed to, so she ignored her symptoms until "[her] body was forced to stop." In retrospect, she said:

> *Thinking back on how long I've been feeling a little bit tired or feeling a little bit achy and thinking of all the ways that I made excuses for that, I realized that probably my symptoms have been going on a lot longer than I thought…But I just said, well this is what it's like to be an activist…you're just always tired because you're always doing stuff for the movement or for the community, so just push through it.* [P27]

There were other reasons why diagnosis took a long time. Physicians tended to diagnose the condition after excluding other possibilities, so many participants experienced a period of uncertainty in which they saw multiple health care practitioners and underwent many lab tests before being diagnosed. P05 remarked somewhat facetiously, "It was really crazy…a lot of ER visits, um, got to know doctors very well—all kinds of specialists…and I sit there, and I was like, I should have been a doctor. Because at this point, I have done almost every test you can think of."

Participants' responses to diagnosis varied, but many did not want to be diagnosed with fibromyalgia due to their impressions of the condition. P15 said of the moment when her physician made her preliminary diagnosis:

> *I remember thinking, "No!" That's one of the things I never wanted to have, because…it's like, Chronic Fatigue Syndrome or back problems…you can't really see it, and nobody believes it's real. And it's one of those things that makes people out all the time from work, and…people think you're faking it…I thought, "Oh God! Of all things!"* [P15]

A few participants mentioned that their mother or other relative had fibromyalgia or chronic pain, and the possibility of a genetic basis to fibromyalgia has been hypothesized in previous literature [39]. P20 remarked that she had not really believed her mother: "I thought that something had just happened to my mom, that she was making it up. Because this was in the '70s, when she was diagnosed with fibromyalgia. And I'm like, what kind of made up stuff is that?" So when P20 was diagnosed, she thought: "Please don't give me that. Anything but that."

Being diagnosed with fibromyalgia could be bittersweet. At 24, P11 thought that she might have had fibromyalgia and went through the next several years having lab tests and seeing different doctors. In a Reddit post, she wrote of her diagnosis at 30: "For me, it was relief, to finally have an answer (an answer I thought was RIGHT, as I'd thought it was fibro for a while but had never brought it up) but also a bit sad as I'm stuck with this for the rest of my life!" P24 also went through a period of frustration at the lack of answers, and she said that when she and her physician finally found a treatment regimen that worked, "that visit with her was kind of bittersweet because it was like, great, something's working, I have an answer—but it's fibromyalgia, and I'm going to have this for the rest of my life."

The path to diagnosis was often long and stressful. Nevertheless, being diagnosed was important because the diagnosis enabled participants to move forward in terms of figuring out how to manage their condition.

Acceptance

After participants were diagnosed, it often took time for them to move towards acceptance, which consisted of two parts: acceptance of the diagnosis and acceptance of the illness. In terms of the diagnosis, participants seemed to come to accept it because their symptoms matched clinical descriptions of fibromyalgia. P10 initially did not believe that she had it, but "as time progressed, and I had other symptoms, like migraines…that went along with fibromyalgia, as I read more about fibromyalgia, I kind of accepted that I had fibromyalgia."

The second part involved an acceptance of the illness as being there to stay. In the beginning, some participants felt that the illness was temporary, and they were looking for a way to "fix it," for the "magic pill" [P05] or the "magic bullet" [P17]. P15 described her experience:

> *2013 was going to be my year of…health…it was going to be the year that I got myself back. Yeah right…at a certain point, I adjusted to a year of concentrating on wellness, instead of just, "Oh, I'm going to be…cured." Because I kind of felt like, "I'm going to cure myself!"…I think it's kind of like a pipe dream that some people like me will cling to and…I need to accept…I think you have to grieve like you have to grieve any other loss or death…you have to go, "Okay that's the old me," and "this is the new me."* [P15]

Self-Management

Achieving an acceptable level of self-management was often multidimensional, including both symptom and emotion management, and was predicated upon acceptance:

> *For once in a very long time, I felt like I could handle the fibromyalgia...I was starting to realize: ok, it's a part of my life, and I started noticing some of the triggers a little bit better, also the best way to manage some of the symptoms, and also not being so mad at myself or my body.* [P05]

The concept of self-management does not mean the elimination of symptoms, but rather, reaching a point where patients believe that they are able to manage their symptoms or that the extent to which they experience symptoms is "acceptable." For many, this may mean "wellness." Patients may still experience "flares," but to a lesser extent. The level of functioning for each individual might differ significantly, but there is a pragmatism to it in the sense of finding solutions that fit people's lives: "…basically what I have learned is that you just manage your life" [P21].

All participants made changes to their lifestyles. Many made dietary changes to avoid trigger foods; others had strategies such as having nuts on hand to avoid hypoglycemic episodes. Many found that exercise was helpful, particularly yoga. Participants also used alternative therapies such as massage therapy, acupuncture, meditation, and hypnotherapy. Participants reported that meditation and hypnotherapy were effective for both pain management and emotion regulation.

P21's timeline aptly illustrates the main health management features (Figure 1). She started out her journey with a gas tank that was always low, meaning that she was constantly fatigued and struggling with different health issues. Along the way, she saw multiple doctors (represented by the stethoscopes). Towards the end of her journey, she encountered and tried multiple alternative modalities (represented by the trees). At the end, she developed an effective management strategy and was able to consistently maintain a fuller gas tank.

Information Seeking

In terms of information seeking, the predominant pattern was a move from active information seeking to monitoring information sources with intermittent focused searching.

Table 2. Participant characteristics.

Characteristic	Category	n	%
Age			
	21-30	4	17.4
	31-40	4	17.4
	41-50	2	8.7
	51-60	7	30.4
	61-70	5	21.7
	71-80	1	4.3
Gender			
	Female	22	95.7
	Male	1	4.3
Race/Ethnicity			
	White	20	87.0
	Black	2	8.7
	Asian	1	4.3
Education			
	Some college	2	8.7
	2-year or 4-year college degree in progress	1	4.3
	2-year or 4-year college degree	8	34.8
	Graduate degree	11	47.8
	Graduate degree in progress	1	4.3
Employment status[a]			
	Student	3	13.0
	Employed full-time	11	47.8
	Not employed	1	4.3
	Retired	9	39.1
Received disability			
	Yes	8	34.8
	No	15	65.2
Illness duration			
	≤4 years	3	13.0
	4 years	20	87.0
Social media participation			
	Non-user/lurker	9	39.1
	Infrequent participator	5	21.7
	Frequent participator	9	39.1

[a] Participants may belong to more than one category.

Active Information Seeking

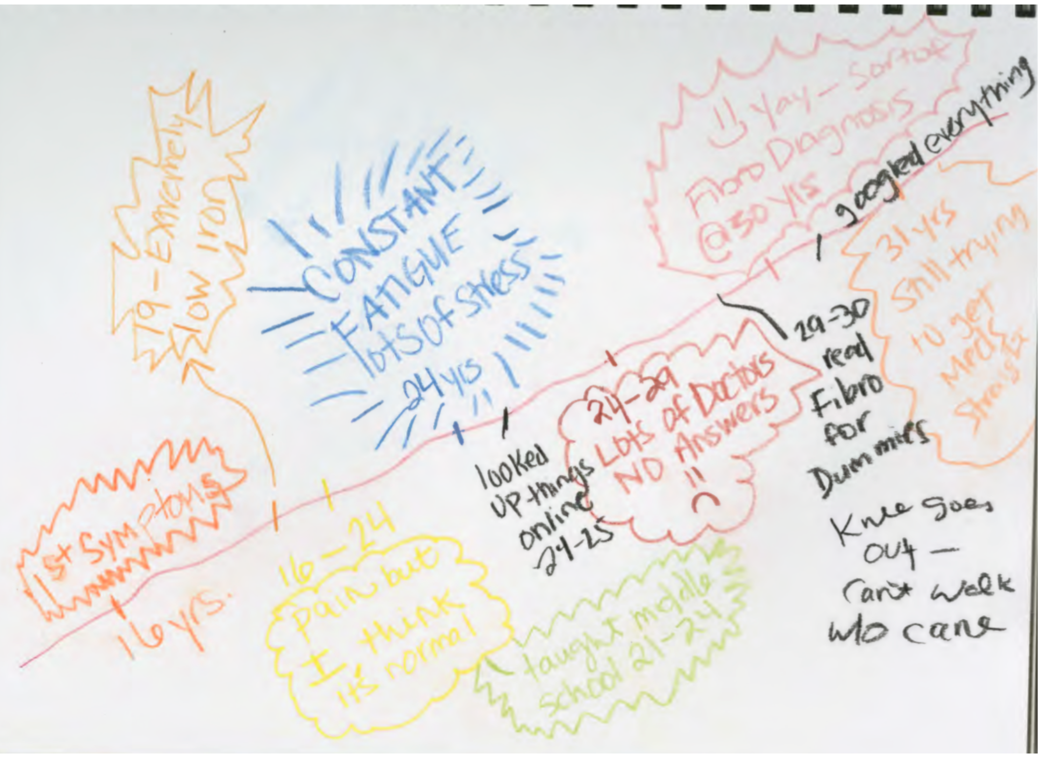
In general, participants engaged in active information seeking toward the beginnings of their illness journeys. Prior to knowing what they had, participants looked for conditions that had similar symptoms; others used symptom checkers. Some participants suspected that they had fibromyalgia and discussed it with their doctors. Participants employed a diverse array of information sources including print (newspapers, magazines, books) and digital media (Twitter, informational websites, discussion forums, blogs, webinars, e-newsletters, and e-books), people (health care practitioners, authors, family, and friends), informational and emotional support venues, patient education courses, and others (commercials, radio, and television).

Once participants had an idea that fibromyalgia was what they had, they would engage in more extensive information seeking. When P17 was first diagnosed, she read “everything [she] could get her hands on.” Prior to her diagnosis, P11 sought answers both online and through her doctors, but after she was diagnosed, she “googled everything on creation” (Figure 2).

A period of confusion often followed the diagnosis as participants searched for information and found no clear answers. Many participants said that they saw multiple doctors and had numerous lab tests. P19 had “this battery of tests for, you know, we call it the symphony of catastrophic diseases? Lupus, MS…” P05 said that one doctor thought it was fibromyalgia; another said arthritis, and “they’re like, we’re not exactly sure. So it was a very uncertain time in terms of figuring it out because it wasn’t getting any better” [P05]. P06’s encounters with health care practitioners did not appear to be leading towards a resolution. Thus, she ended up trying to figure things out herself: “I was doing research on my own and realizing that there was no medical consensus about what fibromyalgia was or how to treat it, so I really ended up doing a lot of research on my own” [P06].

Some participants found the diagnosis empowering in that it enabled them to do something to help themselves. In the case of P09, it helped in her search for information: “Once I had a name, I searched for fibro communities. Before that, I kind of trawled the Internet looking for places where other people talked about it…I searched for the symptoms, ignored what the forum was, and just sort of talked in various forums.” Participants found it frustrating to not know what was happening with them, and active information seeking often continued through the point of diagnosis, until they developed an effective management approach.

Figure 2. P11’s illness journey timeline.



Transition to Monitoring

Eventually, study participants came to accept their illness and learned to manage it. Along with these changes, participants also engaged in less information seeking. There were various reasons. First, because information seeking was often symptom-driven, as participants were able to get their symptoms under control and/or learned to manage their condition better, they felt less of a need for information. When asked if she currently searched for information, P09 responded: “The symptoms fit the diagnosis, and while it’s frustrating to have that diagnosis and I don’t like it, and I wish it were something that were curable, I’ve mostly stopped, um, because the current treatment regimen is helping.” Many participants reached a point where they just wanted to move on:

> *For me, you just kind of reach a point where it’s like (sigh), “It is what it is. I’m going to continue to eat as healthy as I can. I’m going to continue to walk every day. I’m going to continue to lead as healthy a life as possible.” But I really am kind of done trying to figure it all out. I just want to get on with my life…When I have a bad day, “Oh well,” I don’t really question it anymore.* [P14]

Participants also stopped seeking information because they felt that they knew what was out there, and there was no new information to be found. P06 said, “I occasionally get back online and kind of look up and see where the research is at. Every now and then I’ll see a research study highlighted about fibromyalgia and I’ll read it just to see if there’s any major breakthroughs [chuckle], but there never are.” Most participants tried to maintain some level of awareness of fibromyalgia research through “monitoring,” that is, subscribing to e-newsletters from services such as Medscape. There is a lingering sentiment of wanting to know: “I’m still signed up for a couple of newsletters, but I don’t look at them on a regular basis. They flood…they come to my inbox and I don’t want to…unsubscribe…there are moments…I just want to see latest conversations, and latest research...So I keep them…they all go into a folder” [P05].

Searching for information on an as-needed basis also served to reduce information overload: “[I] started looking for specific things for specific problems…I wanted to piece [together] what would cause different areas of the symptoms, instead of looking at it as a whole, ‘cause then it was just overwhelming” [P05]. Thus, on the whole, participants eventually settled into a pattern of monitoring. But once in a while, the appearance of new symptoms, serendipitous encounters with new information, and other events might trigger some focused searching.

If a patient develops a new condition, they may cease monitoring and cycle back to active information seeking. For example, after P17 developed fibromyalgia, she engaged in active information seeking and participated in online discussions, but eventually her participation waned. She started seeking information and participating again, after being diagnosed with alopecia.

Information Consumption and Use Processes

Participants engaged in information consumption and use processes throughout the course of their journey. Several key processes emerged: forming a coherent representation of the conceptual space, evaluation and synthesis of information, taking charge of one’s health care, and iterative problem solving.

Forming a Coherent Representation of the Concept Space

Over time, participants came to understand the concept space in different ways. P05 became acquainted with the scientific explanation: “I know the biology and the science behind fibromyalgia, what they say about it, the causes they don’t really know about it…” Many came to know fibromyalgia in terms of the symptoms: “Mostly when I was still learning what fibromyalgia is, I was looking at symptoms and stuff like that…at all these different websites explaining what is going on, and what is its effect, and how people with fibromyalgia are going to feel” [P13]. P06 surveyed the online space and selected treatments based on her own comparison of patient reports: “I felt like I was doing all the major recommendations…massage, getting a lot of rest, the one particular drug that a lot of people have had success with, the guaifenesin.” There are differences in the ways that participants represented this space, but each formed an understanding of the space that they could accept, in other words, that was coherent to them.

At some point in their illness journeys, many participants came to a point of saturation, where they felt as if there was “nothing new” [P20] and that they knew “all there was to know” [P25]. This coincided with the transition to monitoring described earlier.

Evaluation and Synthesis of Information

As they were coming to understand the concept space, participants continually encountered and evaluated information. Many participants read extensively about fibromyalgia and synthesized across sources. They developed their own heuristics for evaluating the quality of information. One common rule was that they dismissed information that “promised a cure” [P09]. P22 looked “to see if they’re accurate about the basic mechanics of how it [fibromyalgia] works.” Others looked for consensus across multiple sites.

P13 and P27 engaged in another type of synthesis, involving comparison of explanatory perspectives on fibromyalgia. P13 quickly realized that allopathic medicine’s explanation of fibromyalgia did not satisfy him and moved on to study Chinese medicine. P27 said, “As soon as the doctors are thinking, okay, this might be fibromyalgia, I started doing research on the Internet, but then also checked out at least ten fibromyalgia books from the library, just to read different perspectives on what fibromyalgia is and, like, differing ways that you can treat it.”

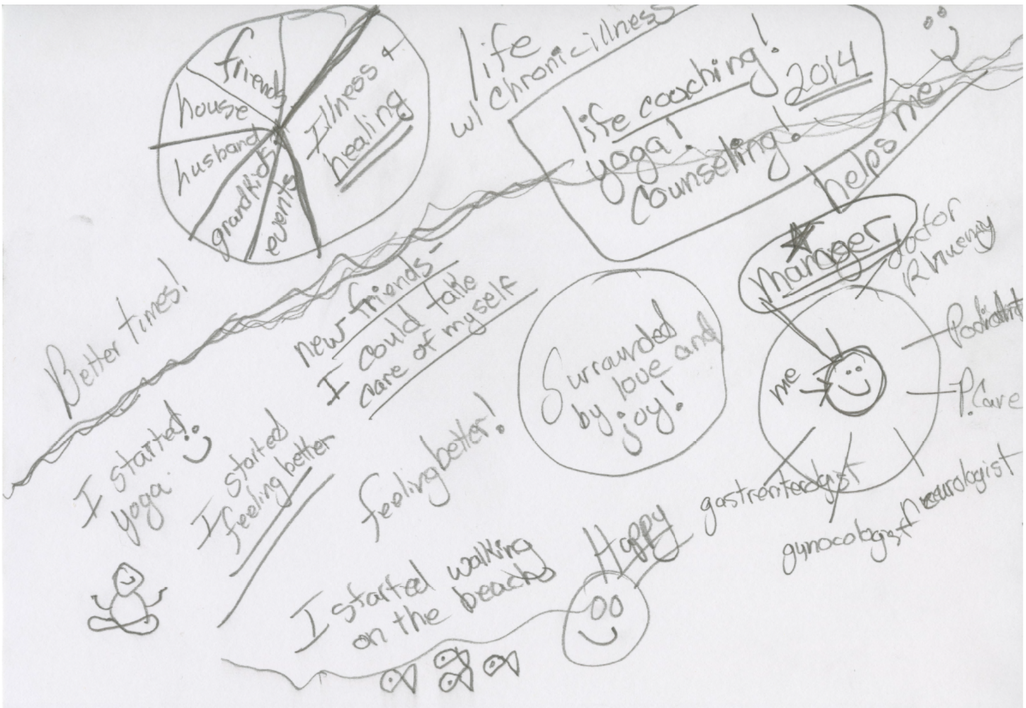
Taking Charge of One’s Own Health Care

Over time, many participants realized that they needed to take charge of their own health care. They showed this initiative in various ways. P15, like many others, went through a prolonged period of lab tests and consultations prior to being diagnosed. During that time, she realized that even if she were diagnosed, she would refuse medication, so she needed to take matters into her own hands: “I was not getting what I wanted to get with the doctors and all that, so I thought, ‘Well, what would you do differently if you had the diagnosis?…Whatever that is, you need to start doing it now’” [P15]. Then she began an elimination diet, which involved progressively removing items from her diet until she figured out what she was sensitive to.

Though health care practitioners may be experts in their respective areas, patients are likely to have a more intimate understanding of their own body. P12 explains the rationale for taking charge: “Doctors know some things, and you know some things. And you’ve got to have somebody who lets you put that together, ‘cause you’re the expert on your body, and they might be the expert on some treatments, but then you’re the one that has to sort of be your own case coordinator, and monitor your body.”

This was not a role that participants naturally took on: “It took me a long time to be the manager of my own health system. I expected doctors to kind of manage my life for me. It took me a long time to realize that, no, I’m in charge of this. The doctors that work for me are a team, and I manage that team” [P14]. P14 depicts herself as a manager of her multidimensional care team (Figure 3, right).

Figure 3. P14's illness journey timeline.



Iterative Problem Solving

Over the course of their illness, participants also engaged in episodes of problem solving to address the physical problems that they experienced.

Figuring out a management strategy was often an iterative process involving trial and error. For example, in the case of exercise, participants often needed to experiment to find the right type of exercise and amount that they could handle. P17's story is a case in point: "I got myself an exercise bicycle…I worked up to ten minutes a day…but then the other 24…23 hours a day I was in the bed. So I figured that's not going to work." She said that eventually, "I learned to evaluate myself, how tired I was getting, and how I was feeling, so I could better pace myself and rest when I needed to, and that made a huge difference...And yoga helped a lot in helping me become self-aware" [P17].

Another common issue was identifying food sensitivities and allergies. Some participants, such as P15, researched how to do this on their own. P24 used a mobile app called Pain Coach to track her food intake. This enabled her to figure out that gluten was causing her a problem, and then she eliminated it from her diet. P26 underwent lab tests and a rotation diet to figure out the foods to which she was sensitive.

Participants progressively made adjustments and/or engaged in additional information seeking based on evolutions in their thoughts and often, in their symptoms. P15 described this as "peeling back layers":

> *Like with the nutrition, say I have an issue with certain types of foods…that's one thing, and then I am getting better nutrition, not the processed things…more organic stuff, and that's peeling off another layer…and getting better exercise and more movement, of the proper kinds of movement that don't cause me to have pain. That peels off another layer. And that exposes something else.* [P15]

Not all of participants' energies were engaged in problem solving via information seeking; there was also internal sense-making. Participants found it frustrating that there were so many unexplained symptoms, and they were constantly trying to figure out the root cause of their problems: "If you have any intelligence at all and you want to get better, you want to try to figure out why you woke up feeling so bad. So I would go back and go through all the foods that I ate and go through everything. Did I go through these stresses?" [P14].

Discussion

Principal Findings

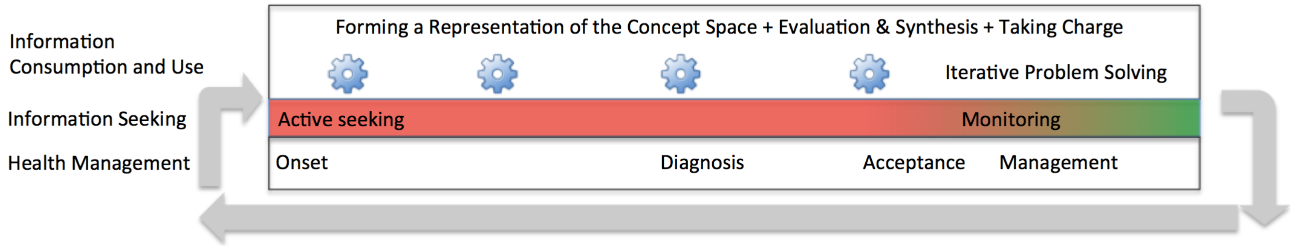
This paper reported the findings of a qualitative study of fibromyalgia patients' illness journeys. At the outset, there were health-related features: moving from onset to diagnosis, acceptance, and development of an acceptable level of health management. Information seeking changed over time, particularly in terms of a transition from active information seeking to monitoring. Last, patients engaged in information consumption and use processes: forming a coherent representation of the conceptual space, evaluation and synthesis of information, taking charge of one's health, and iterative problem solving.

Aligning the themes from the interview content temporally affords an integrated conceptualization of how health management and information behaviors are related over time (Figure 4). Patients engage in active information seeking at the beginning of their journeys, beginning with cognizance of their condition and extending through diagnosis and acceptance. As they begin to develop an acceptable level of management, their information seeking tapers to a pattern of monitoring with intermittent focused searching. The spacing of the four phases (ie, onset, diagnosis, acceptance, and management) is intended to reflect their relative temporal differences, though this may change if we observe a decrease in times to diagnosis.

Alongside these developments, participants continually engage in information consumption and use. They form and refine their interpretations of the concept space. They also engage in information evaluation and synthesis activities, which become more sophisticated over time but decrease due to lessened need. They learn to take charge of their health care. Periods of iterative problem solving to address issues such as irritable bowel, fatigue, and sleep problems also occur. The information consumption and use processes might also be thought of as activities that individuals become increasingly skilled at over time. A set of arrows from monitoring back to active information seeking indicates that patients may traverse the process again for a new condition.

The journey described in this paper reflects the predominant patterns among study participants. Though most participants engaged in extensive information seeking, a few participants did not. P18 said, “I didn’t really look into it [fibromyalgia]…I just kind of accepted it for what it was and didn’t worry about it.” P07 said that she was never really a very curious person. Both participants ended up learning more about fibromyalgia serendipitously, decades after they were diagnosed, when they engaged in exercise that inadvertently led to health information encounters. For P10 and P25, who had conditions that pre-dated fibromyalgia, there also seemed to be less of an impact.

Figure 4. The relationship of information behavior and health management over time.



Note: Spacing of the four phases, onset, diagnosis, acceptance and management is intended to reflect their relative temporal differences, though this may change if we observe a decrease in times to diagnosis.

Comparison With Prior Research

Though there has been considerable work investigating the lived experiences of fibromyalgia patients (eg [5,40-42]), at least to this author’s knowledge, there is no existing work that has taken a qualitative approach to investigate the relationship between health management and information behavior in fibromyalgia patients over time. The results of this study illustrated that, over time, participants became clearer and more accepting of their condition. These developments were accompanied by an increased awareness of and ability to use information sources to improve their health management, as well as improved communication with physicians and other health care providers.

The study findings share similarities with existing research in health literacy and self-management in chronic illness. In this study, participants developed skills that have also been identified in a meta-synthesis of self-management in chronic illness (eg, taking ownership of health needs, adjusting to illness, and activating resources) [43]. Additionally, the study findings showed that participants developed skills that have been associated with increased health literacy, such as becoming more active in clinical consultations, and greater autonomy and empowerment in decision making [44-46]. Previous research testing an Internet-based self-management intervention for fibromyalgia has also demonstrated that increased knowledge can lead to better health outcomes [47]. This convergence in the study findings and the self-management literature suggests that some of the lessons learned from this study might be incorporated in the design and delivery of self-management education.

Implications for Information System Design

There are various ways that information technology could support fibromyalgia patients’ information needs. First, to make sense of their condition, participants attempted to synthesize information across diverse source types and from multiple explanatory perspectives. Because they are not focusing on a single information source, tools that help patients make sense of and compare information sources could be particularly helpful. Building interfaces that enable patients to discern and make sense of explanatory perspectives has also been suggested in a previous study concerning information about Lyme disease [48]. Systems that help users understand and evaluate health information from different perspectives could be invaluable for conditions in which there are many treatment options, multiple alternative perspectives, and unclear treatment protocols.

Participants also expressed frustration because there were so many factors that could be influencing their health, and it was difficult to disentangle them (eg, P14). Thus, the development of tools to analyze different types of personal health data and the integration of knowledge bases to provide additional information are important directions for future development. Fibromyalgia patients are also more likely to have comorbidities [49], which can make it seem like work to track data [50].

Last, once patients start developing a picture of the concept space, they experience less of a need to seek information but are still interested in keeping up with the research. Patients who engage in monitoring could benefit from tools that automatically process newsfeeds and flag articles for perusal.

Limitations and Future Directions

Though this study provided valuable knowledge about how people use information in the context of chronic illness, there are limitations. The participants in this study had all reached acceptance, most had achieved a stable level of health management, and almost all had stopped actively seeking information. As such, the study afforded a glimpse of participants' journeys through their eyes, at a particular point in their journeys. There are potential problems with retrospective recall, including errors in memory, lack of clarity about past events, and differences in interpretation of one's history over time. Some persons may never reach acceptance or develop effective management strategies; their perspectives are not reflected in this sample.

Thus, an important priority for future research is to work with patients earlier in their illness journeys. Though participants in this study reported developing a more coherent representation of the concept space, more familiarity with and ability to evaluate information sources, and increased ability to take charge of their health care over time, there is still much that we do not know about how these skills evolve. Additional research focusing on critical time periods such as postdiagnosis, and important activities, such as problem solving and sense-making about symptoms, could inform the design of patient education programs.

Acknowledgments

The author would like to thank Dr Barbara M. Wildemuth for her guidance and suggestions through the process of conducting this research, and the study participants for sharing their experiences.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Interview 1 Guide.

[PDF File (Adobe PDF File), 142KB - jmir_v18i10e269_app1.pdf]

Multimedia Appendix 2

Interview 2 Guide.

[PDF File (Adobe PDF File), 35KB - jmir_v18i10e269_app2.pdf]

References

1. Bellato E, Marini E, Castoldi F, Barbasetti N, Mattei L, Bonasia DE, et al. Fibromyalgia syndrome: etiology, pathogenesis, diagnosis, and treatment. Pain Res Treat 2012;2012:426130 [FREE Full text] [doi: 10.1155/2012/426130] [Medline: 23213512]
2. Häuser W, Wolfe F. Diagnosis and diagnostic tests for fibromyalgia (syndrome). Reumatismo 2012;64(4):194-205. [Medline: 23024964]
3. Wolfe F, Brähler E, Hinz A, Häuser W. Fibromyalgia prevalence, somatic symptom reporting, and the dimensionality of polysymptomatic distress: results from a survey of the general population. Arthritis Care Res (Hoboken) 2013 May;65(5):777-785 [FREE Full text] [doi: 10.1002/acr.21931] [Medline: 23424058]
4. Arnold L, Crofford L, Mease P, Burgess S, Palmer S, Abetz L, et al. Patient perspectives on the impact of fibromyalgia. Patient Educ Couns 2008 Oct;73(1):114-120 [FREE Full text] [doi: 10.1016/j.pec.2008.06.005] [Medline: 18640807]
5. Crooks VA. Exploring the altered daily geographies and lifeworlds of women living with fibromyalgia syndrome: a mixed-method approach. Soc Sci Med 2007 Feb;64(3):577-588. [doi: 10.1016/j.socscimed.2006.09.025] [Medline: 17079063]
6. Lempp HK, Hatch SL, Carville SF, Choy EH. Patients' experiences of living with and receiving treatment for fibromyalgia syndrome: a qualitative study. BMC Musculoskelet Disord 2009;10:124 [FREE Full text] [doi: 10.1186/1471-2474-10-124] [Medline: 19811630]
7. Kool MB, van Middendorp H, Boeije HR, Geenen R. Understanding the lack of understanding: invalidation from the perspective of the patient with fibromyalgia. Arthritis Rheum 2009 Dec 15;61(12):1650-1656 [FREE Full text] [doi: 10.1002/art.24922] [Medline: 19950317]
8. Kool MB, Geenen R. Loneliness in patients with rheumatic diseases: the significance of invalidation and lack of social support. J Psychol 2012;146(1-2):229-241. [doi: 10.1080/00223980.2011.606434] [Medline: 22303622]
9. Armentor JL. Living with a contested, stigmatized illness: experiences of managing relationships among women with fibromyalgia. Qual Health Res 2015 Dec 14:-. [doi: 10.1177/1049732315620160] [Medline: 26667880]
10. Söderberg S, Lundman B, Norberg A. Struggling for dignity: the meaning of women's experiences of living with fibromyalgia. Qual Health Res 1999 Sep;9(5):575-587. [doi: 10.1177/104973299129122090] [Medline: 10558368]

11. Madden S, Sim J. Creating meaning in fibromyalgia syndrome. Soc Sci Med 2006 Dec;63(11):2962-2973. [doi: 10.1016/j.socscimed.2006.06.020] [Medline: 16949713]
12. Undeland M, Malterud K. The fibromyalgia diagnosis: hardly helpful for the patients? A qualitative focus group study. Scand J Prim Health Care 2007 Dec;25(4):250-255 [FREE Full text] [doi: 10.1080/02813430701706568] [Medline: 18041660]
13. Sim J, Madden S. Illness experience in fibromyalgia syndrome: a metasynthesis of qualitative studies. Soc Sci Med 2008 Jul;67(1):57-67. [doi: 10.1016/j.socscimed.2008.03.003] [Medline: 18423826]
14. Walitt B, Fitzcharles M, Hassett AL, Katz RS, Häuser W, Wolfe F. The longitudinal outcome of fibromyalgia: a study of 1555 patients. J Rheumatol 2011 Oct;38(10):2238-2246. [doi: 10.3899/jrheum.110026] [Medline: 21765102]
15. Lachapelle DL, Lavoie S, Boudreau A. The meaning and process of pain acceptance. Perceptions of women living with arthritis and fibromyalgia. Pain Res Manag 2008;13(3):201-210 [FREE Full text] [Medline: 18592056]
16. McCracken LM, Eccleston C. Coping or acceptance: what to do about chronic pain? Pain 2003 Sep;105:197-204.
17. Rodero B, Casanueva B, Luciano JV, Gili M, Serrano-Blanco A, García-Campayo J. Relationship between behavioural coping strategies and acceptance in patients with fibromyalgia syndrome: elucidating targets of interventions. BMC Musculoskelet Disord 2011;12:143 [FREE Full text] [doi: 10.1186/1471-2474-12-143] [Medline: 21714918]
18. Rooks DS, Gautam S, Romeling M, Cross ML, Stratigakis D, Evans B, et al. Group exercise, education, and combination self-management in women with fibromyalgia: a randomized trial. Arch Intern Med 2007 Nov 12;167(20):2192-2200. [doi: 10.1001/archinte.167.20.2192] [Medline: 17998491]
19. Bennett RM, Jones J, Turk DC, Russell IJ, Matallana L. An internet survey of 2,596 people with fibromyalgia. BMC Musculoskelet Disord 2007;8:27 [FREE Full text] [doi: 10.1186/1471-2474-8-27] [Medline: 17349056]
20. Daraz L, MacDermid JC, Wilkins S, Gibson J, Shaw L. Information preferences of people living with fibromyalgia – a survey of their information needs and preferences. Rheumatol Rep 2011 Sep 22;3:e7 [FREE Full text] [doi: 10.4081/rr.2011.e7]
21. Chen AT. Exploring online support spaces: using cluster analysis to examine breast cancer, diabetes and fibromyalgia support groups. Patient Educ Couns 2012 May;87(2):250-257. [doi: 10.1016/j.pec.2011.08.017] [Medline: 21930359]
22. Ressler PK, Bradshaw YS, Gualtieri L, Chui KK. Communicating the experience of chronic pain and illness through blogging. J Med Internet Res 2012;14(5):e143 [FREE Full text] [doi: 10.2196/jmir.2002] [Medline: 23092747]
23. van Uden-Kraan CF, Drossaert CH, Taal E, Shaw BR, Seydel ER, van de Laar MA. Empowering processes and outcomes of participation in online support groups for patients with breast cancer, arthritis, or fibromyalgia. Qual Health Res 2008 Mar;18(3):405-417. [doi: 10.1177/1049732307313429] [Medline: 18235163]
24. van Uden-Kraan CF, Drossaert CH, Taal E, Seydel ER, van de Laar MA. Participation in online patient support groups endorses patients' empowerment. Patient Educ Couns 2009 Jan;74(1):61-69. [doi: 10.1016/j.pec.2008.07.044] [Medline: 18778909]
25. Merolli M, Gray K, Martin-Sanchez F, Lopez-Campos G. Patient-reported outcomes and therapeutic affordances of social media: findings from a global online survey of people with chronic pain. J Med Internet Res 2015;17(1):e20 [FREE Full text] [doi: 10.2196/jmir.3915] [Medline: 25616273]
26. Chen AT. Information seeking over the course of illness: the experience of people with fibromyalgia. Musculoskeletal Care 2012 Dec;10(4):212-220. [doi: 10.1002/msc.1022] [Medline: 22736537]
27. Nonnecke B, Preece J. Lurker demographics: counting the silent. : roc SIGCHI Conf Hum Factors Comput Syst Internet ACM; 2000 Presented at: SIGCHI conference on Human Factors in Computing Systems; April 1-6, 2000; The Hague, The Netherlands p. 73-80 URL: http://dl.acm.org/citation.cfm?id=332409 [doi: 10.1145/332040.332409]
28. Ridings C, Gefen D, Arinze B. Psychological barriers: Lurker and poster motivation and behavior in online communities. Commun Assoc Inf Syst 2006;18(1):16 [FREE Full text]
29. Chen AT. Information use and illness representations: Understanding their connection in illness coping. J Assn Inf Sci Tec 2014 Apr 16;66(2):340-353. [doi: 10.1002/asi.23173]
30. Thygesen MK, Pedersen BD, Kragstrup J, Wagner L, Mogensen O. Utilizing a new graphical elicitation technique to collect emotional narratives describing disease trajectories. Qual Rep 2011 Mar 11;16(2):596-608 [FREE Full text]
31. St. Jean B. I just don't know what I don't know!”: a longitudinal investigation of the perceived usefulness of information to people with type 2 diabetes. In: Proc Am Soc Info Sci Tech. 2013 Jan 24 Presented at: Annual Meeting of the Association for Information Science and Technology; Oct 26-30, 2012; Baltimore, MD p. 1-10. [doi: 10.1002/meet.14504901030]
32. Sheridan J, Chamberlain K, Dupuis A. Timelining: visualizing experience. Qual Res 2011 Oct 20;11(5):552-569. [doi: 10.1177/1468794111413235]
33. Smith JA, Osborn M. Interpretative phenomenological analysis. In: Smith JA, editor. Qualitative Psychology: A Practical Guide to Research Methods. Thousand Oaks, CA: Sage Publications Inc; Jan 17, 2008:53-80.
34. Brocki JM, Wearden AJ. A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. Psychol Health 2006 Feb;21(1):87-108. [doi: 10.1080/14768320500230185]
35. Starks H, Trinidad SB. Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. Qual Health Res 2007 Dec 01;17(10):1372-1380. [doi: 10.1177/1049732307307031]
36. Charmaz K. Constructing Grounded Theory. Thousand Oaks, CA: Sage Publications Inc; 2014.

37. Corbin J, Strauss A. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. Thousand Oaks, CA: Sage Publications Inc; 2008.
38. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
39. Neumann L, Buskila D. Epidemiology of fibromyalgia. Curr Pain Headache Rep 2003 Oct;7(5):362-368. [Medline: 12946289]
40. Råheim M, Håland W. Lived experience of chronic pain and fibromyalgia: women's stories from daily life. Qual Health Res 2006 Jul;16(6):741-761. [doi: 10.1177/1049732306288521] [Medline: 16760533]
41. Sallinen M, Kukkurainen ML, Peltokallio L, Mikkelsson M, Anderberg UM. Fatigue, worry, and fear--life events in the narratives of women with fibromyalgia. Health Care Women Int 2012;33(5):473-494. [doi: 10.1080/07399332.2011.645967] [Medline: 22497330]
42. Juuso P, Skär L, Olsson M, Söderberg S. Meanings of feeling well for women with fibromyalgia. Health Care Women Int 2013;34(8):694-706. [doi: 10.1080/07399332.2012.736573] [Medline: 23530542]
43. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of self-management in chronic illness. J Nurs Scholarsh 2012 Jun;44(2):136-144 [FREE Full text] [doi: 10.1111/j.1547-5069.2012.01444.x] [Medline: 22551013]
44. Nutbeam D. The evolving concept of health literacy. Soc Sci Med 2008 Dec;67(12):2072-2078. [doi: 10.1016/j.socscimed.2008.09.050] [Medline: 18952344]
45. Edwards M, Wood F, Davies M, Edwards A. The development of health literacy in patients with a long-term health condition: the health literacy pathway model. BMC Public Health 2012;12:130 [FREE Full text] [doi: 10.1186/1471-2458-12-130] [Medline: 22332990]
46. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, (HLS-EU) Consortium Health Literacy Project European. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health 2012;12:80 [FREE Full text] [doi: 10.1186/1471-2458-12-80] [Medline: 22276600]
47. Camerini L, Schulz PJ. Effects of functional interactivity on patients' knowledge, empowerment, and health outcomes: an experimental model-driven evaluation of a web-based intervention. J Med Internet Res 2012;14(4):e105 [FREE Full text] [doi: 10.2196/jmir.1953] [Medline: 22810046]
48. Mankoff J, Kuksenok K, Kiesler S, Rode JA, Waldman K. Competing online viewpoints and models of chronic illness. 2011 Presented at: Proc SIGCHI Conf Hum Factors Comput Syst Internet ACM; May 7-12, 2011; Vancouver, BC p. 589-598 URL: http://dl.acm.org/citation.cfm?id=1979027 [doi: 10.1145/1978942.1979027]
49. Weir PT, Harlan GA, Nkoy FL, Jones SS, Hegmann KT, Gren LH, et al. The incidence of fibromyalgia and its associated comorbidities: a population-based retrospective cohort study based on International Classification of Diseases, 9th Revision codes. J Clin Rheumatol 2006 Jun;12(3):124-128. [doi: 10.1097/01.rhu.0000221817.46231.18] [Medline: 16755239]
50. Ancker JS, Witteman HO, Hafeez B, Provencher T, Van de Graaf M, Wei E. “You Get Reminded You're a Sick Person”: Personal Data Tracking and Patients With Multiple Chronic Conditions. J Med Internet Res 2015;17(8):e202 [FREE Full text] [doi: 10.2196/jmir.4209] [Medline: 26290186]

Edited by G Eysenbach; submitted 31.10.15; peer-reviewed by L Whitehead, S Oh, B Hafeez; comments to author 03.04.16; revised version received 27.07.16; accepted 14.09.16; published 25.10.16.

Please cite as:
Chen AT
The Relationship Between Health Management and Information Behavior Over Time: A Study of the Illness Journeys of People Living With Fibromyalgia
J Med Internet Res 2016;18(10):e269
URL: http://www.jmir.org/2016/10/e269/
doi:10.2196/jmir.5309
PMID:27780794

Original Paper

Participant Recruitment and Engagement in Automated eHealth Trial Registration: Challenges and Opportunities for Recruiting Women Who Experience Violence

Jane Koziol-McLain[1], RN, PhD; Christine McLean[2], DipIndRelns, PGDipCounsTh; Maheswaran Rohan[3], PhD; Rose Sisk[3], BSc (Hons); Terry Dobbs[2], MA; Shyamala Nada-Raja[4], PhD; Denise Wilson[5], RN, PhD; Alain C Vandal[3], PhD

[1]Centre for Interdisciplinary Trauma Research, Faculty of Health and Environmental Sciences, Auckland University of Technology, Auckland, New Zealand

[2]Centre for Interdisciplinary Trauma Research, Auckland University of Technology, Auckland, New Zealand

[3]Department of Biostatistics and Epidemiology, Auckland University of Technology, Auckland, New Zealand

[4]Department of Preventive and Social Medicine, University of Otago, Dunedin, New Zealand

[5]Taupua Waiora Centre for Māori Health Research, Auckland University of Technology, Auckland, New Zealand

Corresponding Author:
Jane Koziol-McLain, RN, PhD
Centre for Interdisciplinary Trauma Research
Faculty of Health and Environmental Sciences
Auckland University of Technology
A-9
Private Bag 92006
Auckland, 1142
New Zealand
Phone: 64 9 921 9670
Fax: 64 9 921 9796
Email: jane.koziol-mclain@aut.ac.nz

Abstract

Background: Automated eHealth Web-based research trials offer people an accessible, confidential opportunity to engage in research that matters to them. eHealth trials may be particularly useful for sensitive issues when seeking health care may be accompanied by shame and mistrust. Yet little is known about people's early engagement with eHealth trials, from recruitment to preintervention autoregistration processes. A recent randomized controlled trial that tested the effectiveness of an eHealth safety decision aid for New Zealand women in the general population who experienced intimate partner violence (isafe) provided the opportunity to examine recruitment and preintervention participant engagement with a fully automated Web-based registration process. The trial aimed to recruit 340 women within 24 months.

Objective: The objective of our study was to examine participant preintervention engagement and recruitment efficiency for the isafe trial, and to analyze dropout through the registration pathway, from recruitment to eligibility screening and consent, to completion of baseline measures.

Methods: In this case study, data collection sources included the trial recruitment log, Google Analytics reports, registration and program metadata, and costs. Analysis included a qualitative narrative of the recruitment experience and descriptive statistics of preintervention participant engagement and dropout rates. A Koyck model investigated the relationship between Web-based online marketing website advertisements (ads) and participant accrual.

Results: The isafe trial was launched on September 17, 2012. Placement of ads in an online classified advertising platform increased the average number of recruited participants per month from 2 to 25. Over the 23-month recruitment period, the registration website recorded 4176 unique visitors. Among 1003 women meeting eligibility criteria, 51.55% (517) consented to participate; among the 501 women who enrolled (consented, validated, and randomized), 412 (82.2%) were accrued (completed baseline assessments). The majority (n=52, 58%) of the 89 women who dropped out between enrollment and accrual never logged in to the allocated isafe website. Of every 4 accrued women, 3 (314/412, 76.2%) identified the classified ad as their referral source, followed by friends and family (52/412, 12.6%). Women recruited through a friend or relative were more likely to self-identify as indigenous Māori and live in the highest-deprivation areas. Ads increased the accrual rate by a factor of 74 (95% CI 49–112).

Conclusions: Print advertisements, website links, and networking were costly and inefficient methods for recruiting participants to a Web-based eHealth trial. Researchers are advised to limit their recruitment efforts to Web-based online marketplace and classified advertising platforms, as in the isafe case, or to social media. Online classified advertising in “Jobs–Other–volunteers” successfully recruited a diverse sample of women experiencing intimate partner violence. Preintervention recruitment data provide critical information to inform future research and critical analysis of Web-based eHealth trials.

ClinicalTrial: Australian New Zealand Clinical Trials Registry (ANZCTR): ACTRN12612000708853; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?ACTRN=12612000708853 (Archived by WebCite at http://www.webcitation/6lMGuVXdK)

(J Med Internet Res 2016;18(10):e281) doi:10.2196/jmir.6515

KEYWORDS

eHealth; recruitment; dropout; intimate partner violence; Web-based trials

Introduction

Violence against women is a global epidemic. It is estimated that one in every three women experiences physical or sexual violence by an intimate partner [1]. The negative impact of intimate partner violence (IPV) on the health and well-being of women and their children has been documented for over two decades [1,2]. While primary prevention efforts are required to reduce the prevalence of this human rights violation [3,4], it is also necessary to provide evidence-based essential services that promote the safety and well-being of those experiencing abuse [5]. However, women’s ability to access services is often constrained by the ongoing pattern of coercive and controlling behaviors that isolate a woman from both informal and formal support systems [6,7].

Recognizing the growing number of people who turn to the Internet to seek help [8,9], eHealth interventions have the potential to provide an accessible, safe, cost effective resource for women experiencing violence. eHealth interventions can provide a pathway for women to access health, justice, and civil society essential services. Innovative, interactive eHealth interventions for women who experience abuse are being developed and tested internationally [10-14]. In developing this evidence base, it is critical to examine the processes of recruiting women who are experiencing abuse for Web-based trials. In this study we examined the recruitment experience for the New Zealand isafe trial [15] that tested a Web-based safety decision aid for women who experience abuse.

Help Seeking Among Women Who Experience Abuse

Qualitative research findings document that women implement a range of both active and passive strategies to keep themselves and their children safe from a partner’s coercive controlling behaviors [16-18]. They often tell friends, family, or coworkers (informal networks) about the abuse they are experiencing. These informal sources of support, however, often lack the understanding and skill to provide helpful responses [7,19]. Compared with disclosing abuse within informal networks, disclosing abuse within a formal service is less common. In countries with high rates of violence against women, and attitudes that condone abuse, less than 2% of women may access formal services [20,21]. In contrast, a 2003 survey of women in two New Zealand regions found that 52% reported seeking help from one or more formal services, although 40% of abused women reported that no one had tried to help them [22]. Barriers to seeking formal assistance reported by women include, for example, fear of repercussions from their partner, lack of trust, lack of confidentiality, fear of their children being removed, fear of deportation, potential loss of financial security (eg, if their partner is jailed), self-blame, feeling stigmatized, and the desire to not bring shame to themselves and their family [19,23-27]. Some women may have disclosed abuse in the past but received a response that minimized their abuse, was judgmental (victim blaming), or gave simplistic advice to leave their partner [28]. Barriers to effective help seeking are compounded when women experience multiple inequities. Such historical, social, cultural, structural, economic, and political contexts can result in mistrust of health institutions and racist and discriminatory responses that further entrap women [29,30]. Many of the root causes of violence directed against indigenous women, such as colonization resulting in historical trauma and racism, also contribute to and sustain unresponsive and potentially harmful institutional responses. This is most certainly the case for New Zealand Māori [31,32]. Web-based interventions have the potential to provide these women a confidential, culturally appropriate, nonjudgmental resource.

Violence Against Women Intervention Research Recruitment

Recruiting women who experience violence for research testing intervention effectiveness can be particularly challenging for ethical, safety, and scientific rigor reasons [33,34]. Women are often recruited through government services or community agencies, which requires attention to relationship building with the agency, ideally with some provision for reciprocity [33]. Recruitment is generally advised by experts in the field to be done personally, in face-to-face, one-to-one encounters by trained, sensitive researchers who are skilled in managing unanticipated situations, and are ideally of the same culture as the women [33]. How this face-to-face recruitment process can be translated to the computer user interface in eHealth interventions has received little attention [35].

In a recent systematic review of studies testing advocacy interventions for women who experience violence [36], 8 of the 13 included studies recruited women from health care settings, 4 from domestic violence shelters (1 also recruited from social service agencies), and 1 from an urban community center. Of note, 2 Web-based trials were excluded from the systematic review due to not meeting the criteria for being advocacy based. Across the studies, reviewers identified variations in baseline type and severity of abuse, commitment to the relationship, participant age, ethnicity, and socioeconomic status, all of which can influence recruitment and dropout (attrition) and, in turn, study validity.

eHealth Trial Recruitment Best Practice

Alongside the rapid growth of eHealth innovations are calls that programs be sufficiently tested. Dissemination models [37,38] and research standards [39] provide important resources for researchers, funders, and policy makers. Appreciating that "[randomized controlled trials] of Web-based interventions pose very specific issues and challenges," the Consolidated Standards of Reporting Trials (CONSORT) -EHEALTH checklist was developed [39]. However, one aspect of eHealth trials that has garnered insufficient attention is the Web-based recruitment process. To understand Web-based recruitment and where there may be risk of bias, preintervention information is needed about the number of people who are potential participants, those who are eligible, those who consent, and those who complete baseline measures.

There is generally a lack of guidance regarding how external validity can be assessed and promoted in trials that involve Web-based recruitment. Scrutiny of recruitment and preintervention dropout experience in eHealth trials will inform our understanding of eHealth effectiveness and utility, trial representativeness, and the risk of fraudulent participation [40]. Few studies have addressed the representativeness of Web-based recruitment. In a review of 16 studies reporting dropout in Web-based interventions for psychological disorders, preintervention dropout (reported in 7 of the 16 studies) ranged from 4% to 52% [41]. Additionally, there is minimal theory to explain how potential participants engage with Web-based recruitment and interventions [35]. Liese and Beck [42] identified a pathway of individual and contextual factors that activate negative beliefs about the success of an intervention that are then hypothesized to lead to dropout. This does not take into account, however, participants' expectations of an intervention effect, nor the altruistic aim of women who experience abuse wanting to help other women [41,43].

isafe Trial

In this study we examined recruitment method effectiveness and early (preintervention) participant engagement for the isafe trial. The isafe trial was part of an international collaborative concurrent replication of the Internet Resource for Intervention and Safety (IRIS) study [11] that was modified for the Aotearoa New Zealand context [14]. The New Zealand trial, tailored for the New Zealand context [14], advanced the IRIS study by offering women fully automated Web-based trial recruitment, eligibility screening, and consent [44]. Both the IRIS and isafe studies had automated Web-based delivery of intervention, violence, and mental health assessments and retention procedures. While procedures to maximize isafe participant safety were paramount, and guided by explicit ethical principles, in this study we focused on recruitment and early participant engagement data. This information provides transparency of our experience for others to learn from, contributes to further refinement of eHealth study reporting guidelines, and informs critique of the isafe trial.

Methods

We report and analyze isafe recruitment and early participant engagement as a case study [45], and include a qualitative narrative of the recruitment experience, as well as analysis of quantitative recruitment and engagement data. Specific aims included describing the recruitment experience, meeting recruitment targets, identifying preintervention engagement with Web-based registration and dropout rates, and examining the effects of study recruitment advertisements on an online community marketplace and classified advertising platform and their sustainability over time.

In the Web-based isafe trial, women were randomly assigned to a safety decision aid intervention or usual safety planning control website. Intervention components included (1) safety priority setting, (2) danger assessment [46], and (3) an individually tailored safety action plan. The control website included standardized (nontailored) safety planning and resource information. Self-reported primary outcome measures, depression and violence exposure, were collected at baseline and 3, 6, and 12 months after baseline. Women were provided a NZ $30 gift voucher at each measurement point in appreciation of their contribution. While the study protocol was previously published [15], in this paper we iterate and expand on the recruitment plan and automated registration process. The study protocol was approved by the Auckland University of Technology ethics committee (AUTEC 12/51) with trial registration (ACTRN12612000708853).

A Priori Recruitment Plan

The target population for the isafe trial was women 16 years of age or older, residing in New Zealand, were English speaking, and were experiencing IPV in their current relationship. The target sample size was 340 women; we sought to enroll an average of 43 women per quarter, achieving the desired sample size over 24 months.

Recruitment was informed by several of our team principles. First, our principle to "be sensitive and inclusive of diversity" meant the program needed to reflect the diversity of women in Aotearoa New Zealand. The design and language used in isafe materials was influenced by women who participated in focus groups convened during the trial planning stage [14]. We also learned that, despite our being advised to collect numerous contacts to maximize retention in longitudinal studies [33], women in our focus groups resented being asked to identify more than one contact. Acknowledging inequities in Internet access, we also collaborated with Aotearoa People's Network, a library collective that facilitates free Internet access across diverse New Zealand settings.

Second, our recruitment was guided by our principle to "maintain the cultural integrity of Māori within the *matatini* (diversity) of *iwi* /tribal differences." The research team *kaumātua* (respected and recognized elder) and Māori team members (DW, TD) informed the development of recruitment plans and details such as ads and language. They also consulted *kanohi ki te kanohi* (face-to-face) with a range of Māori women, *iwi*, and service organization networks and attended conferences (eg, E Tu Whānau) to disseminate information about the isafe study.

Third, our principle to “act in a collaborative manner with our community and research partners” led us to consult with a range of advisors from local, regional, and national IPV service agencies (eg, SHINE, Women’s Refuge) and departments (Ministry of Social Development, It’s Not OK campaign). Team members provided presentations to agency staff and encouraged them to review the Web-based isafe tool using a guest password. Team members often had prior relationships with individuals within these agencies, who were supportive of the isafe resource and testing, and were willing to assist in recruitment.

The a priori recruitment plan was to initiate a dynamic stepped rollout of recruitment strategies over time, guided by recruitment data. The first phase of recruitment relied on the recent recruitment experience of the New Zealand Recovery via Internet from Depression (RID) trial. In the RID trial, short advertisements included in health education television programming (Health TV; Healthy Life Media Ltd, Auckland, New Zealand) in medical waiting rooms proved an effective recruitment method. For isafe, we developed two short video ads to run on televisions in the waiting rooms of 53 primary health care practices, 4 accident and emergency centers, and 3 emergency departments across New Zealand that subscribed to Health TV. Approximately half (28) of the practices served a predominantly Māori population. One or the other of the 30-second ads was to run once every 20 minutes for a period of 4 weeks. Information about the study was included in Health TV newsletters, and the research team communicated with each site offering flyers and isafe referral cards for display in their waiting rooms to supplement the television ad. The primary method of recruitment for the IRIS study was community ads on craigslist [11], which is not commonly used in New Zealand. While the team considered recruiting through social media sites such as Facebook, we were reluctant to do so due to security and confidentiality concerns. In addition to Health TV, the first phase of recruitment included plans for distribution of digital, print, and face-to-face recruitment ads. We prepared both mainstream and Māori-focused ads.

We monitored recruitment weekly, including review of Google Analytics (Google, Mountain View, CA, USA) reports and the isafe registration website. Summary data were available every 6 months in open Data Monitoring Committee reports. Recruitment methods were documented in a log and costs recorded. We budgeted NZ $17,000 for recruitment costs. This included $10,000 for production of Health TV ads and $4500 for running the ads. An additional $2500 was budgeted for other print and media recruitment methods.

Web-Based Automated Registration Pathway

The automated registration pathway included the following 6 steps.

Welcome Page

People who found their way to the isafe website [44] were presented a welcome screen that provided a simple “Kia ora and welcome to the isafe study” message followed by 3 questions: “Are you a woman who is worried about your relationship?”, “Are you afraid of your partner sometimes?”, and “Do you sometimes wonder if you are safe?” From the welcome page, interested women were directed to click Sign Up to learn more about the study.

Sign Up Page

The sign up page provided study participant information that included, for example, the invitation to participate, purpose of the study and what would be involved, risk and benefits, confidentiality information, and how to contact the research team if site visitors had any questions. At the end of the participant information was the text “Thank you for carefully reading this information. If you are interested in taking part in this study press Next.” Clicking Next took them to the eligibility assessment.

Eligibility Page

On the eligibility page was the text “Please check the following to ensure that you are eligible to participate. This study was developed for women who are experiencing abuse in their current relationship. Please tick all that apply.” Items included the following: (*a*) In the last 6 months, I have been hit, kicked, punched, choked, or otherwise physically hurt by my current partner, (*b*) In the last 6 months, my partner has forced me into sexual activities or coerced me into sexual activities with threats, (*c*) In the last 6 months, my partner has threatened to harm me physically, (*d*) In the last 6 months, I have felt unsafe in my relationship, (*e*) I am a female, (*f*) I am 16 years or older, (*g*) I have computer access that is safe, (*h*) I have Internet access that is safe, and (*i*) I have an email address that is safe. Women who selected 1 or more of the abuse items (*a* – *d*) and each of the remaining items (*e*–*i*) advanced to the consent page. Those who did not meet eligibility criteria were thanked and referred to the resource page for general information; to reduce the risk of fraudulent entries, ineligible site visitors were blocked from using the browser Back button to return to the eligibility criteria. Women without a safe email were provided instructions on how they could obtain one.

Consent Page

Women who met the eligibility criteria completed the consent process by ticking their agreement to each of the consent items, ending with “I agree to be in this study.” Then, participant information was collected, including name, address, date of birth, safe email address, any special safety instructions for follow-up communications, and an alternative safe contact to facilitate retention. Women were also asked where they had learned about isafe (source of referral) and the number of children living in their home under the age 18 years that they were responsible for.

Automated Validation

We used a validation process to minimize the risk of fraudulent participant entry (such as duplicate entry). Validation was automated by matching the consenting participant’s name and address against the New Zealand Electoral Roll file (dated May 9, 2012) or by manual validation. Manual validation was completed by a research team member conducting a logic check of participant information (such as birthday) against information gathered by Google and Facebook searching or alternatively by sending an email request for confirmation of electoral roll status from the participant.

Automated Enrollment

Once validated, women were issued an automated email with their username, password, and the secure website address. For women validated by research staff, there was a delay from consent to email from an hour up to 2 days. Women had a 6-week window to enter the secure website and complete the baseline survey. Automated reminder emails were sent during the 6-week window. Once a woman completed the baseline measures she was considered to be accrued. This was the end of the preintervention phase of recruitment.

Team members received automated email notifications as potential participants progressed through the registration process. The trial registration database allowed team members to monitor participants' progress from registration through to the 12-month follow-up.

Data Collection and Analysis

Data sources included the study recruitment log, study financials, weekly Google Analytics reports, online marketing website visit reports, isafe registration administration data, and isafe metadata. Our analysis began with an examination of our study recruitment log to produce a narrative of the recruitment journey. We then examined people's engagement in the isafe website, beginning with hits documented in Google Analytics (if country = New Zealand and acquisition = new user) and progressing through the preintervention pathway (using isafe registration administration data), noting dropouts. We next calculated the rates of accrual per month and day and compared accrual rates during the school holiday and non-school holiday periods. We report participant characteristics (age, children, referral source, and deprivation quintile based on consent address meshblock [47]) at both enrollment and accrual. The effectiveness of recruitment methods was considered, with cost per accrued participant calculated.

Given the novelty of recruiting through a series of location-specific Web-based online marketing website (Trade Me; Trade Me Ltd, Wellington, New Zealand) ads, we analyzed the efficiency of the ads by location and frequency of ads. The cumulative participant accrual versus number of ads for each region was graphed. We used the Koyck model [48,49], which links ads and sales in the econometric literature, to investigate the direct and lag effects of ads on accrual. The model was implemented using negative binomial regression with logarithmic link, accounting for regional variation with random effects. We investigated effects from the number of ad campaigns run in a region and school holidays. The analysis was undertaken with R version 3.2.0 (R Foundation for Statistical Computing), using the glmmADMB package [50].

Results

Recruitment Experience

The isafe recruitment experience can be easily separated into two distinct periods that we describe as *challenging* and *opportunities*.

The Challenging Period: September 17, 2012 to May 20, 2013

With the launch of the isafe trial on September 17, 2012, the a priori recruitment plan was implemented. The isafe ad ran in waiting room televisions for a 6-week period (September 17 to October 31, 2012). Study recruitment information was distributed nationally to IPV service agencies. Māori and mainstream recruitment leaflets and flyers were distributed through networks. Both IPV and general health agencies posted isafe links on their websites.

Our initial recruitment efforts were unsuccessful. With each passing month, we expanded our recruitment reach through additional digital, print, and face-to-face networks. We posted our video ad on YouTube (YouTube LLC, San Bruno, CA, USA) and increased the number of websites that provided a link to isafe (though many were time limited). We initiated additional newspaper advertisements. Flyers and ads in e-newsletters were distributed through universities and district health boards. Overall, these efforts were time and resource intensive—and ineffective.

At the end of 8 months, only 15 women had enrolled. The recruitment rate between September 17, 2012 and May 20, 2013 was approximately 2 women per month and made us question the feasibility of conducting the study. To develop an alternative recruitment strategy, we consulted with the university communications and marketing team, convened a recruitment think tank lunch to which we invited health promotion students, and consulted IRIS researchers (N Glass PhD, RN and A Clough, written and oral communication, April 2013) again; they iterated that they attributed their recruitment success to accessing women directly through an online classified advertisements website (craigslist; Craigslist Inc, San Francisco, CA, USA).

The Opportunities Period: May 21, 2013 to August 31, 2014

The team recognized the need to directly reach a wider audience of women. The leading online marketplace and classified advertising platform in New Zealand is Trade Me. While initial investigations had not identified a suitable section on the site for a research notice, we decided to trial an ad for "Research Study on Safety in Relationships" in the "Jobs–Other–volunteers" section. The ad included the mention "You will be reimbursed for your time." Beginning May 21, 2013, a 4-week ad ran in five New Zealand locations. This short trial resulted in 21 participants: the opportunities phase had begun. While we expected that some might confuse the trial with a work opportunity, that was not the case. Review of our study log of phone calls (to our free phone study number) and emails identified only two queries about a work opportunity, both from men. Thereafter, at regular intervals, an additional 56 isafe ads were placed across 32 New Zealand cities, towns, and localities. We purposefully selected localities over time based on population size, proportion of Māori and Pacific people, high IPV rates (Recorded Crime Victim Statistics—Victimisations data generated from Statistics New Zealand [51]), and a large rural component.

During the opportunities phase, other recruitment efforts continued. For example, a collaboration between the isafe team and Auckland New Zealand Police resulted in a 3-month isafe recruitment drive (December to February 2014); New Zealand Police agreed to refer women to isafe during routine family violence callout follow-up visits. A second collaboration involved the Auckland Regional Community Alcohol and Drug Services, who agreed to post flyers and make isafe referrals to their clients.

At the conclusion of the Trade Me ad campaign, by the end of August 2014, a total of 412 women had been accrued to the isafe study, exceeding our recruitment target of 340 well within the allocated timeline (Figure 1). The recruitment rate increased from 2 women per month during the challenging period to 25 women per month during the opportunities period (May 21, 2013 to August 31, 2014).

Preintervention Participant Engagement

Figure 2 outlines preintervention engagement based on the automated registration steps. The study website had over 4000 unique visitors, with 36.11% (1508/4176) reviewing the study participant information and 31.15% (1301/4176) engaging with the eligibility criteria. Among the 1003 women meeting eligibility criteria, 51.55% (517) consented to participate. Among the 501 women who enrolled (consented, validated, and randomized) in isafe, 412 (82.2%) were accrued (completed all baseline assessments). Among the 89 women who dropped out between enrollment and accrual, the majority (n=52, 58%) never logged in to the allocated isafe website. We acknowledge the nonstandard occurrence of baseline assessment after randomization, attributable to technical constraints.

Approximately 1 in every 10 unique visitors to our website became an accrued participant. The overall accrual rate per day was 0.58 (412 participants/713 days). During the 42 days of summer holiday (December 20 to January 10 over 2 years), no participants were recruited.

Figure 1. Expected and actual accrual to the isafe study, September 17, 2012 to August 31, 2014.

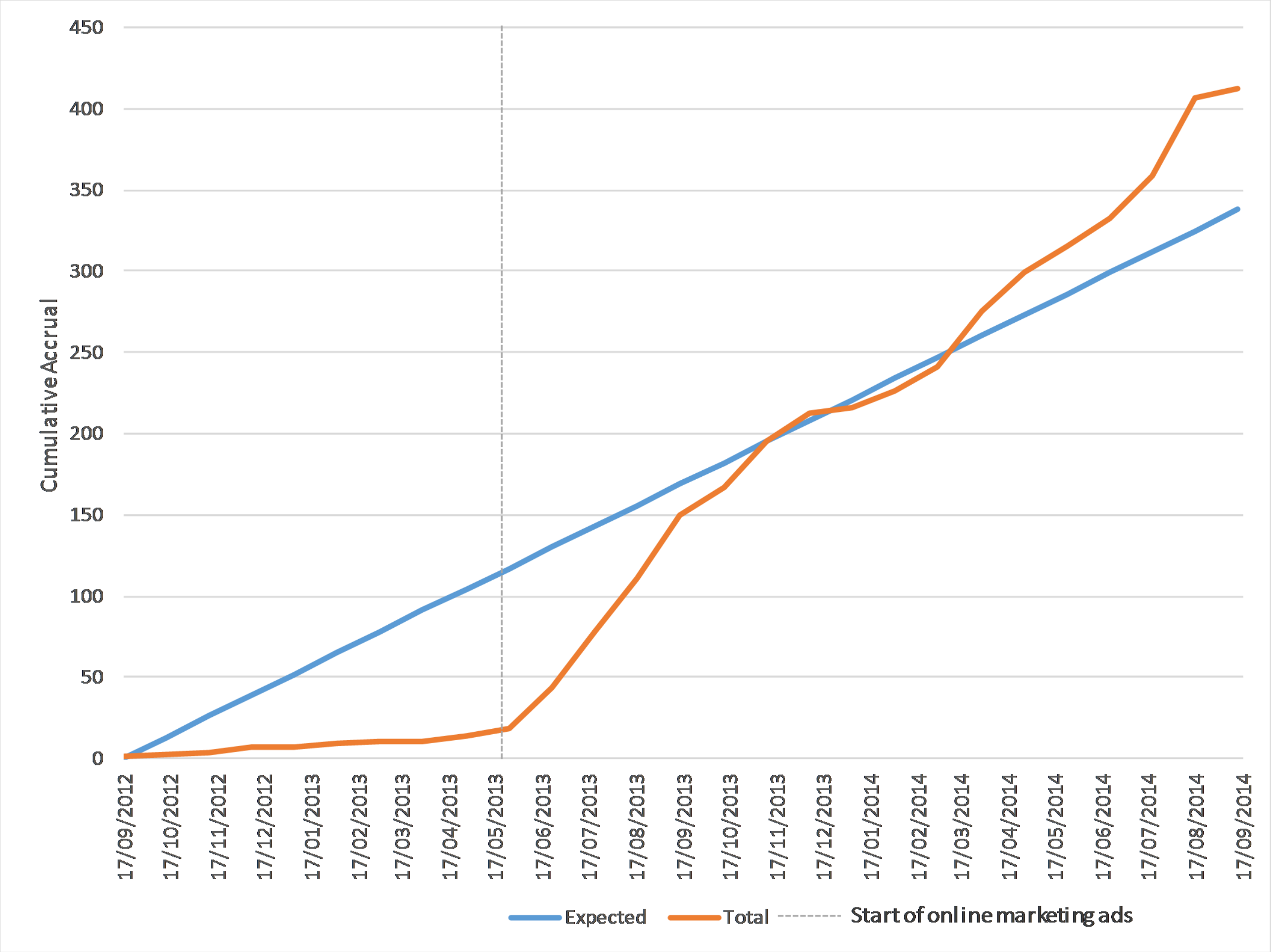
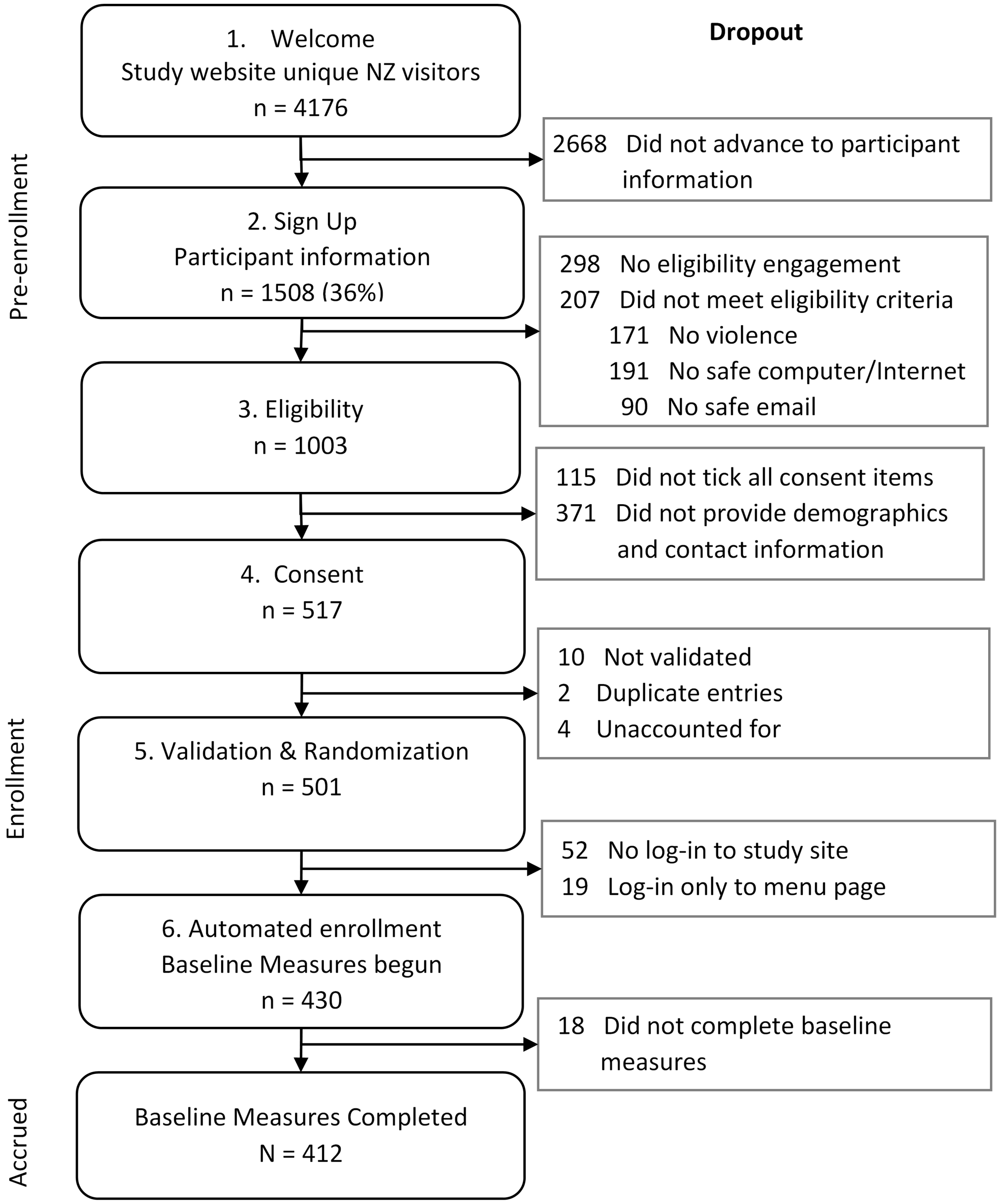


Figure 2. The isafe website preintervention participant engagement and recruitment.



Preintervention Participant Characteristics

Table 1 provides the characteristics of those who completed enrollment and those who went on to be accrued. Based on information provided at the time of consent, we noted no important differences between enrolled and accrued women in regard to age, having one or more children in the home, reporting two or more types of violence (among the four eligibility criteria), or deprivation. Accrued women were typically young, experienced multiple types of violence, and lived in higher-deprivation neighborhoods. Among accrued women, 27% self-identified as Māori (14.9% of people living in New Zealand identify with Māori ethnicity [52]). Women from most territorial regions in New Zealand were represented (Figure 3).

Table 1. Characteristics of enrolled versus accrued participants in isafe.

Characteristics	Enrolled (consented) (n=501)	Accrued (completed baseline measures) (N=412)
Age in years		
Range	16–65	16–59
Mean (SD)	31.2 (10.0)	30.8 (9.9)
One or more children in the home, n (%)	230 (46)	186 (45)
Violence (among 4 types of violence), n (%)		
One type of violence	132 (26.3)	110 (26.7)
Two or more types of violence	369 (73.7)	302 (73.3)
Referral source, n (%)		
Online marketing ad (Trade Me)	377 (75.2)	314 (76.2)
Friend or relative	59 (11.8)	52 (12.6)
Domestic violence service provider	19 (3.8)	10 (2.4)
Health TV/medical clinic	9 (1.8)	9 (2.2)
CADS[a]	4 (0.8)	3 (0.7)
Newspaper	3 (0.6)	3 (0.7)
New Zealand Police	2 (0.4)	2 (0.5)
YouTube	2 (0.4)	1 (0.2)
Other	26 (5.2)	18 (4.4)
Deprivation quintiles (based on consent address), n (%)		
1 (lowest deprivation)	44 (8.8)	42 (10.2)
2	75 (15.0)	62 (15.0)
3	105 (21.0)	81 (19.7)
4	115 (23.0)	97 (23.5)
5 (highest deprivation)	149 (29.7)	123 (29.9)
Unknown	13 (2.6)	7 (1.7)
Ethnicity (self-identified; could select >1 ethnicity), n (%)[b]		
Māori		113 (27.4)
Pacific		42 (10.2)
Asian		42 (10.2)
New Zealand European		297 (72.1)

[a] CADS: Community Alcohol and Drug Services.

[b] Data not collected at time of enrollment.

Figure 3. isafe study accrual rates across New Zealand territorial authorities.

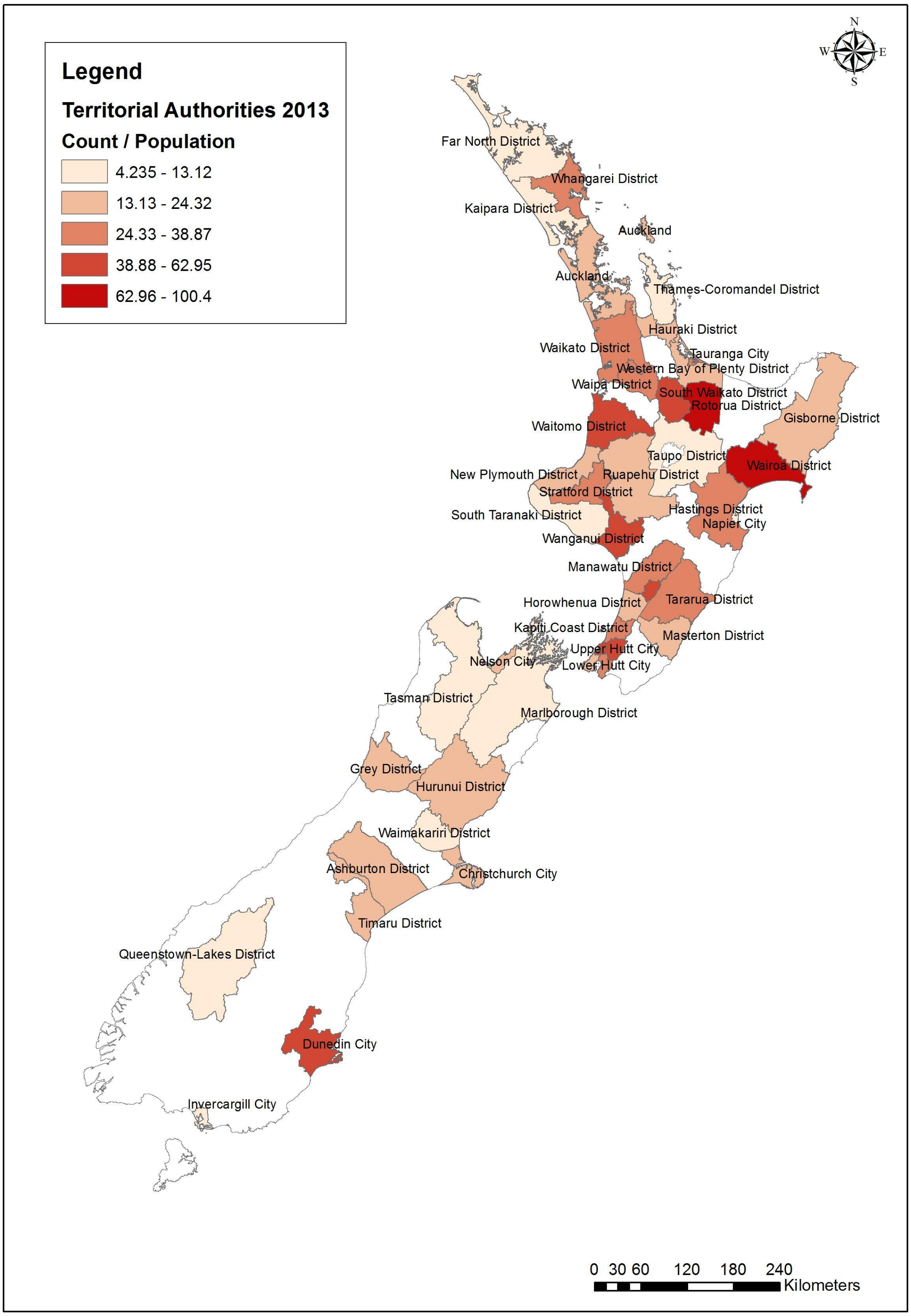


Table 2. Recruitment efficiency for the isafe study.

Recruitment type	Staff resource	Direct cost (NZ $)	No. of accrued participants	Cost per participant (NZ $)
Health clinic television ads (Health TV; development and running)	Low	12,256	9	1362
Online marketing ads (Trade Me)	Low	6831	314	22
Print ads (newspapers)	Low	829	3	276
Flyers (printing)	High	910	Unknown	Unknown
Networking with service providers	High	230	10	23
Not assigned to a costed recruitment method			76	unknown
TOTAL		21,056	412	51

Table 3. Characteristics of accrued participants (N=412) in isafe by referral source.

Characteristics	Referral source		
	Friend/relative (n=52)	Trade Me (n=314)	Other (n=46)
Age in years			
Mean (SD)	30.83 (9.06)	30.68 (10.11)	31.72 (9.8)
Range	17–57	16–59	17–57
One or more children in the home, n (%)	19 (36.5)	148 (47.1)	19 (41.3)
Two or more types of violence, n (%)	38 (73.1)	230 (73.2)	34 (73.9)
Deprivation quintile, n (%)			
1 (lowest deprivation)	2 (3.8)	34 (10.8)	6 (13.0)
2	8 (15.4)	48 (15.3)	6 (13.0)
3	6 (11.5)	68 (21.7)	7 (15.2)
4	15 (28.8)	72 (22.9)	10 (21.7)
5 (highest deprivation)	21 (40.4)	85 (27.1)	17 (37.0)
Ethnicity self-identified as Māori	21 (40.4)	83 (26.4)	9 (19.6)

Recruitment Methods

A total of 3 of every 4 women (76%) recruited to isafe identified Trade Me as their referral source (Table 1). The next most common referral source was through friends and family (12.6%). We do not know how friends and family heard about isafe, whether from seeing an ad on Health TV or Trade Me, for example. Recruitment costs totaled NZ $21,056 ($4056 overspend). The cost per participant ranged from $1362 for the development and running of television ads in medical clinics, to $22 for online marketing ads (Table 2). The online marketing ads were both efficient in cost and staff time. While networking direct costs were low, the required staffing resource was significant.

There were some notable differences in participant characteristics by referral source (Table 3). Women recruited through a friend or relative were more likely to self-identify as Māori and live in the highest-deprivation areas. Women recruited through Trade Me were more likely to have children in the home and less likely to live in the highest-deprivation areas.

Online Marketing Ad Effects

We examined the online marketing website (Trade Me) ad impact on accrual weekly during recruitment. Research staff attributed (matched) accrued women to a Trade Me ad based on location and date of accrual (research staff were blinded to women's self-report of referral source). Research staff attributed a total of 327 (13 more than what women reported) accruals to Trade Me ads. We placed 61 ads in 32 locations throughout New Zealand during the period May 2013 to August 2014. Individual locations had between 1 and 5 ads. The ads resulted in a total of 65,067 views on the marketing website. Individual ads produced between 0 and 9 participants while the ad was running.

The lag effect duration of ads past the publication period was estimated at 0.3 day (95% CI –0.3 to 1.2), not significantly distinct from an absence of actual lag effect (*P*=.3). We therefore refitted the model without the lag effect, but included the number of ads previously run in the region and an indicator for school holidays, for neither of which we could account in the original Koyck model. The base recruitment rate was estimated by the model at 0.017 participant per 100,000 person-weeks (95% CI 0.011–0.024). On average, ads increased the accrual rate by a factor of 74 while they were running (95% CI 49–112). Running several ads over time in the same region was associated with a significant decrease of the accrual rate, by a factor of 0.71 after each ad campaign (95% CI 0.64–0.78). School holidays were found not to be significant (*P*=.21) and were not retained in the model. There was fairly strong regional variation, with fitted regional random rate ratios ranging from 0.17 to 6.2.

Discussion

The recruitment target for the Web-based isafe intervention trial for women who experience abuse was to accrue 340 women over a 24-month period. This target was achieved. On the automated study registration website, within 23 months, 4176 people visited the website, 501 women enrolled, completing the consent and validation process, and 412 (82.2%) women were accrued, having completed baseline measures. However, these simple recruitment statistics mask the challenges to and opportunities for recruitment that were experienced in the preintervention recruitment phase of the study.

The recruitment rate during the 8-month *challenging* period (2 women per month) represented an inefficient, financially wasteful period of recruitment print ads, website links, and networking. In contrast, the recruitment rate during the 16-month *opportunities* period (25 women per month) was valuable in both efficiency and cost. Job ads for volunteers in the largest available online consumer marketing and classified advertising website in New Zealand (Trade Me) were viewed over 65,000 times; 3 of every 4 participants identified the job ad as their source of referral to isafe. Staff time in managing and monitoring the advertising process was minimal. Interestingly, we estimate that if we had had administrative capacity to monitor high flows of participants into the trial, by running a blitz of ads across New Zealand every 6 weeks, we might have achieved our sample size within 6 months. Our challenges and opportunities experience is similar to that reported by Loxton et al [53], where the average number of daily responses for recruiting young women to the Australian Longitudinal Study on Women's Health increased 5-fold with the introduction of targeted Facebook advertisements. The current I-DECIDE Australian trial is also using Facebook and achieving expected recruitment rates [10].

When targeting participants within a large population, marketing websites or social media recruitment methods are advised. The decreasing effectiveness of ad campaigns as they are repeated, either through exhaustion of the recruitment population or lessened sensitivity to the ads, is a factor to bear in mind. Other recruitment considerations include holiday periods, the type of topic that is being researched, characteristics of the target group, and digital media tools that the group are most likely to use. Working with colleagues experienced in social and health marketing fields is also helpful. One of the strengths of Web-based studies is being able to recruit diverse populations. In our case, we successfully recruited women from across New Zealand; 1 in 4 women self-identified as Māori, and women living in high-deprivation neighborhoods were overrepresented. Of note, our preintervention data highlight the important contribution of friends and family in referring high-risk women to research, particularly for Māori women.

The 18% isafe preintervention dropout rate from enrollment (consent, validation, and randomization) to accrual (completion of baseline measures) is just below the weighted average of 21% (range 4% to 52%) reported by Melville et al [41] for trials of Web-based interventions for psychological disorders. Calculating preintervention dropout rate from earlier steps in the automated Web-based registration process, however, results in dropout rates of 59% (from eligibility assessment) to 20% (from consent criteria), indicating the importance of clarifying at which point dropout is being measured. Improved linkage between registration and intervention (and control) websites may reduce dropout between enrollment and accrual in future studies.

Limitations

This case study shares the experience of one trial in New Zealand. The available social media and populist platforms vary internationally and are sure to change over time. For the isafe study, while networking with community agencies was less valuable for recruitment, it was valuable in promoting referral links from the isafe program to services. Clarity of purpose for partnering with agencies and organizations will contribute to the efficiency and safety of the trial and its participants, as well as improve the overall trial quality and knowledge transfer.

In this case study, we collected significant standardized information on preintervention engagement with our Web-based study registration site. We do not know, however, the characteristics of people who visited the site, but dropped out prior to providing contact information. Nor do we know the reasons why people may have visited the site, such as for curiosity or help seeking, but disengaged.

In addition, the comparison of enrolled and accrued participant characteristics by referral type was based on participants' self-report. In contrast, our online marketplace (Trade Me) analysis of effect modelling was based on research staff attributing accrued participants to an ad during weekly recruitment reviews based on participant and ad location and timing. This process underestimated the number of participants recruited through Trade Me by 13. In addition, our assignment of deprivation is based on the address provided by the study participant. This likely includes error due to variation in socioeconomic status within neighborhoods, the housing instability of women who experience violence [54], and women electing to enter an address other than their own due to issues of privacy, safety, or mistrust.

Conclusions

Populist website recruitment methods can successfully recruit a diverse sample of participants for studies addressing sensitive topics such as violence against women. We hope our transparency in reporting preintervention participant engagement will influence others to do the same during this period of rapid growth in the number of eHealth intervention trials with automated Web-based registration. As suggested by van Gemert-Pijnen et al, "Now it is time to recapitulate the lessons learnt. We need a holistic approach to e-health development that is evidence-based and people-centred, that takes into account how people live within their own environments and that focuses on responding to stakeholders' needs and improving care" [55]. With sensitivity and research rigor, Web-based interventions have the potential to provide women a confidential, culturally appropriate, nonjudgmental resource to support their pursuit of safety and well-being.

Acknowledgments

We thank the women who participated in this study for going on this journey with us as we seek to be better helpers and develop better resources. We thank our community partners who provided affirmation that the work was important and to keep going. We acknowledge our international colleagues who have been generous in sharing their knowledge and wisdom in conducting Web-based research with women who experience abuse, in particular, Nancy Glass, Karen Eden, Amber Clough, Kelsey Hegarty, and Marilyn Ford-Gilboe. We also thank the Trade Me representatives who navigated us through the online marketing system opportunities. Finally, we owe a debt of gratitude to James Case, our lead software engineer. This study was funded by the New Zealand Health Research Council. They had no role in the review or approval of the manuscript for publication.

Conflicts of Interest

None declared.

References

1. World Health Organization. Global and Regional Estimates of Violence Against Women: Prevalence and Health Effects of Intimate Partner Violence and Non-Partner Sexual Violence. Geneva, Switzerland: World Health Organization; 2013.
2. Campbell JC. Health consequences of intimate partner violence. Lancet 2002 Apr 13;359(9314):1331-1336. [doi: 10.1016/S0140-6736(02)08336-8] [Medline: 11965295]
3. Ellsberg M, Arango D, Morton M, Gennari F, Kiplesund S, Contreras M, et al. Prevention of violence against women and girls: what does the evidence say? Lancet 2015 Apr 18;385(9977):1555-1566. [doi: 10.1016/S0140-6736(14)61703-7] [Medline: 25467575]
4. World Health Organization, London School of HygieneTropical Medicine. Preventing Intimate Partner and Sexual Violence Against Women: Taking Action and Generating Evidence. Geneva, Switzerland: World Health Organization; 2010.
5. United Nations Entity for Gender Equalitythe Empowerment of Women, World Health Organization, United Nations Population Fund, United Nations Development Programme, United Nations Office on Drugs and Crime. Essential Services Package for WomenGirls Subject to Violence. New York, NY: UN Women, WHO, UNFPA, UNDP, UNODC; 2015.
6. Stark E. Coercive Control: How Men Entrap Women in Personal Life. New York, NY: Oxford University Press; 2009.
7. Family Violence Death Review Committee. Fifth Report: January 2014 to December 2015. Wellington, NZ: New Zealand Health Quality & Safety Commission; 2016. URL: https://www.hqsc.govt.nz/assets/FVDRC/Publications/FVDRC-5th-report-Feb-2016.pdf [accessed 2016-10-20] [WebCite Cache ID 6lPl01eUM]
8. Crothers C, Smith P, Urale P, Bell A. The Internet in New Zealand. Auckland, NZ: Institute of Culture, Discourse & Communication, Auckland University of Technology; 2016. URL: http://www.aut.ac.nz/__data/assets/pdf_file/0003/635835/WIPNZ-Report-060515.pdf [accessed 2016-10-20] [WebCite Cache ID 6lPkrxzmk]
9. Dunahee M, Lebo H. The World Internet Project International Report, 6th edition. Los Angeles, CA: University of Southern California; 2016. URL: http://www.digitalcenter.org/wp-content/uploads/2013/06/2015-World-Internet-Report.pdf [accessed 2016-10-20] [WebCite Cache ID 6lPkl1lWz]
10. Hegarty K, Tarzia L, Murray E, Valpied J, Humphreys C, Taft A, et al. Protocol for a randomised controlled trial of a web-based healthy relationship tool and safety decision aid for women experiencing domestic violence (I-DECIDE). BMC Public Health 2015 Aug 01;15:736 [FREE Full text] [doi: 10.1186/s12889-015-2072-z] [Medline: 26231225]
11. Eden KB, Perrin NA, Hanson GC, Messing JT, Bloom TL, Campbell JC, et al. Use of online safety decision aid by abused women: effect on decisional conflict in a randomized controlled trial. Am J Prev Med 2015 Apr;48(4):372-383. [doi: 10.1016/j.amepre.2014.09.027]
12. Glass N, Eden KB, Bloom T, Perrin N. Computerized aid improves safety decision process for survivors of intimate partner violence. J Interpers Violence 2009 Dec 29;25(11):1947-1964. [doi: 10.1177/0886260509354508]
13. iCANPLan4Safety. London, ON: Western University; 2016. URL: http://icanplan4safety.ca [accessed 2016-08-19] [WebCite Cache ID 6jrkdECQc]
14. Young-Hauser AM, Eden KB, Wilson D, Koziol-Mclain J. Intimate partner violence: modifying an internet-based safety decision aid to a New Zealand context. J Technol Hum Serv 2014 Nov 26;32(4):297-311. [doi: 10.1080/15228835.2014.967905]
15. Koziol-McLain J, Vandal AC, Nada-Raja S, Wilson D, Glass NE, Eden KB, et al. A web-based intervention for abused women: the New Zealand isafe randomised controlled trial protocol. BMC Public Health 2015;15:56 [FREE Full text] [doi: 10.1186/s12889-015-1395-0] [Medline: 25637195]

16. Zakar R, Zakar MZ, Krämer A. Voices of strength and struggle: women's coping strategies against spousal violence in Pakistan. J Interpers Violence 2012 Nov;27(16):3268-3298. [doi: 10.1177/0886260512441257] [Medline: 22585115]
17. Merritt-Gray M, Wuest J. Counteracting abuse and breaking free: the process of leaving revealed through women's voices. Health Care Women Int 1995;16(5):399-412. [doi: 10.1080/07399339509516194] [Medline: 8576012]
18. Campbell J, Rose L, Kub J, Nedd D. Voices of strength and resistance: a contextual and longitudinal analysis of women’s responses to battering. J Interpers Violence 1998 Dec 01;13(6):743-762. [doi: 10.1177/088626098013006005]
19. Sylaska KM, Edwards KM. Disclosure of intimate partner violence to informal social support network members: a review of the literature. Trauma Violence Abuse 2014 Jan;15(1):3-21. [doi: 10.1177/1524838013496335] [Medline: 23887351]
20. Bibi S, Ashfaq S, Shaikh F, Qureshi PMA. Prevalenceinstigating factors and help seeking behavior of physical domestic violence among married women of HyderabadSindh. Pak J Med Sci 2014 Jan;30(1):122-125 [FREE Full text] [doi: 10.12669/pjms.301.4533] [Medline: 24639844]
21. Naved RT, Azim S, Bhuiya A, Persson LA. Physical violence by husbands: magnitude, disclosure and help-seeking behavior of women in Bangladesh. Soc Sci Med 2006 Jun;62(12):2917-2929. [doi: 10.1016/j.socscimed.2005.12.001] [Medline: 16426717]
22. Fanslow JL, Robinson EM. Help-seeking behaviors and reasons for help seeking reported by a representative sample of women victims of intimate partner violence in New Zealand. J Interpers Violence 2010 May;25(5):929-951. [doi: 10.1177/0886260509336963] [Medline: 19597160]
23. Evans M, Gregory A, Feder G, Howarth E, Hegarty K. “Even ‘daily’ is not enough”: how well do we measure domestic violence and abuse? A think-aloud study of a commonly used self-report scale. Violence Vict 2016;31(1):3-26. [doi: 10.1891/0886-6708.VV-D-15-00024] [Medline: 26645540]
24. Bullock L, Bloom T, Davis J, Kilburn E, Curry MA. Abuse disclosure in privately and medicaid-funded pregnant women. J Midwifery Womens Health 2006;51(5):361-369. [doi: 10.1016/j.jmwh.2006.02.012] [Medline: 16945784]
25. Othman S, Goddard C, Piterman L. Victims' barriers to discussing domestic violence in clinical consultations: a qualitative enquiry. J Interpers Violence 2014 May;29(8):1497-1513. [doi: 10.1177/0886260513507136] [Medline: 24323695]
26. Spangaro J, Koziol-McLain J, Zwi A, Rutherford A, Frail M, Ruane J. Deciding to tell: qualitative configurational analysis of decisions to disclose experience of intimate partner violence in antenatal care. Soc Sci Med 2016 Apr;154:45-53. [doi: 10.1016/j.socscimed.2016.02.032] [Medline: 26943013]
27. Petersen R, Moracco KE, Goldstein KM, Clark KA. Moving beyond disclosure: women's perspectives on barriers and motivators to seeking assistance for intimate partner violence. Women Health 2004;40(3):63-76. [Medline: 15829446]
28. Wilson D, Smith R, Tolmie J, de Haan I. Becoming better helpers: rethinking language to move beyond simplistic responses to women experiencing intimate partner violence. Policy Q 2015;11(1):25-31.
29. Stockman JK, Hayashi H, Campbell JC. Intimate partner violence and its health impact on ethnic minority women [corrected]. J Womens Health (Larchmt) 2015 Jan;24(1):62-79 [FREE Full text] [doi: 10.1089/jwh.2014.4879] [Medline: 25551432]
30. Spangaro J, Herring S, Koziol-Mclain J, Rutherford A, Frail M, Zwi AB. 'They aren't really black fellas but they are easy to talk to': factors which influence Australian Aboriginal women's decision to disclose intimate partner violence during pregnancy. Midwifery 2016 Aug 6;41:79-88. [doi: 10.1016/j.midw.2016.08.004] [Medline: 27551857]
31. Came H. Sites of institutional racism in public health policy making in New Zealand. Soc Sci Med 2014 Apr;106:214-220. [doi: 10.1016/j.socscimed.2014.01.055] [Medline: 24583568]
32. Dobbs T, Eruera M. Kaupapa Māori Wellbeing Framework: The Basis for Whānau Violence Prevention and Intervention. Auckland, New Zealand: New Zealand Family Violence Clearinghouse; 2014.
33. Dutton M, Holtzworth-Munroe A, Jouriles E, McDonald R, Krishnana S, McFarlane J. Recruitment and Retention in Intimate Partner Violence Research. Rockville, MD: U.S. Department of Justice; 2003.
34. Btoush R, Campbell JC. Ethical conduct in intimate partner violence research: challenges and strategies. Nurs Outlook 2009;57(4):210-216. [doi: 10.1016/j.outlook.2008.10.005] [Medline: 19631063]
35. Feather JS, Howson M, Ritchie L, Carter PD, Parry DT, Koziol-McLain J. Evaluation methods for assessing users’ psychological experiences of web-based psychosocial interventions: a systematic review. J Med Internet Res 2016;18(6):e181 [FREE Full text] [doi: 10.2196/jmir.5455] [Medline: 27363519]
36. Rivas C, Ramsay J, Sadowski L, Davidson LL, Dunne D, Eldridge S, et al. Advocacy interventions to reduce or eliminate violence and promote the physical and psychosocial well-being of women who experience intimate partner abuse. Cochrane Database Syst Rev 2015(12):CD005043. [doi: 10.1002/14651858.CD005043.pub3] [Medline: 26632986]
37. Gaglio B, Phillips SM, Heurtin-Roberts S, Sanchez MA, Glasgow RE. How pragmatic is it? Lessons learned using PRECIS and RE-AIM for determining pragmatic characteristics of research. Implement Sci 2014;9:96 [FREE Full text] [doi: 10.1186/s13012-014-0096-x] [Medline: 25163664]
38. Glasgow RE, Phillips SM, Sanchez MA. Implementation science approaches for integrating eHealth research into practice and policy. Int J Med Inform 2014 Jul;83(7):e1-11. [doi: 10.1016/j.ijmedinf.2013.07.002] [Medline: 23910896]
39. Eysenbach G, CONSORT-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of Web-based and mobile health interventions. J Med Internet Res 2011;13(4):e126 [FREE Full text] [doi: 10.2196/jmir.1923] [Medline: 22209829]

40. Lane TS, Armin J, Gordon JS. Online recruitment methods for web-based and mobile health studies: a review of the literature. J Med Internet Res 2015;17(7):e183 [FREE Full text] [doi: 10.2196/jmir.4359] [Medline: 26202991]
41. Melville KM, Casey LM, Kavanagh DJ. Dropout from Internet-based treatment for psychological disorders. Br J Clin Psychol 2010 Nov;49(Pt 4):455-471. [doi: 10.1348/014466509X472138] [Medline: 19799804]
42. Liese BS, Beck T. Back to basics: fundamental cognitive therapy skills for keeping drug-dependent individuals in treatment. NIDA Res Monogr 1997;165:207-232. [Medline: 9243552]
43. McCann SK, Campbell MK, Entwistle VA. Reasons for participating in randomised controlled trials: conditional altruism and considerations for self. Trials 2010;11:31 [FREE Full text] [doi: 10.1186/1745-6215-11-31] [Medline: 20307273]
44. isafe. Auckland, NZ: Auckland University of Technology; 2016. URL: https://www.isafe.aut.ac.nz/ [accessed 2016-08-19] [WebCite Cache ID 6jrlMduKK]
45. Yin RK. Case Study Research: Design and Methods. 5th edition. Thousand Oaks, CA: Sage; 2014.
46. Campbell JC, Webster DW, Glass N. The danger assessment: validation of a lethality risk assessment instrument for intimate partner femicide. J Interpers Violence 2009 Apr;24(4):653-674. [doi: 10.1177/0886260508317180] [Medline: 18667689]
47. Atkinson J, Salmond C, Crampton P. NZDep2013 Index of Deprivation. Wellington, NZ: Department of Public Health, University of Otago; 2014. URL: http://www.otago.ac.nz/wellington/otago069936.pdf [accessed 2016-10-20] [WebCite Cache ID 6lPl9eFB5]
48. Koyck L. Distributed Lags and Investment Analysis. Amsterdam: North-Holland; 1954.
49. McCann JM, Morey RC, Raturi AS. Confidence interval for the total advertising impact and its mean duration under Koyck models. J Acad Marketing Sci 1991 Sep;19(4):333-340. [doi: 10.1007/bf02726508]
50. Fournier DA, Skaug HJ, Ancheta J, Ianelli J, Magnusson A, Maunder MN, et al. AD Model Builder: using automatic differentiation for statistical inference of highly parameterized complex nonlinear models. Optimization Methods Software 2012 Apr;27(2):233-249. [doi: 10.1080/10556788.2011.597854]
51. Statistics New Zealand. NZ.Stat. 2016. URL: http://nzdotstat.stats.govt.nz/wbos/Index.aspx [accessed 2016-10-21] [WebCite Cache ID 6lQS6cCco]
52. Statistics New Zealand. 2013 Census QuickStats about Māori - Tables. Wellington, NZ: Statistics New Zealand; 2013. URL: http://www.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-about-maori-english.aspx [accessed 2016-10-20] [WebCite Cache ID 6lPmG0y15]
53. Loxton D, Powers J, Anderson AE, Townsend N, Harris ML, Tuckerman R, et al. Online and offline recruitment of young women for a longitudinal health survey: findings from the Australian Longitudinal Study on Women's Health 1989-95 cohort. J Med Internet Res 2015;17(5):e109 [FREE Full text] [doi: 10.2196/jmir.4261] [Medline: 25940876]
54. Rollins C, Glass NE, Perrin NA, Billhardt KA, Clough A, Barnes J, et al. Housing instability is as strong a predictor of poor health outcomes as level of danger in an abusive relationship: findings from the SHARE Study. J Interpers Violence 2012 Mar;27(4):623-643. [doi: 10.1177/0886260511423241] [Medline: 21987519]
55. van Gemert-Pijnen JE, Wynchank S, Covvey HD, Ossebaard HC. Improving the credibility of electronic health technologies. Bull World Health Organ 2012 May 1;90(5):323-33A [FREE Full text] [doi: 10.2471/BLT.11.099804] [Medline: 22589561]

Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
IPV: intimate partner violence
IRIS: Internet Resource for Intervention and Safety
RID: Recovery via Internet from Depression

Edited by G Eysenbach; submitted 24.08.16; peer-reviewed by A Taft, A Hattery; comments to author 12.10.16; revised version received 14.10.16; accepted 15.10.16; published 25.10.16.

Please cite as:
Koziol-McLain J, McLean C, Rohan M, Sisk R, Dobbs T, Nada-Raja S, Wilson D, Vandal AC
Participant Recruitment and Engagement in Automated eHealth Trial Registration: Challenges and Opportunities for Recruiting Women Who Experience Violence
J Med Internet Res 2016;18(10):e281
URL: https://www.jmir.org/2016/10/e281/
doi:10.2196/jmir.6515
PMID:27780796

Original Paper

Education-Based Gaps in eHealth: A Weighted Logistic Regression Approach

Laura Amo[1], MA, PhD

State University of New York at Buffalo, Buffalo, NY, United States

Corresponding Author:
Laura Amo, MA, PhD
State University of New York at Buffalo
259 Jacobs Hall
Buffalo, NY, 14260
United States
Phone: 1 716 645 5346
Email: lccasey@buffalo.edu

Abstract

Background: Persons with a college degree are more likely to engage in eHealth behaviors than persons without a college degree, compounding the health disadvantages of undereducated groups in the United States. However, the extent to which quality of recent eHealth experience reduces the education-based eHealth gap is unexplored.

Objective: The goal of this study was to examine how eHealth information search experience moderates the relationship between college education and eHealth behaviors.

Methods: Based on a nationally representative sample of adults who reported using the Internet to conduct the most recent health information search (n=1458), I evaluated eHealth search experience in relation to the likelihood of engaging in different eHealth behaviors. I examined whether Internet health information search experience reduces the eHealth behavior gaps among college-educated and noncollege-educated adults. Weighted logistic regression models were used to estimate the probability of different eHealth behaviors.

Results: College education was significantly positively related to the likelihood of 4 eHealth behaviors. In general, eHealth search experience was negatively associated with health care behaviors, health information-seeking behaviors, and user-generated or content sharing behaviors after accounting for other covariates. Whereas Internet health information search experience has narrowed the education gap in terms of likelihood of using email or Internet to communicate with a doctor or health care provider and likelihood of using a website to manage diet, weight, or health, it has widened the education gap in the instances of searching for health information for oneself, searching for health information for someone else, and downloading health information on a mobile device.

Conclusion: The relationship between college education and eHealth behaviors is moderated by Internet health information search experience in different ways depending on the type of eHealth behavior. After controlling for college education, it was found that persons who experienced more fruitful Internet health information searches are generally less likely to engage in eHealth behaviors.

(J Med Internet Res 2016;18(10):e267) doi:10.2196/jmir.5188

KEYWORDS

information storage and retrieval; eHealth; models, statistical

Introduction

People often turn to the Internet to obtain health-related information [1-4]. As of 2012, 72% of adult Internet users in the United States reported looking online for health-related information [5]. The term *eHealth* emerged in the early 2000s [6,7] with eHealth behaviors defined as online-mediated health self-management behaviors. There is extant research suggesting that eHealth behaviors can help people take better care of themselves and can lead to optimal health outcomes [8-10]. However, while more and more Americans are engaging in different eHealth behaviors, there is evidence of a digital divide across socioeconomic lines. Specifically, college-educated individuals have a higher likelihood of engaging in eHealth behaviors relative to individuals without a college education

[11,12]. Thus, the benefits associated with eHealth behaviors may be less accessible to persons without a college degree.

In order for eHealth behaviors to translate into positive health outcomes, a person must have the ability and motivation to (1) find information, (2) understand it, and (3) follow through with the appropriate behaviors. Information foraging [13] is a theory that can help explain how information is acquired; eHealth literacy [14] can be used to explain understanding and comprehension; and psychobehavioral models can be used to explain how information is processed, internalized, and translated into behavior.

Information foraging theory describes information retrieval in terms of cost and benefits [13] and has been used to understand health information-seeking behaviors [15]. Information foraging is based on information value, information patches, information scents, and information diet [16]. According to information foraging theory, foraging persists if information that is retrieved is useful and relevant [13], and an information search is maximized when multiple information sources are utilized, which is particularly pertinent in online environments where a multitude of information sources are readily available.

Information foraging for health information online is interconnected to eHealth literacy. Health literacy is defined as the ability to access and use information about health and medicine [17] to make choices about health care, prevention, and promotion [18,19,20]. More specifically, eHealth literacy is defined as “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem” [14,21]. Health literacy is related to health outcomes; individuals who are better able to understand and utilize health information tend to experience better health outcomes [22-27] and tend to have higher rates of insurance coverage [2]. However, while health literacy is strongly associated with health outcomes, a large number of Americans are at a disadvantage—as of 2001, it was estimated that about 30 million Americans have below basic health literacy [2].

Nevertheless, in order to develop literacy of any kind, information needs to be gathered first. Information foraging may be conceptualized as a prerequisite to developing literacy, including eHealth literacy, and thus cannot be overlooked when examining eHealth behaviors. However, information foraging has not received attention in the eHealth literature. In this paper, I focus on aspects of the information foraging process in predicting different eHealth behaviors. I examine how recent eHealth search experiences are associated with eHealth behaviors and explore whether the quality of recent eHealth search experiences reduces education-based gaps in eHealth behaviors.

> *Q1: Do recent eHealth search experiences relate to eHealth behaviors?*
>
> *Q2: Does eHealth search experience moderate the relationship between college education and eHealth behaviors?*

Among most of the existing research studies on eHealth, there are several limitations. First, there tends to be a lack of statistical rigor; with the exception of a few recent studies [11,28], research on eHealth behaviors tends to focus on prevalence (ie, percentage) as opposed to association with eHealth literacy. Causal models are optimal [29,30], and research that explores significant associations with eHealth behaviors and the relationships between health literacy and eHealth behaviors is also important [11]. Another limitation of existing eHealth studies is that researchers tend to assume homogeneity among all Internet users in regard to how the Internet is used for health information; in certain research studies [31,32], Internet users are compared with nonInternet users with the assumption that both groups are uniform. However, there is evidence of a digital divide that extends beyond Internet access [11,33]. The digital divide does not just pertain to access, but also for the purpose and utility of Internet use. Internet users may use the Internet in very different ways to manage health and search for health-related information. In this study, I examine the education-based digital divide by examining how college-educated Internet users differ from noncollege-educated Internet users in terms of eHealth experiences and behaviors.

Methods

Data

The data used in this study are from the Health Information National Trends Survey (HINTS) 4, Cycle 1 data collection in 2014 [34]. The HINTS uses a 2-stage stratified random sampling method. See HINTS manual for more information on stratification. In keeping with Kontos et al’s methods, the sample is composed of Internet users. To directly address the construct of eHealth literacy, a filter was also applied such that only persons who had used the Internet for the most recent search of health-related information (n=1458, after list-wise deletion).

Weighting

The final person weights were calculated in 4 steps: calculating household-level base weight, adjusting for household-level nonresponse, calculating person-level base weights, and calibrating person-level weights to population counts (or control totals). In order to address the nonindependence of observations and design effect, the final person weights were normalized. The final person weights were multiplied by the total number of observations in the analytic sample over the sum of the final person weights (See Figure 1).

Figure 1. Equation for normalized weight.

$$Normalized\ Weight = \frac{1}{p_i}\frac{n}{\sum w}$$

where $1/pi$ is the final person weight, n is the number of observations, and Σw is the sum of the final person weights.

Variables

Health: Self-reported rating of health based on a five-point scale where 1=*Poor* and 5=*Excellent*.

Age (years): The 4 age groups were *18-34* (reference), *35-49*, *50-64*, *65-74*, and *75 and older*. Each of the age groups was transformed into a dummy variable.

Salary: The 5 groups were below US $20000, US $20000-$34999, US $35000-$49999, US $50000-$749999, and US $75000 and over (reference).

Male: A dummy code where 1=*male* and 0=*female*.

Employed: A dummy code where 1=*employed* and 0=*unemployed*.

History of Cancer in Family: A dummy code was created where 1=*yes* and 0=*no*.

History of personal cancer in lifetime: A dummy code where 1=*yes* and 0=*no*.

Insurance coverage: A dummy code where 1=*yes* and 0=*no*.

USA birthplace: A dummy code where 1=*yes* and 0=*no*.

College degree: A dummy code indicating whether or not a respondent had a college degree or higher (0=*no*, 1=*yes*).

Some college: A dummy code indicating whether or not a respondent had attended but not completed college (0=*no*, 1=*yes*).

High school or below: A dummy code indicating whether or not a respondent had a high school degree or below (0=*no*, 1=*yes*).

Hispanic: A dummy code where 1=*yes* and 0=*no*.

Non-Hispanic black: A dummy code where 1=*yes* and 0=*no*.

Other race: A dummy code where 1=*yes* and 0=*no*.

Non-Hispanic white: A dummy code where 1=*yes* and 0=*no*. This variable was the reference category for race.

Married: A dummy code where 1=*yes* and 0=*no*. This served as a reference category for the single/divorced/widowed variable.

Single/Divorced/Widowed: A dummy code where 1=*yes* and 0=*no*.

Number of children in the household: The number of children aged 18 years old and younger who were living in the household at the time of survey administration.

Most recent check-up: Responses were captured as ordinal data where higher values indicated less recent visits. Specifically, 1=*Within the past year*, 2=*Within the past 2 years*, 3=*Within past 5 years*, 4=*5 or more years ago*, 5=*Don't know*, and 6=*Never*.

Frequency of doctor visits within 12 months: Responses were captured as ordinal data where 0=*None*, 1=*1 time*, 2=*2 times*, 3=*3 times*, 4=*4 times*, 5=*5 – 9 times*, and 6=*10 or more times*. This excluded emergency room (ER) visits.

Home ownership: A dummy code where 1=*yes* and 0=*no*.

Past experiences with eHealth: Participants had all used the Internet to perform the most recent search of health-related information. In relation to this search, participants were asked to rate the following statements on a five-point scale, where 1=*Strongly Agree* and 5=*Strongly Disagree*: "It took a lot of effort to get the information you needed," "You felt frustrated during your search for the information," "You were concerned about the quality of the information," and "The information you found was hard to understand." Estimates of internal reliability using Cronbach alpha=.862. Original scoring was retained such that higher scores reflected less effort, less frustration, less confusion, and less difficulty in understanding health-related information as retrieved from the Internet.

eHealth care behaviors: Indicated whether or not an individual had (1) bought medicine or vitamins online, (2) looked for a health care provider online, (3) tracked personal health information online, or (4) used email or the Internet to communicate with health care provider. Each of the 4 behaviors was coded such that 0=*no* and 1=*yes*.

eHealth information behaviors: Indicated whether or not an individual had (1) searched for health information for themselves, (2) searched for health information for someone else, (3) used a website to manage health or weight, or (4) downloaded health information to a mobile device. Each of the 4 behaviors was coded such that 0=*no* and 1=*yes*.

Social eHealth behaviors: Indicated whether or not an individual had (1) used a social networking site to read and share about medical issues, (2) wrote in an online diary or blog that was health-related, and (3) participated in an online support group. Each of the 3 behaviors was coded such that 0=*no* and 1=*yes*.

Analysis

The analysis consisted of 12 logistic regression models predicting each of the eHealth behaviors characterized by Kontos et al [11]. Logistic regression is a form of regression used when the outcome variable is dichotomous; in this analysis, each of the outcomes is binary where 0="No" and 1="Yes." Assumptions of normality are violated in this type of regression and the outcomes are therefore transformed using the logarithmic transformation [35,36]. Interactions between college education and health literacy were grand-mean centered to reduce multicollinearity [36]. This procedure consisted of finding the mean of both college education and health literacy, subtracting each value from the mean, then multiplying the 2 centered terms to produce a grand-mean centered interaction between college education and health literacy [36]. In addition to reporting the beta values, I also report the odds ratios for each term and the pseudo R^2 for each model. In logistic regression, the two pseudo- R^2 indices are Cox and Snell's R^2 and Nagelkerke's R^2 [37].

Results

eHealth Care Behaviors

Descriptive statistics for the sample are provided in Table 1, and results from the logistic regressions are provided in Multimedia Appendices 1–3. Internet users were engaged in eHealth care behaviors at a moderate rate: 325 of 1585 Internet users (about 20%) bought medicine or vitamins online; 223 of 1585 (about 14%) looked for health care providers online; 1093 of 1584 (about 69%) tracked personal health information; and 767 of 1585 (about 48%) used email or the Internet to communicate with a doctor or health care provider.

Consistent with prior research, college education was significantly positively related to some of the eHealth care behaviors. Compared with persons who had completed high school or less, persons who had at least a 4-year college degree had significantly higher likelihood of looking for health care providers (beta=.783, *P*=.001) and using email or the Internet to communicate with the doctor (beta=.403, *P*=.006). College education did not have a significant association with likelihood of buying medicine or vitamins online (beta=.181, *P*=.37) or tracking personal health information (beta=.138, *P*=.40).

The relationship between eHealth information search experience and health care behaviors was mostly negative (see Multimedia Appendix 1). Specifically, eHealth information search experience was significantly negatively related to likelihood of buying medicine or vitamins online (beta=-.196, *P*=.04) and tracking personal health information (beta=-.98, *P*=.02). In other words, persons who had more positive and less frustrating past experiences with eHealth information hunting were significantly less likely to use the Internet to buy medicine or vitamins online and to track personal health information online. While eHealth information search experience was negatively related to the likelihood of looking online for health care providers (beta=-.20, *P*=.08), the relationship was not statistically significant with alpha=.05; the quality of previous eHealth information search experiences was not associated with the likelihood of using email or Internet to communicate with a doctor (beta=.011, *P*=.89). In terms of change in odds ratios [35,37], a one standard deviation increase in quality of eHealth information search experience was associated with a .822 decrease in the odds of buying medicine or vitamins online, a .816 decrease in the odds of looking for health care providers, and a .82 decrease in the odds of tracking personal health information.

The quality of eHealth information search experience did not significantly alter the college gap in terms of likelihood of buying medicine or vitamins online (beta=.136, *P*=.46), looking for health care providers (beta=-0.095, *P*=.66), and tracking personal health information (beta=0.290, *P*=.07). However, the quality of eHealth information search experience did significantly reduce the education gap in terms of likelihood to use email or the Internet to communicate with the doctor or health care provider (beta=-.416, *P*=.006). As shown in Multimedia Appendix 1, the full models accounted for between 9-14% of the variance in the likelihood of buying medicine or vitamins online, between 8-15% of the variance in the likelihood of looking for health care providers, between 5-7% of the variance in the likelihood of tracking personal health information online, and between 9-12% of the variance in the likelihood of using email or the Internet to communicate with the doctor.

eHealth Information Behaviors

Internet users also used the Internet to engage in eHealth information behaviors. Of 1818 Internet users, 1632 (nearly 90%) indicated using the Internet to search for health information for himself or herself; 189 of 1568 Internet users (about 12%) used the Internet to search for health information for someone else; 715 of 1580 (about 45%) used the Internet to access websites to assist with managing diet, weight, or health; and 269 of 1586 (about 15%) downloaded health-related information to a mobile device.

College education was significantly positively related to one health information behavior. Compared with persons who had completed high school or less, persons who had at least a 4-year college degree had significantly higher likelihood of looking for health information for another person (beta=1.125, *P*≤.001). College education was not, however, significantly related to the likelihood of searching for health information for self (beta=.336, *P*=.23), using a website to help with diet, health, or weight (beta=.356, *P*=.006), or to the likelihood of downloading health information to a mobile device (beta=-.143, *P*=.51).

The relationship between eHealth information search experience and health care behaviors was mostly negative. Specifically, more positive eHealth information search experiences were negatively related to likelihood of searching for health information for self (beta=-.288, *P*=.07), looking for health information for another person (beta=-.441, *P*≤.001), and downloading health information to a mobile device (beta=-.033 *P*=.75). The quality of previous eHealth information search experience was positively related to the likelihood of using a website to help with diet, health, or weight (beta=.249, *P*=.1), but the relationship was not statistically significant.

The quality of eHealth information search experience significantly reduced the college gap in terms of using a website to help with diet, weight, or health (beta=-.401, *P*=.009). In other words, persons with a college degree were more likely to use a website to help with diet, weight, or health. If previous eHealth information search experiences had been more positive and less frustrating, the gap between college-educated and noncollege-educated Internet users was significantly reduced.

Interestingly, as opposed to reducing the education-based gap, the quality of eHealth information search experience exacerbated the gap in terms of likelihood of searching for health information for self (beta=.102, *P*=.02), searching for health information for another person (beta=.761, *P*=.001), and downloading health information to a mobile device (beta=.421, *P*=.045). As shown in Multimedia Appendix 2, the full models accounted for (1) between 6-14% of the variance in the likelihood of using the Internet to search for health information for self, (2) between 6-11% of the variance in the likelihood of using the Internet to search for health information for another person, (3) between 9-13% of the variance in the likelihood of using a website to help with diet, health, or weight, and (4) between 8-13% of the variance in the likelihood of downloading health information to a mobile device.

Table 1. Descriptive statistics on Internet users (n=2056).

Variables	n	Min	Max	Mean	SD
Health	1819	1	5	3.603	0.907
Age (years)					
18-34 (reference)	1827	0	1	0.356	0.479
35-49	1827	0	1	0.315	0.465
50-64	1827	0	1	0.251	0.434
65-74	1827	0	1	0.053	0.223
≥75	1827	0	1	0.017	0.129
Salary (US $)					
<20000	1827	0	1	0.164	0.371
20000 – 34999	1827	0	1	0.131	0.337
35000 – 49999	1827	0	1	0.104	0.306
50000 – 74999	1827	0	1	0.179	0.383
75000 + (reference)	1827	0	1	0.352	0.478
Male	1805	0	1	0.453	0.498
Employed	1827	0	1	0.631	0.483
History of cancer in family	1827	0	1	0.648	0.478
History of cancer in self	1827	0	1	0.057	0.232
Insurance	1827	0	1	0.806	0.395
Born in United States	1827	0	1	0.886	0.318
Education					
High school or below	1827	0	1	0.213	0.410
Some college	1827	0	1	0.328	0.470
College or more	1827	0	1	0.447	0.497
Race or ethnicity					
Hispanic	1827	0	1	0.113	0.317
Non-Hispanic black	1827	0	1	0.088	0.283
Other race	1827	0	1	0.708	0.455
Non-Hispanic white (reference)	1827	0	1	0.066	0.248
Marital status					
Married or living as married	1827	0	1	0.566	0.496
Single divorced, widowed, or separated	1827	0	1	0.419	0.494
Number of children	1777	0	9	0.643	1.036
Most recent check-up	1811	1	6	1.932	1.333
Frequency doctor visit in 12 months	1819	0	6	2.410	1.880
eHealth search experience	1812	−2.36	1.36	−0.034	0.960
Home-owner	1807	0	1	0.610	0.488
Health information for self	1818	0	1	0.898	0.303
Bought medicine or vitamins online	1585	0	1	0.205	0.404
Online support group	1592	0	1	0.055	0.228
Email or Internet to communicate with doctor	1585	0	1	0.484	0.500

Variables	n	Min	Max	Mean	SD
Website to help with diet, weight, or physical health	1580	0	1	0.453	0.498
Looked for health care provider	1586	0	1	0.141	0.348
Download health related information to mobile device	1586	0	1	0.170	0.375
Social networking site to read and share about medical	1591	0	1	0.039	0.194
Wrote an health-related online diary or blog	1585	0	1	0.206	0.404
Kept track of personal information	1584	0	1	0.690	0.463
Health information for someone else	1568	0	1	0.120	0.325
Valid N (list-wise)	1458				

Social eHealth Care Behaviors

According to the results, Internet users demonstrated less use of Internet for social eHealth care behaviors, relative to the other eHealth behaviors. Only 62 of 1591 Internet users (about 4%) indicated using the Internet to participate in a social networking group for health-related reasons; 326 of 1585 (about 21%) indicated writing in an online blog that was health-related; and 88of 1592 (about 6%) participated in an online support group for health-related purposes.

College education was significantly positively related to one of the social health behaviors. Compared with persons who had completed high school or less, persons who had at least a 4-year college degree had significantly higher likelihood of writing in an online diary or participate in a health-related blog (beta=.783, *P*≤.001); people with at least a college degree were twice as likely to engage in this social health care behavior. There was no education gap in terms of the likelihood of using a social networking site to read and share medical-related information (beta=.171, *P*=.71) or participating in an online support group (beta=-.118, *P*=.75).

The relationship between the quality of eHealth information search experience and social health behaviors was all negative, but not statistically significant. Specifically, the quality of eHealth information search experience was negatively related to the likelihood of using a social networking site to read and share medical-related information (beta=-.187, *P*=.36) and participating in an online support group (beta=-.047, *P*=.64), and with the likelihood of writing in an online diary or participating in a health-related blog (beta=-.247, *P*=.14).

The quality of eHealth information search experience did not significantly alter the college gap in terms of likelihood of using a social networking site to read and share medical-related information (beta=-.47, *P*=.25), writing in an online diary or participating in a health-related blog (beta=-.079, *P*=.68), and participating in an online support group (beta=-.404, *P*=.23). As shown in Multimedia Appendix 3, the full models accounted for between 6-22% of the variance in likelihood of using a social networking site to read and share medical information, between 10-17% of the variance in the likelihood of writing in an online diary or participating in a health-related blog, and between 6-19% of the variance in the likelihood of participating in an online support group.

Discussion

Principal Findings

Health self-management is a major objective for new health care models such as the Chronic Care model [38]. Ideally, technology will improve decision making surrounding health care and medicine and allow traditionally vulnerable populations to be better informed. However, findings from this study confirm that there are persistent gaps in eHealth behaviors across educational lines. Among people who used the Internet as primary means for searching health-related information, those with at least a 4-year college degree were significantly more likely to engage in at least four of the eHealth behaviors explored in this study (ie, looking for a health care provider, using email or the Internet to communicate with a doctor, searching for health information for someone else, and writing in an online diary or blog for health-related reasons).

Beyond these persistent educational gaps in eHealth behaviors, findings from this study suggest that at least in some instances, these educational gaps are exacerbated when considering how persons feel and react to recent eHealth search experiences. This may mean that college education is not necessarily directly related to eHealth behaviors yet obtaining a college education may provide the ancillary benefit of making persons “better” foragers of eHealth information. In short, there appears to be a complex relationship between college education, eHealth experiences, and eHealth behaviors where additional statistical mediators and moderators are important to probe in future research. Indeed, the quality of recent eHealth experiences was significantly negatively associated with the likelihood of engaging in at least nine of the twelve eHealth behaviors investigated herein. This finding is, at first, quite troubling. However, it makes sense that if a person experiences a high-quality information search and obtains adequate information during the information foraging process, then perhaps certain eHealth behaviors are therefore not necessary.

In 2 instances, quality of recent eHealth information search experience reduced the education-based gap; eHealth search experience reduced the gap between college-educated and noncollege-educated persons in terms of the likelihood of using email or the Internet to communicate with a doctor or physician and use of website to manage diet, weight, or health. The negative moderating effect of eHealth search experience on the education-based gap in using email or the Internet to communicate with the doctor or health care provider may be related to the ways in which health care is being managed on the provider's end. Currently, there is a trend for doctors and health care providers to use technology for record keeping, appointment making, and patient requests. Another potential explanation is that patients, regardless of college education, find communication via technology to be more convenient and cost saving (ie, not having to go visit the doctor in person).

The other moderating negative effect of eHealth literacy was with regard to use of website to manage diet, weight, or health; persons without a college degree who have higher eHealth literacy are more likely to use a website to manage diet, weight, or health. Overall, this eHealth behavior was fairly prevalent (about 45% of the sample engaged in this behavior) among persons without a college degree who engaged in this behavior, regardless of eHealth literacy.

Limitations

There were a number of limitations to this study. First, the data are cross-sectional and longitudinal analysis could not be performed. Design of the study is such that casual inference cannot be made. Second, the data are secondary, meaning that omitted variable bias is also an issue. There is no way to control for information that was not included in the primary data collection, such as quality of primary health provider (eg, board certification, quality of education, year MD received), and these types of characteristics are very likely to make a difference in the relationships that were studied.

Despite these limitations, the findings from this study open the door to other questions that need to be explored in the eHealth landscape. There are other sociodemographic variables that need to be addressed in relation to eHealth behaviors, for example, while education-based gaps in eHealth behaviors may not be reduced by quality of recent eHealth search experience as measured herein, racial-based gaps should also be investigated. If persons from a certain social or economic background experience eHealth information searches differently than other groups, this is an important issue to consider. Perhaps most importantly, there is also a need to evaluate temporal models that explore how eHealth search experience and eHealth literacy are associated with different types of eHealth behaviors and how these eHealth behaviors subsequently impact health outcomes; if eHealth behaviors fail to positively relate to health outcomes after controlling for other covariates in the model, eHealth discrepancies between socioeconomic and racial groups may not be problematic. Assuming that eHealth behaviors indeed make a difference and can be influenced by variables amenable to intervention such as eHealth search experience and literacy, future studies should also consider the role of specific types of websites (eg, design, interface, services) that are most commonly used for eHealth behaviors.

Conclusion

eHealth is a promising new frontier in health access and care. However, as findings from this study show, there are socioeconomic gaps in eHealth behaviors that may not be easily addressed. Moreover, the quality of eHealth information search experiences may serve to reduce the likelihood of eHealth behaviors. Existing research into eHealth tends to assume that eHealth behaviors are a "good outcome," and that persons who are not engaging in eHealth behaviors are at a disadvantage. However, this assumption may not be correct. Persons who are not engaging in eHealth behaviors may not have to because of (1) better health, (2) access to other health alternatives or resources that have not been identified in the research, or (3) because previous eHealth information searches were successful and questions were answered. Moving forward, researchers and policy-makers will be better served by framing eHealth behaviors as component to a much larger, extremely complex web of behavior, cognition, social influence, and future health outcomes as opposed to an absolute positive outcome directly related to optimal health for all.

Conflicts of Interest

None declared.

Multimedia Appendix 1

eHealth information search experience and college education: health care behaviors.

[PDF File (Adobe PDF File), 26KB - jmir_v18i10e267_app1.pdf]

Multimedia Appendix 2

eHealth information search experience and college education: health information behaviors.

[PDF File (Adobe PDF File), 26KB - jmir_v18i10e267_app2.pdf]

Multimedia Appendix 3

eHealth information search experience and college education: social health behaviors.

[PDF File (Adobe PDF File), 25KB - jmir_v18i10e267_app3.pdf]

References

1. Hsu W, Chiang C, Yang S. J Med Internet Res. 2014. The Effect of Individual Factors on Health Behaviors Among College Students: The Mediating Effects of eHealth Literacy URL: http://doi.org/10.2196/jmir.3542 [accessed 2016-01-10] [WebCite Cache ID 6kQOJhH9F] [Medline: 25499086]
2. Baker DW, Gazmararian JA, Williams MV, Scott T, Parker RM, Green D, et al. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. Am J Public Health 2002 Aug;92(8):1278-1283. [Medline: 12144984]
3. Licciardone JC, Smith-Barbaro P, Coleridge ST. Use of the Internet as a resources for consumer health information: Results of the Second Osteopathic Survey of Health Care in America (OSTEOSURV-II). J Med Internet Res 2001;3(4):31. [doi: 10.2196/jmir.3.4.e31] [Medline: 11772546]
4. Houston TK, Allison JJ. Users of internet health information: Differences by health status. J Med Internet Res . DOI 10.2196/jmir.4.2.e 2002;4(2):e7. [doi: 10.2196/jmir.4.2.e7]
5. Pew Research Center. pewinternet. 2015. Health Fact Sheet URL: http://www.pewinternet.org/fact-sheets/health-fact-sheet/ [accessed 2016-09-10] [WebCite Cache ID 6kQkxk7Hi]
6. Eng T. The ehealth landscape: a terrain map of emerging information and communication technologies in health and health care. Princeton, NJ: Robert Wood Johnson Foundation; 2001.
7. Eysenbach G. What is e-health? J Med Internet Res 2001;3(2):E20 [FREE Full text] [doi: 10.2196/jmir.3.2.e20] [Medline: 11720962]
8. Bianco A, Zucco R, Nobile CG, Pileggi C, Pavia M. Parents seeking health-related information on the Internet: cross-sectional study. J Med Internet Res 2013 Sep;15(9):e204 [FREE Full text] [doi: 10.2196/jmir.2752] [Medline: 24047937]
9. Agency for Healthcare Research Quality. ahrq. 2014. Health Literacy Interventions and Outcomes: An Updated Systematic Review URL: http://archive.ahrq.gov/research/findings/evidence-based-reports/er199-abstract.html [accessed 2015-06-10] [WebCite Cache ID 6kQlXi74E]
10. Lambert SD, Loiselle CG. Health information seeking behavior. Qual Health Res 2007 Oct;17(8):1006-1019. [doi: 10.1177/1049732307305199] [Medline: 17928475]
11. Kontos E, Blake KD, Chou WY, Prestin A. Predictors of eHealth Usage: Insights on the digital divide from the Health Information National Trends Survey 2012. J Med Internet Res 2014;16(7):e172 [FREE Full text] [doi: 10.2196/jmir.3117] [Medline: 25048379]
12. Diaz JA, Griffith RA, Ng JJ, Reinert SE, Friedmann PD, Moulton AW. Patients' use of the internet for medical information. J Gen Intern Med 2002 Mar;17(3):180-185. [doi: 10.1046/j.1525-1497.2002.10603.x]
13. Pirolli P, Card SK. Information foraging. Psychological Review 1999;106(4):643-675 [FREE Full text]
14. Norman CD, Skinner HA. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res 2006 Jun;8(2):e9 [FREE Full text] [doi: 10.2196/jmir.8.2.e9] [Medline: 16867972]
15. Xiao N, Sharman R, Rao H, Upadhyaya S. Factors influencing online health information search: An empirical analysis of a national cancer-related survey. Decision Support Systems 2014 Jan;57:417-427. [doi: 10.1016/j.dss.2012.10.047]
16. Trepess D. interaction-design. 2016. Information foraging theory URL: https://www.interaction-design.org/literature/book/the-glossary-of-human-computer-interaction/information-foraging-theory [accessed 2016-09-10] [WebCite Cache ID 6kQmMsKVV]
17. McCray AT. Promoting health literacy. J Am Med Inform Assoc 2005;12(2):152-163 [FREE Full text] [doi: 10.1197/jamia.M1687] [Medline: 15561782]
18. World Health Organization. World Health Organization. 2013. Health literacy: The solid facts URL: http://www.euro.who.int/__data/assets/pdf_file/0008/190655/e96854.pdf [accessed 2016-09-10] [WebCite Cache ID 6kQmfJzHt]
19. Berkman ND, Davis TC, McCormack L. Health literacy: What is it? Journal of Health Communication: International Perspectives 2010;15(2):9-19. [doi: 10.1080/1081073.2010.499985] [Medline: 20845189]
20. Ratzan SC, Parker RM. Introduction. In: Selden CR, Zorn M, Ratzan SC, Parker RM, editors. National Library of Medicine Current Bibliographies in Medicine: Health Literacy. Bethesda, MD: National Institutes of Health, US Department of Health and Human Services; 2000.
21. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. J Med Internet Res 2006 Nov;8(4):e27 [FREE Full text] [doi: 10.2196/jmir.8.4.e27] [Medline: 17213046]
22. Scott TL, Gazmararian JA, Williams MV, Baker DW. Health literacy and preventive health care use among Medicare enrollees in a managed care organization. Med Care 2002 May;40(5):395-404. [Medline: 11961474]
23. Williams MV, Baker DW, Parker RM, Nurss JR. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. Arch Intern Med 1998 Jan 26;158(2):166-172. [Medline: 9448555]
24. Schillinger D, Grumbach K, Piette J, Wang F, Osmond D, Daher C, et al. Association of health literacy with diabetes outcomes. JAMA 2002;288(4):475-482. [Medline: 12132978]

25. Schillinger D, Piette J, Grumbach K, Wang F, Wilson C, Daher C, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. Arch Intern Med 2003 Jan 13;163(1):83-90. [Medline: 12523921]
26. Baker DW, Parker RM, Williams MV, Clark WS, Nurss J. The relationship of patient reading ability to self-reported health and use of health services. Am J Public Health 1997 Jun;87(6):1027-1030. [Medline: 9224190]
27. Baker DW, Parker RM, Williams MV, Clark WS. Health literacy and the risk of hospital admission. J Gen Intern Med 1998 Dec;13(12):791-798 [FREE Full text] [Medline: 9844076]
28. Mitsutake S, Shibata A, Ishii K, Oka K. Associations of eHealth Literacy With Health Behavior Among Adult Internet Users. J Med Internet Res 2016;18(7):e192 [FREE Full text] [doi: 10.2196/jmir.5413] [Medline: 27432783]
29. Nielsen-Bohlman L, Panzer AM, Kindig DA. Washington, DC: National Academies Press; 2004. Health Literacy: A Prescription to End Confusion URL: https://www.nap.edu/read/10883/chapter/1 [accessed 2015-06-01] [WebCite Cache ID 6kQoYAXC6]
30. Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs AMA. Report of the Council on Scientific Affairs. Journal of American Medical Association 1999;281(6):552-557.
31. Fox S. Pew Internet.: Pew Research Center; 2006 Oct 29. Online Health Search 2006 URL: http://www.pewinternet.org/2006/10/29/online-health-search-2006/ [accessed 2016-09-10] [WebCite Cache ID 6kQpLvndO]
32. Zillien N, Hargittai E. Digital Distinction: Status-Specific Types of Internet Usage. Social Science Quarterly 2009 Apr 13;90(2):274-291. [doi: 10.1111/j.1540-6237.2009.00617.x]
33. Sarkar U, Karter AJ, Liu JY, Adler NE, Nguyen R, López A, et al. Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. J Am Med Inform Assoc 2011 May 1;18(3):318-321 [FREE Full text] [doi: 10.1136/jamia.2010.006015] [Medline: 21262921]
34. Nelson DE, Kreps GL, Hesse BW, Croyle RT, Willis G, Arora NK, et al. The Health Information National Trends Survey (HINTS): development, design, and dissemination. J Health Commun 2004;9(5):443-60; discussion 81. [doi: 10.1080/10810730490504233] [Medline: 15513791]
35. Berry W, Feldman S. Multiple regression in practice. In: University Paper Series on Quantitative Approaches in Social Sciences. Beverly Hills, CA: Sage Publications; 1985.
36. Aiken L, West SG. MultipleRegression: Testing and Interpreting Interactions. Newbury Park, CA: Sage Publications; 1991.
37. Field A. Discovering Statistics Using SPSS. Second edition. London: Sage Publications; 2001.
38. Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? Eff Clin Pract 1998;1(1):2-4. [Medline: 10345255]

Edited by G Eysenbach; submitted 30.09.15; peer-reviewed by J Ancker, J Huh; comments to author 22.11.15; revised version received 05.01.16; accepted 26.08.16; published 12.10.16.

Please cite as:
Amo L
Education-Based Gaps in eHealth: A Weighted Logistic Regression Approach
J Med Internet Res 2016;18(10):e267
URL: http://www.jmir.org/2016/10/e267/
doi:10.2196/jmir.5188
PMID:27733329

Original Paper

The Effectiveness of Lower-Limb Wearable Technology for Improving Activity and Participation in Adult Stroke Survivors: A Systematic Review

Lauren Powell[1], BSc (Hons), MSc; Jack Parker[1], BSc (Hons), PhD; Marrissa Martyn St-James[1], BSc (Hons), MSc, PhD; Susan Mawson[1], BSc (Hons), MCSP, PhD

School of Health and Related Research (ScHARR), University of Sheffield, Sheffield, United Kingdom

Corresponding Author:
Lauren Powell, BSc (Hons), MSc
School of Health and Related Research (ScHARR)
University of Sheffield
Regent Court, 30 Regent Street
Sheffield, S14DA
United Kingdom
Phone: 44 1142228275
Fax: 44 1142220749
Email: l.a.powell@sheffield.ac.uk

Abstract

Background: With advances in technology, the adoption of wearable devices has become a viable adjunct in poststroke rehabilitation. Regaining ambulation is a top priority for an increasing number of stroke survivors. However, despite an increase in research exploring these devices for lower limb rehabilitation, little is known of the effectiveness.

Objective: This review aims to assess the effectiveness of lower limb wearable technology for improving activity and participation in adult stroke survivors.

Methods: Randomized controlled trials (RCTs) of lower limb wearable technology for poststroke rehabilitation were included. Primary outcome measures were validated measures of activity and participation as defined by the International Classification of Functioning, Disability and Health. Databases searched were MEDLINE, Web of Science (Core collection), CINAHL, and the Cochrane Library. The Cochrane Risk of Bias Tool was used to assess the methodological quality of the RCTs.

Results: In the review, we included 11 RCTs with collectively 550 participants at baseline and 474 participants at final follow-up including control groups and participants post stroke. Participants' stroke type and severity varied. Only one study found significant between-group differences for systems functioning and activity. Across the included RCTs, the lowest number of participants was 12 and the highest was 151 with a mean of 49 participants. The lowest number of participants to drop out of an RCT was zero in two of the studies and 19 in one study. Significant between-group differences were found across three of the 11 included trials. Out of the activity and participation measures alone, P values ranged from P=.87 to $P \leq$.001.

Conclusions: This review has highlighted a number of reasons for insignificant findings in this area including low sample sizes, appropriateness of the RCT methodology for complex interventions, a lack of appropriate analysis of outcome data, and participant stroke severity.

(J Med Internet Res 2016;18(10):e259) doi:10.2196/jmir.5891

KEYWORDS

wearable technology; stroke; gait; rehabilitation

Introduction

The worldwide incidence of stroke is set to escalate from 15.3 million to 23 million by 2030 [1]. In the United Kingdom, strokes are the largest single cause of disability [2] resulting in a cost to the economy of £8.9 billion a year [3]. It is estimated that following a stroke, only 15% will gain complete functional recovery for both the upper and lower extremities [4] with walking and mobility being key issues for many stroke survivors who report the importance of regaining mobility [5]. However, with the ever-increasing financial challenges facing the National

Health Service (NHS), service needs cannot be met. Therefore, utilizing information and communication technology together with the implementation of well-evidenced medical technologies is essential for continued rehabilitation for stroke survivors.

The adoption of technological solutions can facilitate patient and caregiver empowerment and a paradigm shift in control and decision making to that of a shared responsibility and self-management [6]. It also has the potential to reduce the administrative burden for care professionals and support the development of new interventions [7]. Incorporating technology into the daily lives of stroke survivors is a key objective in safeguarding a better quality of life for them.

Evidence exists supporting the need for intensity and repetition of motor skills in order to promote neuroplasticity and motor relearning [8]. A number of technological aids with a potential to enhance poststroke motor recovery has been explored [9]. However, many include the use of expensive, large, complex, cumbersome apparatus that necessitates the therapist to be present during use [10]. Therefore inexpensive, externally wearable, commercially available sensors have become a more viable option for independent home-based poststroke rehabilitation [11].

Recent systematic and non-systematic reviews highlight the growing use of externally wearable devices to augment poststroke rehabilitation in both clinical and non-clinical settings for motion analysis and physical activity monitoring [12-15]. These include microelectromechanical systems containing accelerometers, gyroscopes, and magnetometers; fabric and body-worn sensor networks [16]; and physiological monitoring such as blood pressure and oxygen saturation [17,18]. Other wearable devices specifically designed and used for poststroke rehabilitation also include robotics [19], virtual reality [20], Functional Electrical Stimulation (FES) [21], electromyographic biofeedback (EMG-BFB) [22], and Transcutaneous Electrical Nerve Stimulation (TENS) [23,24].

However, while these devices have the potential to reliably measure duration, frequency, intensity, and quality of activity and movement, all of which are key variables for poststroke recovery [8], no reviews have synthesized the effectiveness of these devices for poststroke lower-limb rehabilitation.

The International Classification of Functioning, Disability and Health (ICF) [25] considers the interaction between pathology (body structure and function), impairment (signs and symptoms), activities (functionality), and participation (social integration) and has now become the main conceptual framework for poststroke rehabilitation [26-28]. For this review, we focused on the activities and participation domain of the ICF as this would provide an indication of how the interventions have or have not led to functional gains in everyday life, which is the rehabilitation goal for both clinicians and stroke survivors [28].

Therefore, the aim of this review was to examine how effective external wearable devices are as interventions for improving function of the lower limb in adult stroke survivors.

Methods

The review protocol was registered on PROSPERO (CRD42015020544). The review was undertaken in accordance with the general principles recommended in the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) [29].

Search Methods

The following databases were searched from inception to March 2016: MEDLINE, Web of Science (Core collection), CINAHL, and the Cochrane Library. Medical Subject Headings (MeSH) keywords used were cerebrovascular disorders, hemorrhage, cerebral hemorrhage, self-help devices, telemedicine, physical therapy modalities, physical and rehabilitation medicine, exercise, exercise therapy, exercise movement techniques, self-evaluation programs, sensory feedback, motor skills, gait disorders, neurologic, gait apraxia, and gait ataxia. Text terms used were stroke, technology, physiotherapy, lower limb, rehabilitation, and gait. These were combined with text term synonyms: cerebrovascular accident (CVA), poststroke, cerebrovascular, brain ischemia, IT (information technology), ICT (information and communications technology), assistive technology, telehealth, telecare, telerehabilitation, physical therapy, physiatric, exercise, lower extremity, lower limb, ambulant, walk, locomotion, mobile, move, motion, biofeedback, sensory feedback, advise, result, evaluation, observe, assess, inform, train, therapy, treat, motor skills, motor re-learn, re-educate, re-learn, recovery enhance, promote, support, function, activity, physical, ambulant, and walking. Terms were combined using Boolean logic (“AND”, “OR”). MeSH are specific recognized terms used for the purpose of indexing journal articles and books in electronic databases. Free text terms and synonyms are specific words that the search strategy looks for in the title and abstract.

A copy of the MEDLINE search strategy is presented in Multimedia Appendix 1. Electronic citations were downloaded to Endnote software. The inclusion criteria are described in Table 1.

Table 1. Inclusion and exclusion criteria for this review.

Inclusion criteria	Exclusion criteria
English language articles	Studies including upper limb
Studies recruiting people over the age of 18 years	Studies where the intervention is not clearly defined
Studies evaluating lower-limb and wearable technology	Studies not using one of the chosen 11 outcome measures (see Outcome measurement/assessment below)
Studies reporting an RCT[a]	Studies not reporting an RCT[a]
Studies measuring activity and participation as classified by the World Health Organization ICF[b]	Studies not measuring activity and participation as classified by the World Health Organization ICF[b]

[a] RCT: randomized controlled trial.

[b] ICF: International Classification of Functioning, Disability and Health.

As this is a review of effectiveness, RCTs were chosen as the appropriate study design to answer the research question. Inclusion of non-RCT evidence is outside the scope of this review.

Comparators could be exercise/physical therapy, sham stimulation, conventional gait therapy, or treatment as usual. The primary outcome for this review was changes in activity and participation assessed by any of the following methods: the Rivermead Mobility Index, the Barthel Index, the Berg Balance Scale, the Six Minute Walk Test, the Functional Ambulatory Category, the Timed Up and Go test, the Motricity Index, the Stroke Self-Efficacy Scale, and the Performance-Oriented Mobility Assessment.

Quality Assessment

Methodological quality of included RCTs was assessed using the Cochrane Collaboration risk of bias assessment criteria [30]. This tool addresses specific domains, namely, sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, and selective outcome reporting. For the selective reporting domain, a proxy judgement was made that if a trial reported that a study protocol had been approved and the trial report described primary and secondary outcomes with results, then the trial could be considered at low risk of selective reporting bias. We classified RCTs as being at overall low risk of bias if they were rated as “low” for each of three key domains: (1) allocation concealment [31], (2) blinding of outcome assessment, and (3) completeness of outcome data. RCTs judged as being at high risk of bias for any of these domains were judged at overall high risk. Similarly, RCTs judged as being at unclear risk of bias for any of these domains were judged at overall unclear risk.

Data Extraction

Retrieved titles, abstracts, and/or papers were screened independently by 2 review authors (LAP, JP) to identify studies that met the inclusion criteria. Disagreements were resolved between reviewers through discussion. A standardized form was used for data extraction using Excel. Details of the RCT characteristics, included participants, the intervention, and comparator. Data extraction was carried out by reviewer LP and checked for accuracy by reviewer JP. Missing data were requested from study authors.

Outcome Measurement Assessment

When undertaking a systematic review, it is essential that the quality of the outcome measures used in each study is assessed in order to ensure that the results of the study are valid and reliable. In order to do this, three clear domains need to be considered for each of the outcome measures used: (1) whether the psychometric properties of the scale have been assessed previously [32], (2) whether the clinimetric properties of the scale have been considered [33-37], specifically the Minimally Clinically Important Difference (MCID) [36], and (3) whether the design and analysis of the measurement scale fulfils the requirements of measurement theory [38-40].

We identified all the outcome measures (N=19) used in the 11 trials and reviewed each individually to assess whether they fulfilled the first two domains outlined above. The outcome measures were:

- The Rivermead Mobility Index (RMI)
- 10 Meter Walk Test (10MWT)
- Nottingham Activities of Daily Living Index (ADL)
- The Barthel Index (BI)
- The Berg Balance Scale (BBS)
- 6 Minute Walk Test (6MWT)
- Functional Ambulatory Category (FAC)
- Timed Up and Go Test (TUG)
- Emory Functional Ambulation Profile (EFAP)
- Short Physical Performance Battery (SPPB)
- Performance-Oriented Mobility Assessment (POMA)
- Motricity Index (MI)
- Average Daily Walking Time
- Fastest Safe 15-meter Walking Speed
- Changes in Walking Duration
- Step Numbers
- Daily Walking Activities with an average cadence of walking events (bouts)
- Stroke Impact Scale (SIS)
- Stroke Self-Efficacy Questionnaire (SEQ)

This was established by reviewing the literature on each of the measuring scales. We then examined each measurement scale to establish how the data were scored and how data collected were subsequently analyzed within the results section of each trial.

We classified the measures against the three domains within the World Health Organization ICF, as the aim of this review was to assess the effectiveness of lower-limb wearable technology for improving activity and participation. We wanted to exclude any measurements of “body structures” (impairment) such as the Fugl-Meyer assessment or the Ashworth scale. All 19 outcome measures included were measures of “activity” and 2 were measure of “participation” as classified by the ICF [23].

Data Synthesis

We have presented a narrative overview of the included RCTs with supporting evidence tables and text. A meta-analysis was not undertaken.

Results

Search Results

The electronic searches identified 940 citations following de-duplication. No additional citations were identified through reference searches/other sources. We excluded 780 citations at the title and 128 at abstract stage. We then obtained 32 citations as full-text articles. Of these, 21 were excluded at the full-text stage; details of these excluded studies with the reason for exclusion are shown in Multimedia Appendix 2 [41-59]. Eleven RCTs reported across 11 publications were included in the review (see Figure 1).

Quality Assessment

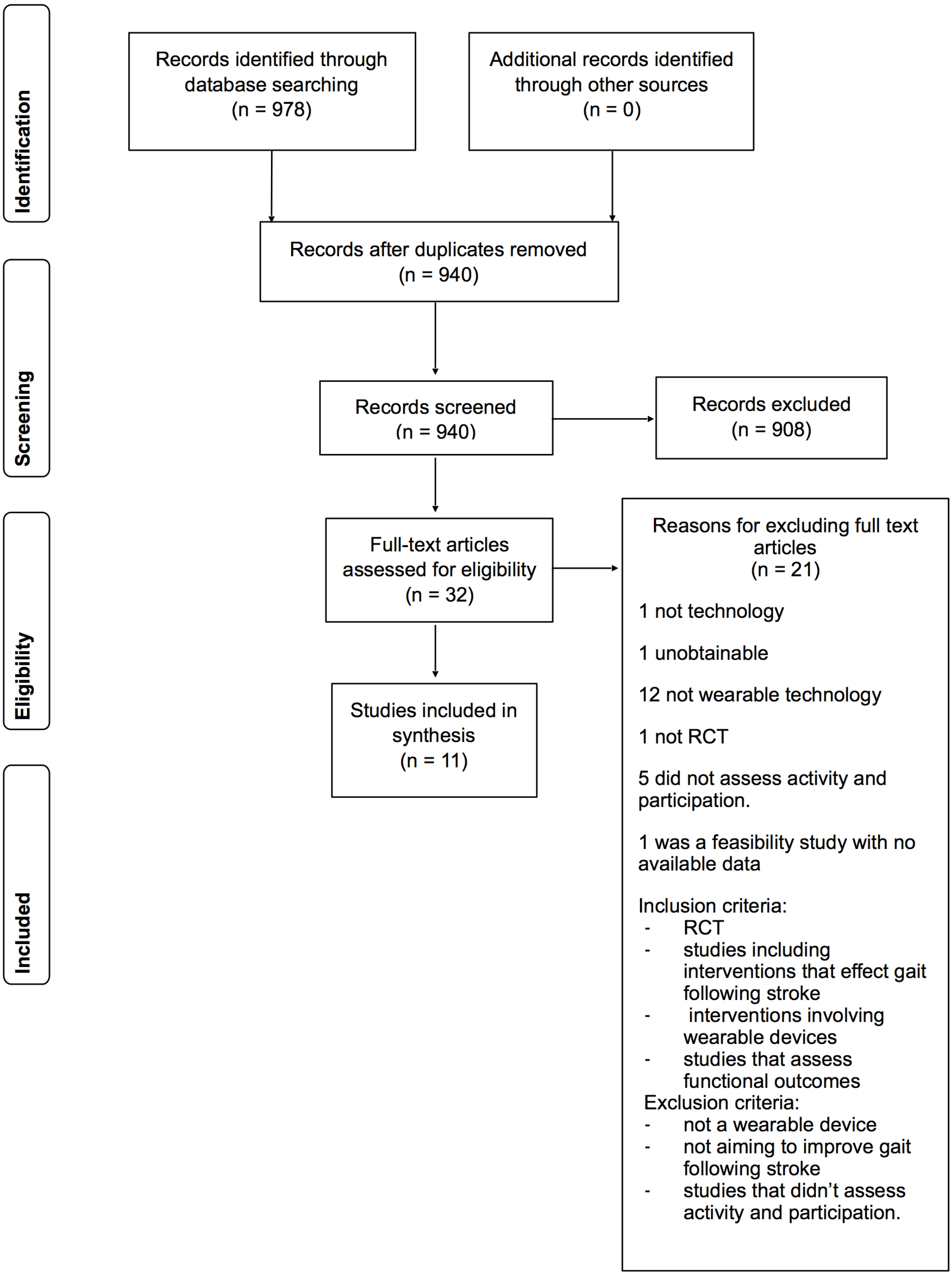
Full details from the Cochrane risk of bias assessment are presented in Multimedia Appendix 3. A summary of the risk of bias assessment is presented in Table 2, and a summary of the outcome measurement quality assessment can be found in Multimedia Appendix 4.

Seven of the 11 included RCTs were considered to be at overall high risk of bias [60-66]. Six of these were judged to be at high risk of an attrition bias [60-63,65,66], and two reported that the outcome assessment was not blinded [64,66]. The remaining three RCTs were considered to be at overall unclear risk of bias. None of the included RCTs were considered to be at high risk for the concealment of allocation domain.

Table 2. Risk of bias summary.

	Random sequence generation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting	Overall
Bauer, 2015 [60]	Low risk	Low risk	High risk	Low risk	High risk	Low risk	High risk
Bradley, 1998 [61]	Unclear	Unclear	Unclear	Unclear	High risk	Unclear	High risk
Dorsch, 2015 [62]	Low risk	Unclear	Unclear	Low risk	High risk	Low risk	High risk
Intiso, 1994 [63]	Unclear	Unclear	Unclear	Low risk	High risk	Unclear	High risk
Mansfield, 2015 [67]	Low risk	Low risk	Unclear	Low risk	Low risk	Low risk	Low risk
Mirelman, 2009 [68]	Unclear	Unclear	High risk	Unclear	Low risk	Unclear	Unclear
Salisbury, 2013 [64]	Low risk	Low risk	Unclear	High risk	Low risk	Unclear	High risk
Shamay, 2009 [65]	Low risk	Unclear	High risk	Low risk	High risk	Unclear	High risk
Solopova, 2011 [69]	Unclear	Unclear	Unclear	Unclear	Low risk	Unclear	Unclear
Stein, 2014 [14]	Unclear	Unclear	Unclear	Unclear	Low risk	Low risk	Unclear
Watanabe, 2014 [66]	High risk	Unclear	High risk	High risk	High risk	Low risk	High risk

Figure 1. Selection of articles for review.



Quality Assessment of Measurement Scales

Eight of the 11 [14,60-62,64,66-68] included RCTs used a combination of ordinal and ratio scales of measurement all with established psychometric properties; however, it was unclear what the minimally clinically important difference (MCID) was for the ratio data. Therefore, the clinical significance of the findings is difficult to establish. Two papers [63,69] used the Bartell Index alone, which has been proven not to be a unidimensional scale. Therefore, the analysis of the data was inappropriate, putting the findings at risk. One paper [65] used ratio levels of measurement, but again the MCID was unclear. Relative results are not reported in the RCTs.

Discussion

Principal Findings

This review set out to answer the question "What is the effectiveness of lower-limb wearable technology for improving activity and participation in adult stroke survivors?" The review found that there is little evidence in the literature to support the use of wearable technologies to improve activity and participation. Following exclusions, outcome measure assessment and quality assessment of RCTs, 11 studies were included (see Table 3).

The interventions used in eight of the 11 RCTs identified made no significant between-group differences in functional and participation abilities in adults post stroke. Three of the 11 studies did demonstrate significant between-group differences. One study that found significant between-group differences recruited 109 participants [65] comparing TENs together with a task-related exercise program modified from the training programs [70] with placebo and exercise and a control with no active treatment. The study provided evidence that the subjects receiving this intervention in a home environment had a significantly greater absolute and percentage increase in gait velocity and a reduction in timed get up and go scores from Week 2 onwards.

Another study recruited 60 participants [67] where all participants wore accelerometers around both ankles and were randomly assigned to either receive feedback on the accelerometer data from their physiotherapist or to not receive feedback. The study provided evidence that providing feedback to the participants significantly improved their cadence of daily walking.

The third study recruited 40 participants [60] where all participants underwent 20 minutes of active leg cycling with or without FES application to the muscles of the paretic upper leg. The study provided evidence for the intervention improving participants gait and balance (measured using the POMA); however, these improvements were not sustained when participants were followed up. It could be argued, however, that the high dropout rate (n=19) could have affected the significance of the lasting effects of the study.

As described fully in the quality assessment section of this paper, seven of the 11 included RCTs were considered to be at overall high risk of bias [66]. However, this does not mean that the interventions were not effective for improving gait for people post stroke. A number of conclusions could be drawn from this result. One may be that interventions that rely heavily on direct clinical input may not be suitable for this population where self-managed interventions may be more appropriate.

A number of measurement scales used in the trials were not incorporated in the outcome data for the review, as they were not validated scales: the Bobath scale [61], the 5X Sit-To-Stand-Test [14], and the California Functional Evaluation 40 [14]. Of the 11 RCTs included in the review, eight used a combination of ordinal and ratio data with proven psychometric properties; however, the clinicmetric properties were not described. The lack of evidence, therefore, in eight studies could have been due to the lack of a clinically meaningful, responsive outcome measurement scale combined with a potential lack of statistical power due to small sample sizes. The three studies that did have significant results used a combination of ordinal and ratio data with only one study [60] that provided estimates of MCID together with appropriate anayisis of the FAC data. While Shamay et al did not consider the clinical meaning or significance of the change in scores, they did report research supporting the “practical significance” of the TUG [71], which found that older adults who were able to complete the TUG task in less than 20 seconds were more likely to be independent in the transfer tasks needed for activites of daily living.

The results from this systematic review should be generalized to a wider stroke population cautiously due to the low recruitment figures for the majority of the included RCTs. Observations of lack of efficacy should also be interpreted with caution, given the uncertainty surrounding the methodological quality of the existing evidence base. Only a small number of papers with small sample sizes were able to be included in this review. Three of the selected studies recruited fewer than 20 participants [61,63,64,72], and only two recruited over 100 participants [62,65]. This could be for a number of reasons including difficulty to recruit a poststroke population to such studies. Despite the plethora of research in poststroke gait research, only 11 RCTs were selected for this review. This could be due to the difficulty of including complex interventions within an RCT design.

An RCT aims to control conditions for each arm of the study, frequently aggregating group data to provide mean values. However, no stroke is the same, recovery varies across individuals, and recovery is naturally accelerated soon after the stroke compared to those who suffered a stroke a long time ago. These factors coupled with different causes and different types of stroke, make it very difficult to control each arm of a study. Therefore, it is difficult to infer if certain interventions improve functionality post stroke or if other variables are responsible. Exploring individual change over time particularly when evaluating novel technologies with complex conditions may provide more valuable information. It has been suggested [73] that the integration of a realist evaluation perspective within an RCT design may be more appropriate and a paradigm shift for evidence-based medicine where “statistically significant benefits may be marginal in clinical practice” [74].

Table 3. Study, participant, and intervention characteristics and results.

Authors, year, country, study design	Number recruited (N) & final follow-up (n) overall and between groups	Gender, mean age, L/R[a] hemisphere stroke, mean time since stroke	Intervention length/ frequency	Activity and participation outcome measure(s)	Activity and participation outcome results summary and reported *P* values
Bauer et al, 2015 [60], Austria, monocentric single-blinded RCT[b], active leg cycling with (intervention) and without (control) FES[c]	N (n)=40 (21). 21 (12), intervention; 19 (9), control	9M/9F[d], 64±11 years, 10R/8L, 42±45 days (control), 12M/7F, 59±14 years, 5R/14L, 62±43 days (intervention)	20 mins, 3x/week over 4 weeks. Total of 12 sessions	FAC[e], 10MWT[f]	The intervention group increased by a median of 2 categories for the FAC and a median of 1 category for the control group (*P*=.01). No significant between-group differences found for the 10MWT (*P*=.65). Significant between-group differences found for the POMA[g] (*P* ≤.001); however, these differences were not maintained at follow-up (*P*=.69)
Bradley et al, 1998 [61], UK, 2-arm RCT, EMG[h] biofeedback (intervention) or EMG biofeedback with EMG switched off (control)	N (n)=23 (21); 12 (12) intervention, 11 (9) control	12M/11F, 77/68 yrs (mild/severe control), 66.6/72.4yrs (mild/severe intervention), 5L/16R, 35.6 days	6 weeks/ 3x/week	RMI, 10MWT, Nottingham ADL	No significant between-group differences (RMI, 10MWT, Notting- ham ADL), although all groups improved in time taken and step count for the 10MWT and all groups improved their Nottingham ADL scores
Dorsch et al, 2015 [62], USA, Phase III randomized single-blind parallel group clinical trial, participants wore accelerometers on each ankle and received speed-only feedback [67] or AF[k]	N (n)=151 (125). 73 (58) SF; 78 (67) AF	28%F/72%M **,** 65.0 ± 13.2yrs, 42%R/29%L, 8.5days [67]; 31%F/69%M, 61.8 ± 15.7yrs, 44%R/34%L, 8days (AF)	Feedback provided 3x/week, weekend use of accelerometers was optional	FAC	No significant between-group differences found for the FAC (*P*=.39), SIS[l]-16 (*P*=.68), 15-M walking speed (*P*=.96) or average daily walking time (*P*=.54)
Intiso et al, 1994 [63], Italy, 2-arm RCT, electromyographic feedback and physical therapy (intervention) or physical therapy only (control)	N (n)=16 (14), 8 (8) intervention, 8 (6) control)	9M,/7F, 53.5yrs (control), 61.3yrs (intervention), 9R/7L, 8.3 months (control), 11.3 months (intervention)	2 months/60 mins daily	BI[m]	No significant between-group differences (BI), 4/8 participants found to have significant increased BI scores
Mansfield et al, 2015 [67], Canada, single-blind RCT, accelerometer with (intervention) and without (control) feedback from physiotherapist	N (n)= 60 (57). 29 (29) intervention; 31 (28) control	20M/9F, 64yrs, 11R/16L/2B, 26 days (intervention) 16M/12F, 61.5yrs, 13R/13L/2B, 23 days (control)	3-26 days per participant in each group. Mode=11 days per participant	BBS[n]	No significant between-group differences step numbers (*P*=.39), changes in walking duration (*P*=.74), number of walking bouts (*P*=.21) or the SEQ[o] (*P*=.48). Significant between-group differences found for daily walking activity with average cadence (*P*=.01)
Mirelman et al, 2009 [68], USA, 2-arm single-blind RCT, training with robotic device coupled with virtual reality training (intervention) or robotic device alone (control)	N (n)=18 (18), 9 (9) intervention, 9 (9) control)	15M/3F, 61yrs (control), 61.8yrs (intervention), 8R/10L, 58.2 months (control), 37.7 months (intervention)	4 weeks/60 mins 3x/week	BBS, 6MWT[p]	No significant between-group differences (6MWT), BBS results/ *P* values not reported

Authors, year, country, study design	Number recruited (N) & final follow-up (n) overall and between groups	Gender, mean age, L/R[a] hemisphere stroke, mean time since stroke	Intervention length/ frequency	Activity and participation outcome measure(s)	Activity and participation outcome results summary and reported *P* values
Salisbury et al, 2013 [64], Scotland, 2-arm feasibility RCT, routine gait re-education and orthotic device (intervention and control) with ankle foot orthosis (control) or FES (intervention)	N (n)=16 (14). 9 (8) intervention, 7 (6) control	6M/10F, 52.6yrs (control), 55.8yrs (intervention), 10R/6L, 69days (control), 51.7 days (intervention)	12 weeks/20 mins 5 days/ week	FAC, 10MWT (velocity & cadence), SIS	No significant between-group differences observed (FAC 6 weeks *P*=.53, 12 weeks *P*=.75; 10MWT velocity/cadence 6 weeks *P*=.46/ *P*=.24, 12 weeks *P*=.87; SIS 6 weeks *P*=.1, 12 weeks *P*=.3)
Shamay, 2009 [65], Hong Kong, 4-arm placebo RCT, 1. transcutaneous electrical nerve stimulation [23], 2. TENS[q]+Exercise, 3. Placebo stimulation+exercise, 4. control group (no active treatment) – home-based program	N (n)=109 (101). 29 (27) control, 28 (25) TENS, 25 (23) placebo+Ex[r], 27 (26) TENS+Ex	85M/24F, 56.5yrs, 57.8yrs (TENS+Ex), 56.9yrs (placebo stimulation+Ex), 55.5yrs (control), 10%R/18%L [23], 10%R/17%L (TENS+Ex), 12%L/13%R (placebo stimulation+Ex), 9%L/20%R (control), 4.9yrs [23], 4.7yrs (TENS+Ex), 4.3yrs (placebo stimulation+Ex), 5yrs (control)	4 weeks/TENS: 60 mins electrical stimulation, TENS+Ex & placebo stimulation + Ex 60 mins of Ex then 60 mins electrical or placebo stimulation. Subjects attended 8 instruction sessions prior to data collection	6MWT, TUG[s]	Compared to all other groups, TENS+Ex group showed significant decreased TUG results (*P*=.01) when compared to the control and TENS group, they cov- ered more distance during the 6MWT (*P* ≤.01)
Solopova et al, 2011 [69], Russia, 2-arm RCT, conventional therapy and FES combined with progressive limb loading (intervention) or conventional therapy only (control)	N (n)=61 (61). 32 intervention, 29 control	33M/28F, 64±18yrs, 19R/42L, 9.3±4.5 days (control), 8.2±4.3 days (intervention)	2 weeks/30 mins 5 days per week	BI	No significant between-group differences, Significant improvements after the intervention in the experimental group were observed (BI *P* ≤.05)
Stein et al, 2014 [14], USA, 2-arm RCT, exercise group therapy (control) or experimental robotic therapy (intervention).	N (n)=12 (10), 12 (10) intervention, 12 (10) control)	58%M (control), 83%M (intervention), 57.6yrs (control), 56.6yrs (intervention), L/R stroke not reported, 88.5 months (control), 49.1 months (intervention)	6 weeks/60 mins 3 days per week	BBS, 6MWT, TUG, 10MWT, EFAP[t]	BBS scores favored the intervention group and the EFAP scores favored the control group. No statistically significant between-group differences observed (BBS, 6MWT, TUG, 10MWT, EFAP)
Watanabe et al, 2014 [66], Japan, 2-arm RCT single leg version of HAL[u] (intervention) or conventional gait training (control).	N (n)=32 (22). 17 (11) intervention, 15 (11) control	11M/11F, 75.6±13.9 (control), 67.0±16.8 (intervention), 11R/11L, 50.6±33.8 days (control), 58.9±46.5 days (intervention)	4 weeks/12 20-min sessions	6MWT, FAC, TUG, SPPB[v]	No significant between-group differences were observed (6MWT, TUG, FAC, SPPB). Intervention group improved more than the control group (FAC *P*=.04)

[a] L/R/B: left/right/both hemisphere stroke.
[b] RCT: randomized controlled trial.
[c] FES: functional electrical stimulation.
[d] M/F: male/female.
[e] FAC: functional ambulatory category.
[f] 10MWT: 10 Meter Walk Test.
[g] POMA: Performance-Oriented Mobility Assessment.
[h] EMG: electromyography.
[i] RMI: Rivermead Mobility Index.
[j] ADL: activities of daily living.
[k] AF: augmented feedback.
[l] SIS: Stroke Impact Scale.
[m] BI: Barthel Index.
[n] BBS: Berg Balance Scale.
[o] SEQ: Stroke Self-Efficacy Questionnaire.
[p] 6MWT: 6 Minute Walk Test.
[q] TENS: transcutaneous electrical nerve stimulation.
[r] Ex: exercise.
[s] TUG: Timed Up and Go Test.
[t] EFAP: Emory Functional Ambulation Profile.
[u] HAL: Hybrid Assistive Limb.
[v] SPPB: Short Physical Performance Battery.

The results of the RCTs were not combined for a meta-analysis due to the varied types and quality of data collected for the primary outcome measures. It would also be difficult to compare primary outcomes across RCTs accurately as there were a wide variety of functional and participation outcome measures used across the 11 RCTs, some of which lacked validity as a measure of activity and participation.

Evidence exists supporting the need for task specificity, intensity, and repetition of motor skills in order to promote neuroplasticity and motor relearning; however, seven of the interventions in this review of RCTs were reliant on staff presence. This automatically eliminates the ability of stroke survivors to self-manage their rehabilitation, increasing both intensity and repetition within a task-specific environment.

This review included 550 participants at baseline and 474 participants at final follow-up, 260 from two studies alone [62,65]. Stroke severity can affect the rate by which individuals recover from a stroke and how they may or may not respond to interventions. Only two [61] of 11 papers in this review reported the stroke severity of their participants. Perhaps the severity was low and therefore it was difficult to infer a significant improvement of function. One paper [65] reported clinically and statistically significant results for the use of lower-limb wearable technologies with rehabilitation, although the technology was TENs, a technology that may not support a self-management paradigm and is not always tolerated by stroke survivors.

Perhaps future research should consider larger sample sizes, with valid, reliable, and responsive measurement tools ensuring clarity when reporting outcomes. Population descriptors should be used when exploring technology enhanced self-management models of poststroke rehabilitation. Outcome measures should be chosen only if they have psychometric or clinimetric properties reported. Where possible, individuals' change over time should be captured and analyzed to ensure we begin to understand what works for whom and in what respect [75].

Conclusion

This review found that there is little evidence in the literature to support the use of wearable technologies to improve activity and participation following a stroke. However, this review has highlighted a number of reasons for a lack of significant findings including low sample sizes, the appropriateness of RCT methodology for complex interventions, a lack of appropriate analysis of outcome data, and participant stroke severity.

Acknowledgments

This research was funded/supported by the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care Yorkshire and Humber. The views and opinions expressed are those of the authors and are not necessarily those of the National Health Service, the National Institute for Health Research, or the UK's Department of Health.

Authors' Contributions

LP carried out the search strategy and wrote the methods section with MMSJ. LP updated the review, and all authors updated their sections. JP acted as a second reviewer for accuracy and wrote the introduction. SM wrote the discussion and the outcome measurement assessment. MMSJ acted as an advisor for the searches and carried out the risk of bias assessment. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

MEDLINE search strategy.

[PDF File (Adobe PDF File), 23KB - jmir_v18i10e259_app1.pdf]

Multimedia Appendix 2

Papers and reasons for exclusion.

[PDF File (Adobe PDF File), 18KB - jmir_v18i10e259_app2.pdf]

Multimedia Appendix 3

Details of quality assessment.

[PDF File (Adobe PDF File), 47KB - jmir_v18i10e259_app3.pdf]

Multimedia Appendix 4

Summary of outcome measure quality assessment.

[PDF File (Adobe PDF File), 36KB - jmir_v18i10e259_app4.pdf]

References

1. Strong K, Mathers C, Bonita R. Preventing stroke: saving lives around the world. Lancet Neurol 2007 Feb;6(2):182-187. [doi: 10.1016/S1474-4422(07)70031-5] [Medline: 17239805]
2. Department of Health: National Stroke Strategy. Department of Health. London: Crown Copyright; 2007.
3. Saka O, McGuire A, Wolfe C. Cost of stroke in the United Kingdom. Age Ageing 2009 Jan;38(1):27-32 [FREE Full text] [doi: 10.1093/ageing/afn281] [Medline: 19141506]
4. Hendricks HT, van LJ, Geurts AC, Zwarts MJ. Motor recovery after stroke: a systematic review of the literature. Arch Phys Med Rehabil 2002 Nov;83(11):1629-1637. [Medline: 12422337]
5. Luker J, Lynch E, Bernhardsson S, Bennett L, Bernhardt J. Stroke Survivors' Experiences of Physical Rehabilitation: A Systematic Review of Qualitative Studies. Arch Phys Med Rehabil 2015 Sep;96(9):1698-1708.e10. [doi: 10.1016/j.apmr.2015.03.017] [Medline: 25847387]
6. Mawson S, Nasr N, Parker J, Davies R, Zheng H, Mountain G. A Personalized Self-Management Rehabilitation System with an Intelligent Shoe for Stroke Survivors: A Realist Evaluation. JMIR Rehabil Assist Technol 2016 Jan 07;3(1):e1. [doi: 10.2196/rehab.5079]
7. National Information Board: Personalised HealthCare 2020. Using Data and Technology to Transform Outcomes for Patients and Citizens: A Framework for Action. 2014. URL: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/384650/NIB_Report.pdf [accessed 2016-09-19] [WebCite Cache ID 6kdpM0yYd]
8. Kleim JA, Jones TA. Principles of experience-dependent neural plasticity: implications for rehabilitation after brain damage. J Speech Lang Hear Res 2008 Feb;51(1):S225-S239. [doi: 10.1044/1092-4388(2008/018)] [Medline: 18230848]
9. Stein J, Hughes R, Hogan N. Technological Aids for Motor Recovery. In: Stein J, Macko RF, Winstein CJ, Zorowitz RD, editors. Stroke Recovery and Rehabilitation. New York: Demos Medical; 2009:307.
10. Parker J, Mountain G, Hammerton J. A review of the evidence underpinning the use of visual and auditory feedback for computer technology in post-stroke upper-limb rehabilitation. Disabil Rehabil Assist Technol 2011;6(6):465-472. [doi: 10.3109/17483107.2011.556209] [Medline: 21314295]
11. Steins D, Dawes H, Esser P, Collett J. Wearable accelerometry-based technology capable of assessing functional activities in neurological populations in community settings: a systematic review. J Neuroeng Rehabil 2014;11:36 [FREE Full text] [doi: 10.1186/1743-0003-11-36] [Medline: 24625308]
12. Gebruers N, Vanroy C, Truijen S, Engelborghs S, De Deyn P. Monitoring of physical activity after stroke: a systematic review of accelerometry-based measures. Arch Phys Med Rehabil 2010 Feb;91(2):288-297. [doi: 10.1016/j.apmr.2009.10.025] [Medline: 20159136]
13. Patel S, Park H, Bonato P, Chan L, Rodgers M. A review of wearable sensors and systems with application in rehabilitation. J Neuroeng Rehabil 2012;9:21 [FREE Full text] [doi: 10.1186/1743-0003-9-21] [Medline: 22520559]

14. Stein J, Bishop L, Stein DJ, Wong CK. Gait training with a robotic leg brace after stroke: a randomized controlled pilot study. Am J Phys Med Rehabil 2014 Nov;93(11):987-994. [doi: 10.1097/PHM.0000000000000119] [Medline: 24901757]
15. Zheng H, Black ND, Harris ND. Position-sensing technologies for movement analysis in stroke rehabilitation. Med Biol Eng Comput 2005 Jul;43(4):413-420. [Medline: 16255421]
16. DeVaul R, Sung M, Gips J, Pentland A. MIThril 2003: applications and architecture. In: ISWC '03. 2003 Presented at: 7th IEEE International Symposium on Wearable Computers; Oct. 21-23, 2003; White Plains, NY.
17. Asada HH, Shaltis P, Reisner A, Rhee S, Hutchinson RC. Mobile monitoring with wearable photoplethysmographic biosensors. IEEE Eng Med Biol Mag 2003;22(3):28-40. [Medline: 12845817]
18. Shaltis PA, Reisner A, Asada HH. Wearable, cuff-less PPG-based blood pressure monitor with novel height sensor. Conf Proc IEEE Eng Med Biol Soc 2006;1:908-911. [doi: 10.1109/IEMBS.2006.260027] [Medline: 17946006]
19. Kwakkel G, Kollen BJ, Krebs HI. Effects of robot-assisted therapy on upper limb recovery after stroke: a systematic review. Neurorehabil Neural Repair 2008;22(2):111-121 [FREE Full text] [doi: 10.1177/1545968307305457] [Medline: 17876068]
20. Laver K, George S, Thomas S, Deutsch JE, Crotty M. Virtual reality for stroke rehabilitation: an abridged version of a Cochrane review. Eur J Phys Rehabil Med 2015 Aug;51(4):497-506 [FREE Full text] [Medline: 26158918]
21. Howlett OA, Lannin NA, Ada L, McKinstry C. Functional electrical stimulation improves activity after stroke: a systematic review with meta-analysis. Arch Phys Med Rehabil 2015 May;96(5):934-943. [doi: 10.1016/j.apmr.2015.01.013] [Medline: 25634620]
22. Teasell RW, Bhogal SK, Foley NC, Speechley MR. Gait retraining post stroke. Top Stroke Rehabil 2003;10(2):34-65. [doi: 10.1310/UDXE-MJFF-53V2-EAP0] [Medline: 13680517]
23. Salter K, Jutai JW, Teasell R, Foley NC, Bitensky J. Issues for selection of outcome measures in stroke rehabilitation: ICF Body Functions. Disabil Rehabil 2005 Feb 18;27(4):191-207. [doi: 10.1080/09638280400008537] [Medline: 15824050]
24. Robbins SM, Houghton PE, Woodbury MG, Brown JL. The therapeutic effect of functional and transcutaneous electric stimulation on improving gait speed in stroke patients: a meta-analysis. Arch Phys Med Rehabil 2006 Jun;87(6):853-859. [doi: 10.1016/j.apmr.2006.02.026] [Medline: 16731222]
25. World Health Organization. International classification of functioning, disability and health. 2001. URL: http://www.who.int/classifications/icf/en/ [accessed 2016-09-13] [WebCite Cache ID 6kUK3N2E2]
26. Geyh S, Cieza A, Schouten J, Dickson H, Frommelt P, Omar Z, et al. ICF Core Sets for stroke. J Rehabil Med 2004 Jul(44 Suppl):135-141 [FREE Full text] [doi: 10.1080/16501960410016776] [Medline: 15370761]
27. Gottlieb A, Golander H, Bar-Tal Y, Gottlieb D. The influence of social support and perceived control on handicap and quality of life after stroke. Aging (Milano) 2001 Feb;13(1):11-15. [Medline: 11292146]
28. Intercollegiate Stroke Working Party. National clinical guideline for stroke. 4th edition edn: Royal College of Physicians; 2012.
29. Moher D, Liberati A, Tezlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. Ann Intern Med 2009;9:151-264. [doi: 10.1371/journal.pmed1000097]
30. Higgins J, Altman D, Sterne J. Cochrane Handbook for Systematic Reviews of Interventions, Version 510.: The Cochrane Collaboration; 2011. Assessing risk of bias in included studies URL: http://handbook.cochrane.org/ [accessed 2016-07-26] [WebCite Cache ID 6jHvWW7Az]
31. Tanaka N, Saitou H, Takao T, Iizuka N, Okuno J, Yano H, et al. Effects of gait rehabilitation with a footpad-type locomotion interface in patients with chronic post-stroke hemiparesis: a pilot study. Clin Rehabil 2012 Aug;26(8):686-695. [doi: 10.1177/0269215511432356] [Medline: 22275464]
32. Tyson S, Connell L. The psychometric properties and clinical utility of measures of walking and mobility in neurological conditions: a systematic review. Clin Rehabil 2009 Nov;23(11):1018-1033. [doi: 10.1177/0269215509339004] [Medline: 19786420]
33. Altaim T. PhD Thesis.: University of Sheffield; 2015. Developing a functional outcome measure for individuals with low back pain within a Jordanian physiotherapy service URL: http://etheses.whiterose.ac.uk/9602/ [accessed 2016-09-19] [WebCite Cache ID 6keC8kydi]
34. de Vet HCW, Terwee CB, Bouter LM. Current challenges in clinimetrics. J Clin Epidemiol 2003 Dec;56(12):1137-1141. [Medline: 14680660]
35. Feinstein AR. An additional basic science for clinical medicine: IV. The development of clinimetrics. Ann Intern Med 1983 Dec;99(6):843-848. [Medline: 6651026]
36. Kirshner B, Guyatt G. A methodological framework for assessing health indices. J Chronic Dis 1985;38(1):27-36. [Medline: 3972947]
37. Okasheh ROA. Clinical measurement of functional outcomes of pulmonary rehabilitation. In: PhD Thesis. United Kingdom: Sheffield Hallam University-British Library; 2011:1.
38. Mawson SJ. Measuring Physiotherapy Outcome in Stroke Rehabilitation. Physiotherapy 1993 Nov;79(11):762-765. [doi: 10.1016/S0031-9406(10)60057-0]
39. Michels E. Measurement in physical therapy. On the rules for assigning numerals to observations. Phys Ther 1983 Feb;63(2):209-215 [FREE Full text] [Medline: 6823471]
40. Stevens SS. On the theory of scales of measurement. Science 1946 Jun 7;103(2684):677-680. [Medline: 20984256]

41. Boysen G, Krarup L, Zeng X, Oskedra A, Kõrv J, Andersen G, ExStroke Pilot Trial Group. ExStroke Pilot Trial of the effect of repeated instructions to improve physical activity after ischaemic stroke: a multinational randomised controlled clinical trial. BMJ 2009;339:b2810 [FREE Full text] [Medline: 19900934]
42. Dragin AS, Konstantinović LM, Veg A, Schwirtlich LB. Gait training of poststroke patients assisted by the Walkaround (body postural support). Int J Rehabil Res 2014 Mar;37(1):22-28. [doi: 10.1097/MRR.0b013e328363ba30] [Medline: 23820295]
43. Alptekin N, Gok H, Geler-Kulcu D, Dincer G. Efficacy of treatment with a kinaesthetic ability training device on balance and mobility after stroke: a randomized controlled study. Clin Rehabil 2008;22(10-11):922-930. [doi: 10.1177/0269215508090673] [Medline: 18955424]
44. Peurala SH, Tarkka IM, Pitkänen K, Sivenius J. The effectiveness of body weight-supported gait training and floor walking in patients with chronic stroke. Arch Phys Med Rehabil 2005 Aug;86(8):1557-1564. [doi: 10.1016/j.apmr.2005.02.005] [Medline: 16084808]
45. Peurala SH, Airaksinen O, Huuskonen P, Jäkälä P, Juhakoski M, Sandell K, et al. Effects of intensive therapy using gait trainer or floor walking exercises early after stroke. J Rehabil Med 2009 Feb;41(3):166-173 [FREE Full text] [doi: 10.2340/16501977-0304] [Medline: 19229450]
46. Ng MFW, Tong RKY, Li LSW. A pilot study of randomized clinical controlled trial of gait training in subacute stroke patients with partial body-weight support electromechanical gait trainer and functional electrical stimulation: six-month follow-up. Stroke 2008 Jan;39(1):154-160 [FREE Full text] [doi: 10.1161/STROKEAHA.107.495705] [Medline: 18006861]
47. Tong RK, Ng MF, Li LS. Effectiveness of gait training using an electromechanical gait trainer, with and without functional electric stimulation, in subacute stroke: a randomized controlled trial. Arch Phys Med Rehabil 2006 Oct;87(10):1298-1304. [doi: 10.1016/j.apmr.2006.06.016] [Medline: 17023237]
48. Lau RWK, Yip SP, Pang MYC. Whole-body vibration has no effect on neuromotor function and falls in chronic stroke. Med Sci Sports Exerc 2012 Aug;44(8):1409-1418. [doi: 10.1249/MSS.0b013e31824e4f8c] [Medline: 22330025]
49. Hidler J, Nichols D, Pelliccio M, Brady K, Campbell DD, Kahn JH, et al. Multicenter randomized clinical trial evaluating the effectiveness of the Lokomat in subacute stroke. Neurorehabil Neural Repair 2009 Jan;23(1):5-13. [doi: 10.1177/1545968308326632] [Medline: 19109447]
50. Lewek MD, Cruz TH, Moore JL, Roth HR, Dhaher YY, Hornby TG. Allowing intralimb kinematic variability during locomotor training poststroke improves kinematic consistency: a subgroup analysis from a randomized clinical trial. Phys Ther 2009 Aug;89(8):829-839 [FREE Full text] [doi: 10.2522/ptj.20080180] [Medline: 19520734]
51. Schwartz I, Sajin A, Fisher I, Neeb M, Shochina M, Katz-Leurer M, et al. The effectiveness of locomotor therapy using robotic-assisted gait training in subacute stroke patients: a randomized controlled trial. PM R 2009 Jun;1(6):516-523. [doi: 10.1016/j.pmrj.2009.03.009] [Medline: 19627940]
52. Ochi M, Wada F, Saeki S, Hachisuka K. Gait training in subacute non-ambulatory stroke patients using a full weight-bearing gait-assistance robot: A prospective, randomized, open, blinded-endpoint trial. J Neurol Sci 2015;353(1-2):130-136. [doi: 10.1016/j.jns.2015.04.033] [Medline: 25956233]
53. van Nunen MPM, Gerrits KHL, Konijnenbelt M, Janssen TWJ, de Haan A. Recovery of walking ability using a robotic device in subacute stroke patients: a randomized controlled study. Disabil Rehabil Assist Technol 2015 Mar;10(2):141-148. [doi: 10.3109/17483107.2013.873489] [Medline: 24611590]
54. Peurala SH, Titianova EB, Mateev P, Pitkänen K, Sivenius J, Tarkka IM. Gait characteristics after gait-oriented rehabilitation in chronic stroke. Restor Neurol Neurosci 2005;23(2):57-65. [Medline: 15990412]
55. Kunkel D, Pickering RM, Burnett M, Littlewood J, Burridge JH, Ashburn A, Stroke Association Rehabilitation Research Centre. Functional electrical stimulation with exercises for standing balance and weight transfer in acute stroke patients: a feasibility randomized controlled trial. Neuromodulation 2013;16(2):168-177. [doi: 10.1111/j.1525-1403.2012.00488.x] [Medline: 22861816]
56. Kakuda W, Abo M, Nakayama Y, Kiyama A, Yoshida H. High-frequency rTMS using a double cone coil for gait disturbance. Acta Neurol Scand 2013 Aug;128(2):100-106. [doi: 10.1111/ane.12085] [Medline: 23398608]
57. Paoloni M, Mangone M, Scettri P, Procaccianti R, Cometa A, Santilli V. Segmental muscle vibration improves walking in chronic stroke patients with foot drop: a randomized controlled trial. Neurorehabil Neural Repair 2010;24(3):254-262. [doi: 10.1177/1545968309349940] [Medline: 19855076]
58. Ng SM, Hui-Chan CWY. Transcutaneous electrical nerve stimulation combined with task-related training improves lower limb functions in subjects with chronic stroke. Stroke 2007 Nov;38(11):2953-2959 [FREE Full text] [doi: 10.1161/STROKEAHA.107.490318] [Medline: 17901383]
59. Jung K, Kim Y, Cha Y, In T, Hur Y, Chung Y. Effects of gait training with a cane and an augmented pressure sensor for enhancement of weight bearing over the affected lower limb in patients with stroke: a randomized controlled pilot study. Clin Rehabil 2015 Feb;29(2):135-142. [doi: 10.1177/0269215514540923] [Medline: 25009199]
60. Bauer P, Krewer C, Golaszewski S, Koenig E, Müller F. Functional electrical stimulation-assisted active cycling--therapeutic effects in patients with hemiparesis from 7 days to 6 months after stroke: a randomized controlled pilot study. Arch Phys Med Rehabil 2015 Feb;96(2):188-196. [doi: 10.1016/j.apmr.2014.09.033] [Medline: 25449195]

61. Bradley L, Hart BB, Mandana S, Flowers K, Riches M, Sanderson P. Electromyographic biofeedback for gait training after stroke. Clin Rehabil 1998 Feb;12(1):11-22. [Medline: 9549021]
62. Dorsch AK, Thomas S, Xu X, Kaiser W, Dobkin BH. SIRRACT: An International Randomized Clinical Trial of Activity Feedback During Inpatient Stroke Rehabilitation Enabled by Wireless Sensing. Neurorehabil Neural Repair 2015 Jun;29(5):407-415. [doi: 10.1177/1545968314550369] [Medline: 25261154]
63. Intiso D, Santilli V, Grasso MG, Rossi R, Caruso I. Rehabilitation of walking with electromyographic biofeedback in foot-drop after stroke. Stroke 1994 Jun;25(6):1189-1192. [Medline: 8202978]
64. Salisbury L, Shiels J, Todd I, Dennis M. A feasibility study to investigate the clinical application of functional electrical stimulation (FES), for dropped foot, during the sub-acute phase of stroke - A randomized controlled trial. Physiother Theory Pract 2013 Jan;29(1):31-40. [doi: 10.3109/09593985.2012.674087] [Medline: 22524182]
65. Ng SM, Hui-Chan CWY. Does the use of TENS increase the effectiveness of exercise for improving walking after stroke? A randomized controlled clinical trial. Clin Rehabil 2009 Dec;23(12):1093-1103. [doi: 10.1177/0269215509342327] [Medline: 19906763]
66. Watanabe H, Tanaka N, Inuta T, Saitou H, Yanagi H. Locomotion improvement using a hybrid assistive limb in recovery phase stroke patients: a randomized controlled pilot study. Arch Phys Med Rehabil 2014 Nov;95(11):2006-2012. [doi: 10.1016/j.apmr.2014.07.002] [Medline: 25010538]
67. Mansfield A, Wong JS, Bryce J, Brunton K, Inness EL, Knorr S, et al. Use of Accelerometer-Based Feedback of Walking Activity for Appraising Progress With Walking-Related Goals in Inpatient Stroke Rehabilitation: A Randomized Controlled Trial. Neurorehabil Neural Repair 2015 Oct;29(9):847-857. [doi: 10.1177/1545968314567968] [Medline: 25605632]
68. Mirelman A, Bonato P, Deutsch JE. Effects of training with a robot-virtual reality system compared with a robot alone on the gait of individuals after stroke. Stroke 2009 Jan;40(1):169-174 [FREE Full text] [doi: 10.1161/STROKEAHA.108.516328] [Medline: 18988916]
69. Solopova IA, Tihonova DY, Grishin AA, Ivanenko YP. Assisted leg displacements and progressive loading by a tilt table combined with FES promote gait recovery in acute stroke. NeuroRehabilitation 2011;29(1):67-77. [doi: 10.3233/NRE-2011-0679] [Medline: 21876298]
70. Carr J, Shepherd R. Neurological Rehabilitation: Optimizing motor performance. Oxford, UK: Butterworth-Heinemann; 1998.
71. Podsiadlo D, Richardson S. The timed “Up & Go”: a test of basic functional mobility for frail elderly persons. J Am Geriatr Soc 1991 Feb;39(2):142-148. [Medline: 1991946]
72. Mirelman A, Patritti BL, Bonato P, Deutsch JE. Effects of virtual reality training on gait biomechanics of individuals post-stroke. Gait Posture 2010 Apr;31(4):433-437. [doi: 10.1016/j.gaitpost.2010.01.016] [Medline: 20189810]
73. Bonell C, Fletcher A, Morton M, Lorenc T, Moore L. Realist randomised controlled trials: a new approach to evaluating complex public health interventions. Soc Sci Med 2012 Dec;75(12):2299-2306. [doi: 10.1016/j.socscimed.2012.08.032] [Medline: 22989491]
74. Greenhalgh T, Howick J, Maskrey N, Evidence Based Medicine Renaissance Group. Evidence based medicine: a movement in crisis? BMJ 2014;348:g3725 [FREE Full text] [Medline: 24927763]
75. Pawson R, Tilley N. Realistic evaluation. London: Sage; 1997.

Abbreviations

10MWT: 10 minute walk test
6MWT: Six Minute Walk Test
BBS: Berg Balance Scale
BI: Barthel Index
EFAP: Emory Functional Ambulation Profile
EMG-BFB: Electromyographic biofeedback
FAC: Functional Ambulatory Category
FES: Functional electrical stimulation
ICF: International Classification of Functioning, Disability and Health
L/R: Left/Right hemisphere stroke
M/F: Male/Female
MCID: Minimally clinically important difference
NHS: National Health Service
MI: Motricity Index
Nottingham ADL: Nottingham Activities of Daily Living Index
POMA: Performance-Oriented Mobility Assessment
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT: Randomised controlled trial
RMI: Rivermead mobility index

SEQ: Stroke Self-Efficacy Questionnaire
SIS: Stroke Impact Scale
SPPB: Short Physical Performance Battery
TENS: Transcutaneous Electrical Nerve Stimulation
TUG: Timed Up and Go Test

Edited by G Eysenbach; submitted 20.04.16; peer-reviewed by B Dobkin, A Tognetti; comments to author 25.07.16; revised version received 02.08.16; accepted 21.08.16; published 07.10.16.

Please cite as:
Powell L, Parker J, Martyn St-James M, Mawson S
The Effectiveness of Lower-Limb Wearable Technology for Improving Activity and Participation in Adult Stroke Survivors: A Systematic Review
J Med Internet Res 2016;18(10):e259
URL: http://www.jmir.org/2016/10/e259/
doi:10.2196/jmir.5891
PMID:27717920

Original Paper

Role of Psychosocial Factors and Health Literacy in Pregnant Women's Intention to Use a Decision Aid for Down Syndrome Screening: A Theory-Based Web Survey

Agathe Delanoë[1], MA; Johanie Lépine[1], PhD; Stéphane Turcotte[1], MSc; Maria Esther Leiva Portocarrero[1], BSc; Hubert Robitaille[1], PhD; Anik MC Giguère[1,2,3], PhD; Brenda J Wilson[4], MRCP, FFPH, MBChB, MSc; Holly O Witteman[1,3,5], PhD; Isabelle Lévesque[6], MD; Laurence Guillaumie[1], PhD; France Légaré[1,5,7], FCFP, CCFP, MD, PhD

[1]Populations Health and Optimal Health Practices Research Group, CHU de Québec-Université Laval, Quebec City, QC, Canada
[2]Quebec Centre of Excellence on Aging, CHU de Québec-Université Laval, Quebec City, QC, Canada
[3]Office of Education and Continuing Professional Development, Faculty of Medicine, Université Laval, Quebec City, QC, Canada
[4]School of Epidemiology, Public Health and Preventive Medicine, University of Ottawa, Ottawa, ON, Canada
[5]Department of Family Medicine and Emergency Medicine, Faculty of Medicine, Université Laval, Quebec City, QC, Canada
[6]Department of Obstetrics and Gynecology, Faculty of Medicine, Université Laval, Quebec City, QC, Canada
[7]Tier 1 Canada Research Chair in Shared Decision Making and Knowledge Translation, Faculty of Medicine, Université Laval, Quebec City, QC, Canada

Corresponding Author:
France Légaré, FCFP, CCFP, MD, PhD
Populations Health and Optimal Health Practices Research Group
CHU de Québec-Université Laval
Ho^pital St-Franc¸ois d'Assise, D6-737
10 rue Espinay
Quebec City, QC, G1L 3L5
Canada
Phone: 1 418 525 4437
Fax: 1 418 525 4194
Email: France.Legare@mfa.ulaval.ca

Abstract

Background: Deciding about undergoing prenatal screening is difficult, as it entails risks, potential loss and regrets, and challenges to personal values. Shared decision making and decision aids (DAs) can help pregnant women give informed and values-based consent or refusal to prenatal screening, but little is known about factors influencing the use of DAs.

Objective: The objective of this study was to identify the influence of psychosocial factors on pregnant women's intention to use a DA for prenatal screening for Down syndrome (DS). We also added health literacy variables to explore their influence on pregnant women's intention.

Methods: We conducted a survey of pregnant women in the province of Quebec (Canada) using a Web panel. Eligibility criteria included age >18 years, >16 weeks pregnant, low-risk pregnancy, and having decided about prenatal screening for the current pregnancy. We collected data based on an extended version of the Theory of Planned Behavior assessing 7 psychosocial constructs (intention, attitude, anticipated regret, subjective norm, descriptive norm, moral norm, and perceived control), 3 related sets of beliefs (behavioral, normative, and control beliefs), 4 health literacy variables, and sociodemographics. Eligible women watched a video depicting the behavior of interest before completing a Web-based questionnaire. We performed descriptive, bivariate, and ordinal logistic regression analyses.

Results: Of the 383 eligible pregnant women who agreed to participate, 350 pregnant women completed the Web-based questionnaire and 346 were retained for analysis (completion rate 350/383, 91.4%; mean age 30.1, SD 4.3, years). In order of importance, factors influencing intention to use a DA for prenatal screening for DS were attitude (odds ratio, OR, 9.16, 95% CI 4.02-20.85), moral norm (OR 7.97, 95% CI 4.49-14.14), descriptive norm (OR 2.83, 95% CI 1.63-4.92), and anticipated regret (OR 2.43, 95% CI 1.71-3.46). Specific attitudinal beliefs significantly related to intention were that using a DA would reassure them (OR 2.55, 95% CI 1.73-4.01), facilitate their reflections with their spouse (OR 1.55, 95% CI 1.05-2.29), and let them know about the advantages of doing or not doing the test (OR 1.53, 95% CI 1.05-2.24). Health literacy did not add to the predictive power of our model (P values range .43-.92).

Conclusions: Implementation interventions targeting the use of a DA for prenatal screening for DS by pregnant women should address a number of modifiable factors, especially by introducing the advantages of using the DA (attitude), informing pregnant women that they might regret not using it (anticipated regret), and presenting the use of DAs as a common practice (descriptive norm). However, interventions on moral norms related to the use of DA should be treated with caution. Further studies that include populations with low health literacy are needed before decisive claims can be made.

(J Med Internet Res 2016;18(10):e283) doi:10.2196/jmir.6362

KEYWORDS

decision aids; behavior; intention; prenatal diagnosis; decision making; health literacy

Introduction

Prenatal tests for Down syndrome have become routine in many developed countries through population-based screening programs [1]. For women, their partners, and clinicians, the decision about whether or not to do the tests can be a difficult one to make [2-4]. The initial decision about screening may seem banal, but it can be the first of a series of increasingly difficult and sensitive decisions. First, although screening results may decrease women's uncertainty, there is still a risk of false-positive or false-negative results. Second, if the results are positive, women are faced with a further decision about amniocentesis, a more invasive test that carries the risk of losing the fetus. Finally, if the results of the amniocentesis are positive, the woman has to decide whether to have an abortion or to prepare for a child with special needs. Thus, each successive decision entails more physically invasive procedures, more significant challenges to women's personal values, and changes in their hopes for the future.

Although more accurate screening tests providing earlier results are increasingly available, such as the new noninvasive prenatal test (NIPT) [5], decisions about prenatal screening still gain in complexity [6-8]. In this rapidly evolving clinical context, several decisional needs are still unmet and new ones are emerging that urgently need to be addressed [5,9,10].

Patient decision aids (DAs) are decision support tools that could help women and their partners to make informed prenatal screening decisions congruent with their values. An informed choice is one in which a patient has understood the evidence related to each option as well as considered what best fits his or her values and preferences and made a decision consistent with this [11]. DAs are therefore designed to help patients to engage in decision making not only by providing best evidence on the options, but also by helping them clarify and communicate what is most important to them about the decision (values and preferences) [12]. DAs have been found to stimulate people to take a more active role in decision making, to increase knowledge, to improve the accuracy of risk perception, to improve congruence between choice and patient values, and to decrease decisional conflict (personal uncertainty) as well as decision regret [12]. Providing detailed information on prenatal testing has been shown to be significantly associated with an increase in patient satisfaction [13] and DAs have been shown to decrease anxiety [14]. Although several DAs are available for prenatal screening, they are not routinely implemented [4,15], and none meet all the International Patient Decision Aids Standards criteria, as our earlier scan has demonstrated [16]. DAs have not yet, in fact, been routinely implemented in many clinical contexts [17]. This has been attributed to health professionals' lack of training in using them, their lack of trust in their content or their disagreement with it, or their belief that patients facing a difficult diagnosis do not want to take responsibility for decisions [17]. The successful implementation of DAs is likely to be affected by a number of factors [18]. A recent study suggested that the main factors influencing health professionals' use of a DA in prenatal care were their positive impression of the DA, its availability in their offices, and their colleagues' approval of its use [19]. Another study showed that, for pregnant women, the main factors were their partner's opinion, the DA being explained by and discussed with the health professional, and whether or not the women had ever encountered a DA before (Leiva Portocarrero, M. Sc., personal written communication, February 2016).

In recent years, adoption of new health-related behaviors, including those needed to help disseminate DAs effectively, has been studied with the help of behavior change theories [20-22]. These theories allow identification of the modifiable factors influencing behavior adoption that should be targeted in implementation interventions in order to produce the needed behavior change [23,24]. Most of these behavior change theories rely on the assessment of the determinants of behavioral intention, which is considered to be the best predictor of behavior adoption [25]. More specifically, the use of a behavior change theory could better enable the identification of a set of behavioral factors influencing pregnant women's intention to use a DA, which could then help in designing an effective implementation intervention.

In addition, in the context of prenatal screening, pregnant women with fewer years of education have reported being less willing to engage in shared decision making (SDM) [26]. This is congruent with a growing body of literature indicating that health literacy is a potential barrier to SDM [27-29] and to the use of DAs [30,31]. Health literacy includes self-confidence, social skills, and social networks as well as literacy and numeracy [32-35], and all these dimensions are likely to affect patients' intention to use a DA [30]. Studies have also demonstrated that health literacy influences patients' motivation to manage their health [36,37] and their attitude toward SDM, especially their desire for involvement in the decision [31,38-44] and for information [45,46], their perception of decisional responsibility [47], their perception of the harms and benefits of treatments [33,48-52], and their capacity to understand genetic information [53] and laboratory test results [54]. Research has also shown that lower health literacy levels among pregnant women are associated with poorer understanding of prenatal screening tests [55].

Measuring how much an enriched set of factors influences the uptake of DAs by patients could inform the design of theory-based interventions to support their implementation in the clinic [56]. Therefore, the aim of this study was to identify the factors influencing pregnant women's intention to use a DA about prenatal screening for Down syndrome. More specifically, the objectives were the following: (1) based on an extended model of behavior change [57], to identify the psychosocial determinants influencing pregnant women's intention to use a DA about prenatal screening for Down syndrome; (2) to explore adding health literacy as a direct determinant of intention or as a variable that could moderate the influence of other direct determinants of intention.

Methods

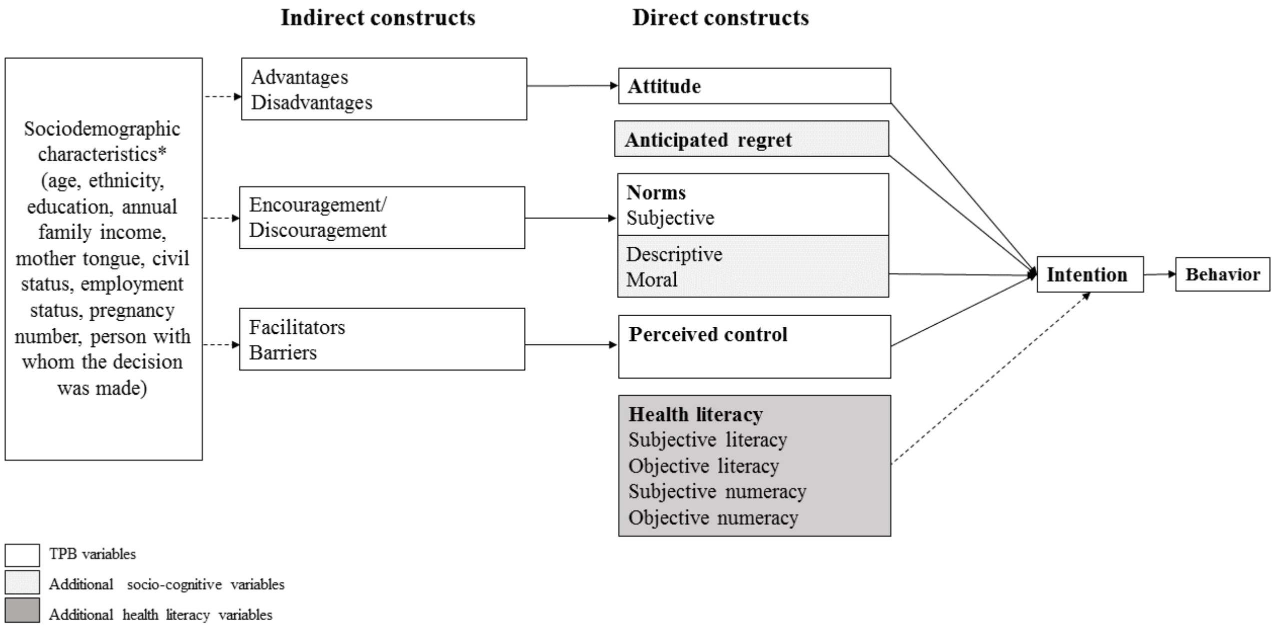
Study Design

This cross-sectional Web-based survey was embedded in a large Canadian research initiative called the PEGASUS project (Personalized Genomics for Prenatal Aneuploidy Screening Using Maternal Blood) aiming to validate the performance and utility of the NIPT in the general population. In this large initiative, our overarching aim was to inform the future implementation of a DA to foster SDM in the context of prenatal screening for Down syndrome. Ethics approval was obtained from the research ethics boards of the Centre intégré universitaire de santé et de services sociaux de la Capitale-Nationale (#2013-2014-29), the Centre intégré de santé et de services sociaux de Chaudière-Appalaches (CER-1415-910), and the CHU de Québec (#B14-02-1929). We used the CHERRIES (Checklist for Reporting Results of Internet E-Surveys) checklist to guide the reporting of our Web-based survey [58].

Theoretical Framework

The theoretical framework of this study was the Theory of Planned Behavior (TPB), which is one of the highest-performing and commonly used theories for identifying the determinants of intention [59]. According to the TPB, the direct determinants of intention are attitude (perceived advantages of adopting the behavior), subjective norm (the perceived social pressure from significant others to perform the behavior), and perceived behavioral control (perceived control over performing the targeted behavior). These direct determinants of intention are respectively associated with indirect constructs: (1) attitudinal beliefs (perceived advantages and disadvantages of using a DA for prenatal screening for Down syndrome during the course of a prenatal care visit during a subsequent pregnancy); (2) normative beliefs (a woman's perceptions of to what extent partner, parents, or friends want her to perform the behavior); and (3) control beliefs (perceived barriers and facilitators of engaging in the behavior) [25]. The identification of beliefs that are associated with the intention to perform the behavior allows the specification of precise targets in future interventions. The extended behavior change model used in this study includes the main determinants of intention according to the TPB (attitude, subjective norm, and perceived control), as well as additional constructs known to improve the predictive capacity of the TPB: (1) anticipated regret, or an estimation of the regret that would result from not adopting the behavior; (2) descriptive norm, or the perceived prevalence of the practice; and (3) moral norm, or the moral principles involved [60-63] (see Figure 1).

Figure 1. Extended model of behavior change. The constructs take into account influence of sociodemographic characteristics*. TPB: Theory of Planned Behavior.



Participants and Recruitment

From September 16, 2015, to October 8, 2015, we recruited eligible pregnant women (Table 1). Eligibility criteria included the following: being at least 18 years old, not less than 16 weeks pregnant, not presenting a high-risk pregnancy (eg, preeclampsia, gestational diabetes, multiple pregnancy), and having already decided about prenatal screening for the current pregnancy. Women who participated in a previous phase of the research were excluded. A private company specialized in polling was mandated to recruit eligible pregnant women in the province of Quebec (Canada) using a Web panel of willing participants in Internet surveys. Canada's health care system consists of 13 (10 provincial and 3 territorial) independent health care systems. In this study, we focused on the province of Quebec, which is the second most populous Canadian province. First, the survey company sent an email invitation to all women on the panel aged from 18 to 44 years. After 2 weeks, to enhance recruitment, the same email invitation was sent to men on the panel aged from 25 to 44 years, as in this age range their partner was more likely to meet our eligibility criteria. The email invitation included the following information: (1) Subject: Research in health services led by Université Laval; (2) Financial compensation: 25 Canadian dollars; (3) Time to answer: next 5 business days; and (4) Personalized link to survey. Nonrespondents received a reminder every 2 weeks until the survey was closed. All interested persons who clicked on the personalized survey link were directed to the closed survey (password-protected) and asked to answer preliminary eligibility questions. Special filters allowed selection of the female partners of recruited men on the panel. Once eligibility criteria were confirmed, eligible women started the voluntary survey.

Data Collection

Participating pregnant women completed the Web-based survey through 39 Web pages that included up to 7 items, always appearing in the same order (see Multimedia Appendix 1). Clear preliminary statements provided information about the study and instructions and allowed participants to confirm their consent. To foster participation, the survey enabled pregnant women to stop the survey at any time and to restart it as long as the personalized survey link was active. No completeness check was possible before submitting the questionnaire. Once an item was answered, the answer could not be changed, as many items were similar and we wanted to test if participants' responses were consistent. Once data collection was completed, the contracted company sent us the data anonymously, which were then stored on our secure network (password-protected).

In earlier research on factors that influence health-related behavior change [64,65], we observed that it is helpful to give participants a vicarious experience of the behavior of interest in order for them to understand it better [66]. As the pregnant women were not expected to have experienced the use of a DA, to help them understand the behavior of interest (action: use; target: a DA for prenatal screening for Down syndrome; context: during the course of prenatal care visits during a subsequent pregnancy; time: not specified), we asked them to watch a 10-minute video first. The video depicted a prenatal care follow-up during which a pregnant woman, her partner, and a health professional used a DA to decide about prenatal screening for Down syndrome. Production of this video had followed a validated process and had proved successful for communicating the behavior of interest [67]. The DA is available in Multimedia Appendix 2. After watching the whole video, eligible women answered the Web-based questionnaire based on the TPB but which included additional psychosocial factors known to influence the uptake of a new behavior [57,60-63]. In a previous step of the project, we had conducted a pilot study to validate this questionnaire [68]. We also measured underlying salient beliefs related to the direct constructs as elicited in a previous qualitative study (Leiva Portocarrero, M. Sc., personal written communication, February 2016). Using 52 closed items scored on a 5-point Likert-type scale, we measured intention, attitude, subjective norm, perceived behavioral control, anticipated regret, descriptive norm, moral norm, attitudinal beliefs, normative beliefs, and control beliefs. Except for attitude and anticipated regret, all direct constructs were assessed with multi-item measures. Anticipated regret was measured with 2 items and attitude with 6 items using bipolar adjective pairs assessing cognitive and affective dimensions of women's attitudes. Cronbach alphas indicated good reliability of multi-items measuring each construct (alpha range .67-.94, Table 2). The questionnaire was developed following Ajzen's guidelines [69] and referred to using a DA to decide about prenatal screening for Down syndrome. All in all, the questionnaire included 52 psychosocial items, 9 sociodemographic items, and 50 health literacy items, for a total of 111 items. It was available in French and English.

To assess health literacy, after consulting with experts in the field [30,48,54,70] and reviewing multiple systematic reviews [71-75], we chose to use both subjective and objective scales. While objective scales measure competencies, subjective scales measure the perception of competencies and have been shown to reduce burden of participants [76-78]. We thus assessed pregnant women's levels of health literacy using the following 4 complementary scales that measure health literacy and numeracy both objectively and subjectively: (1) the short version of the Test of Functional Health Literacy in Adults (S-TOFHLA), the literacy part only, which comprises 36 blank spaces and 4 choices of words to fill the blanks [79,80]; (2) a total of 3 self-administered health literacy questions (3HLQ, 5-point Likert scale: range 0 to 4, final score range 0 to 12) [81]; (3) a total of 3 numeracy questions (3NQ, 3 items, correct answers range 0 to 3) [82]; and (4) the Subjective Numeracy Scale (SNS, 2 subscales of 4 closed questions scored on a 5-point Likert scale, mean score range 1 to 5 for both subscales and complete scale) [76]. Finally, we assessed sociodemographics such as age, clinician in charge of monitoring, mother tongue, ethnicity, civil status, employment status, annual family income, education, and pregnancy number.

Statistical Analysis

Sample Size

Informed by the test-retest of the questionnaire, we postulated that analysis in this study would be best performed using a logistic regression model. On the basis of Peduzzi and colleagues' works on sample size [83] and taking into account all independent variables in this study, we found that a sample of 350 women was sufficient according to the principle of the number of events per variable, which asserts that a minimum of 10 events per variable is required to perform valid logistic regression models [83].

Data Analysis

First, we used simple descriptive statistics (means, standard deviations, medians, quartiles, and percentages) to summarize sociodemographic, sociocognitive, and health literacy variables. For each sociocognitive construct we verified internal consistency by calculating Cronbach alphas, except anticipated regret, for which we did a Spearman correlation. Intention was not normally distributed and, as it could not be transformed successfully, we created 3 categories of intention—scores < 4, scores=4, and scores >4—based on the fact that the subtle gradations that span the 5-point scale made each category distinct in the clinical sense. In line with earlier research on health literacy, we dichotomized all health literacy variables: scores of 3HLQ were dichotomized as inadequate (≤10) or adequate (>10) [52]; scores of 3NQ were dichotomized as < 3 versus 3 correct answers [84]; and scores of SNS were dichotomized at the median (<3.75 vs≥3.75). Scores of S-TOFHLA could not be further analyzed because the lack of variability in the distribution did not enable us to discriminate among the pregnant women's scores. We performed bivariate ordinal logistic regression to measure difference in the distribution of all sociocognitive variables, all sociodemographic variables, and the 4 health literacy variables, according to each of the 3 intention categories. We then performed a first ordinal logistic regression in which only TPB variables were included. We used a backward approach to test the model adjustment with sociodemographic variables. Next, we compared the extended TPB model, including the additional variables of anticipated regret, descriptive norm, and moral norm, with the preceding model. We then added each health literacy variable to the extended model of regression, except for objective literacy (S-TOFHLA), which lacked variability. We also tested the interaction between health literacy variables and all direct constructs. Then, to identify significant underlying beliefs, we replaced significant constructs that determined women's intention with their associated beliefs and performed the regression model with these significant factors (e.g., attitude was replaced by its underlying beliefs). Following a backward approach, we kept significant variables (P<.05). For all comparison models described above, we used deviance to compare the 2 nested models to identify which one was best.

Results

Flow of Participants and Participants' Characteristics

Details on flow of participants are depicted in Figure 2. On the basis of the CHERRIES statement [58], we considered all potentially eligible participants who clicked on the personalized link to visit the survey as unique survey visitors. As the Web survey did not include a middle stage between visiting the website and visiting the first survey page, we adapted the CHERRIES criteria to calculate the study's response rates [58]. Accordingly, view rate (ratio of unique survey visitors/unique receiver of survey invitation), participation rate (ratio of users who agreed to participate/unique survey visitors), and completion rate (ratio of users who finished the survey/users who agreed to participate) were respectively 15.09% (16,943/112,257), 2.26% (383/16,943), and 91.4% (350/383) (Figure 2).

Time of completion was not kept for analysis as participating women could stop and restart the survey. No data were missing as the Web-based questionnaire did not accept unanswered items. Mean age of pregnant women was 31 years. Out of 346 women retained for data analysis, 319 (92.2%) were white, 318 (91.9%) were French-speaking, and 168 (48.6%) had a university degree (see Table 1).

Table 1. Participant characteristics (n=346).

Characteristics	n (%)
Age, years, mean (SD)	30.1 (4.3)
Monitored by	
Obstetrician-gynecologist	201 (58.1)
Family physician	105 (30.3)
Midwife	30 (8.7)
Other	10 (2.9)
Mother tongue	
French	318 (91.9)
English	18 (5.2)
Other	10 (2.9)
Ethnicity	
White	319 (92.2)
African or African American	4 (1.2)
Latin American	5 (1.4)
Arab	8 (2.2)
Chinese	2 (0.6)
Filipino	1 (0.3)
Korean	1 (0.3)
Other	6 (1.8)
Civil status	
Single	23 (6.6)
Not single	323 (93.4)
Employment status	
Full time	269 (77.8)
Part time	45 (13.0)
Unemployed	23 (6.6)
Student	9 (2.6)
Annual family income[a]	
< $29,999	24 (6.9)
$30,000-$59,999	74 (21.4)
$60,000-$99,999	146 (42.2)
>$100,000	82 (23.7)
No answer	20 (5.8)
Education	
No high school	4 (1.2)
High school diploma	25 (7.2)
Professional diploma	61 (17.6)
Collegial diploma	88 (25.4)
University degree	168 (48.6)
Pregnancy number	
First	130 (37.6)
Second	137 (39.6)

Characteristics	n (%)
Third	40 (11.5)
Fourth or more	39 (11.3)
Health literacy, median/total score (% higher level[b])	
Objective literacy	36.00/36 (N/A[c])
Subjective literacy	10.00/12 (51.5)
Objective numeracy	3.00/3 (56.7)
Subjective numeracy (total)	3.88/5 (55.2)

[a] Canadian dollars.

[b] Higher level corresponds to the higher category of each scale when scores were dichotomized.

[c] N/A: not applicable; no further analyses were done for this scale because its lack of variability did not permit dichotomization of the scores.

Figure 2. Flow of participants.

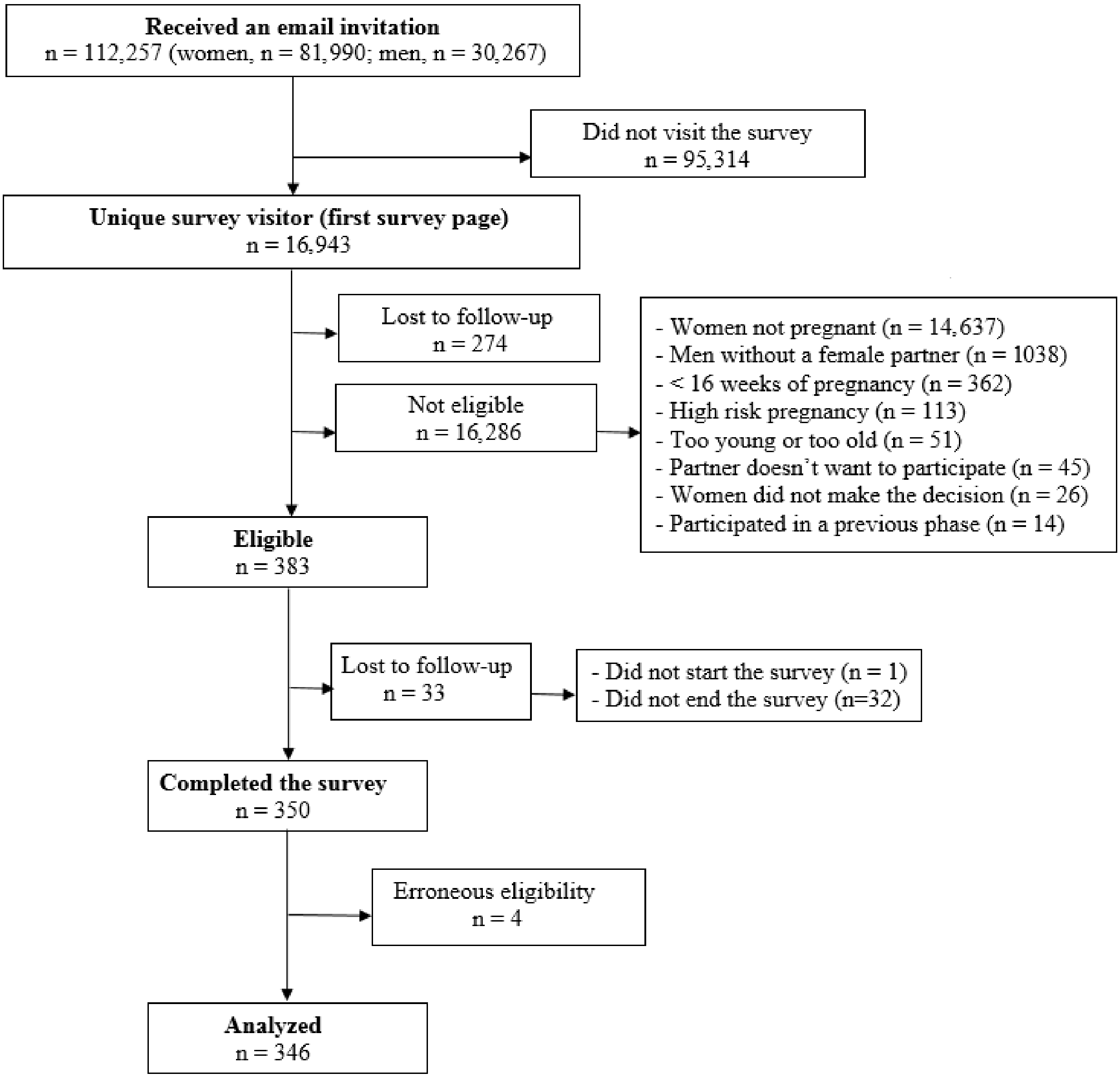


Table 2. Intention and psychosocial factor analysis (n=346).

Construct[a]	Intention score, by category, median (Q1-Q3)			Cronbach alpha	*P* value[b]
	<4 n=109 (31.5%)	4 n=92 (26.6%)	>4 n=145 (41.9%)		
Attitude (6 items)	3.50 (2.33-3.67)	3.67 (3.00-4.00)	4.33 (4.00-4.67)	.85	< .001
Anticipated regret (2 items)	2.00 (1.50-3.00)	3.00 (2.50-3.50)	3.50 (3.00-4.00)	.67[c]	< .001
Subjective norm (3 items)	3.00 (3.00-3.67)	4.00 (3.67-4.33)	4.67 (4.33-5.00)	.84	< .001
Descriptive norm (3 items)	3.00 (2.67-4.00)	4.00 (3.33-4.00)	4.00 (4.00-4.67)	.85	< .001
Moral norm (3 items)	3.33 (3.00-3.67)	4.00 (3.83-4.00)	5.00 (4.67-5.00)	.90	< .001
Perceived control (5 items)	4.00 (3.50-4.25)	4.25 (3.75-4.50)	4.50 (4.25-5.00)	.67	< .001

[a] Range from 1 to 5.

[b] Bivariate ordinal logistic regression.

[c] Spearman correlation.

Descriptive and Bivariate Analyses

Intention to use the DA for deciding about prenatal Down syndrome screening during a subsequent pregnancy, and factors of this intention, showed generally high scores. Among the 346 pregnant women, 109 (31.5%) had an intention score of < 4 out of 5, a total of 92 (26.6%) had an intention score of 4 out of 5, and 145 (41.9%) had an intention score of >4 out of 5. All the direct determinants of intention showed similar scores (≥ 3.00 out of 5, see Table 2 and Multimedia Appendix 3 for details), except anticipated regret, which showed a median score of 2.00. The level of health literacy was generally high. A median score of 36.00 out of 36 was obtained for objective literacy (S-TOFHLA), 10.00 out of 12 for subjective literacy (3HLQ), 3.00 out of 3 for objective numeracy (3NQ), and 3.88 out of 5 for subjective numeracy (SNS total score; Table 1).

With our bivariate analysis, we found that all sociocognitive factors were significantly associated with intention (*P*<.001 for all, Table 2).

No sociodemographic and health literacy variable was significantly associated with intention (Multimedia Appendices 4 and 5). In exploring correlations between health literacy variables and sociocognitive constructs, we found the most frequent association was with perceived control, which showed significant associations with all health literacy variables except objective numeracy (Multimedia Appendix 6). In addition, we observed that all health literacy scales were correlated among themselves (rho range .14-.89, *P* value range .007-.001; see Multimedia Appendix 6).

Multivariate Analysis

Finally, we identified the most significant factors in women's intention to use the DA. In the first multivariate model, including only TPB variables, attitude (odds ratio, OR, 13.38, 95% CI 6.40-27.90), subjective norm (OR 3.64, 95% CI 2.33-5.70), and perceived control (OR 2.36, 95% CI 1.43-3.90) were significant factors of pregnant women's intention (Table 3). No sociodemographic variable was added to the model.

In the second multivariate model, still based on the TPB but including the additional variables of anticipated regret, descriptive norms, and moral norms, we found that attitude (OR 9.16, 95% CI 4.02-20.85), moral norm (OR 7.97, 95% CI 4.49-14.14), descriptive norm (OR 2.83, 95% CI 1.63-4.92), and anticipated regret (OR 2.43, 95% CI 1.71-3.46) were significant factors of pregnant women's intention (Table 3). Comparison of deviance showed that the model that included additional sociocognitive variables better explained pregnant women's intention (Δ deviance=41.33, *P*>.05, Table 3).

To investigate whether health literacy predicted pregnant women's intention in our theoretical model, we sequentially added each health literacy variable to the ordinal logistic regression model and observed that the pregnant women's intention was not affected by health literacy (Table 3). In addition, no interaction term was identified between health literacy variables and direct constructs determining intention. We performed structural equation modeling in parallel with our stepwise regression model and observed the same results (data not shown but available from authors).

To identify significant underlying beliefs, we performed another ordinal logistic regression model with beliefs related to attitude, as attitude was the only significant construct with underlying beliefs. We found 3 significant beliefs related specifically to the attitude construct, namely, that the use of a DA (1) would reassure pregnant women (OR 2.55, 95% CI 1.73-4.01), (2) would facilitate their reflection with their spouse (OR 1.55, 95% CI 1.05-2.29), and (3) would let them know about the advantages of doing or not doing a prenatal screening test for Down syndrome (OR 1.53, 95% CI 1.05-2.24; Table 4).

Table 3. Significant determinants of pregnant women’s intention (n=346).

Construct	Odds ratio (95% CI)					
	TPB[a]	Extended TPB	Extended TPB and subjective numeracy	Extended TPB and subjective literacy	Extended TPB and objective numeracy	Extended TPB and objective literacy[b]
Attitude	13.38 (6.40-27.90)	9.16 (4.02-20.85)	9.13 (4.00-20.84)	9.26 (4.06-21.11)	9.58 (4.14-22.12)	N/A[c]
Subjective norm	3.64 (2.33-5.70)	0.91 (0.51-1.61)	0.91 (0.51-1.61)	0.90 (0.50-1.60)	0.89 (0.50-1.59)	N/A
Perceived control	2.36 (1.43-3.90)	1.69 (0.92-3.08)	1.68 (0.91-3.09)	1.75 (0.95-3.22)	1.65 (0.89-3.03)	N/A
Anticipated regret	N/A	2.43 (1.71-3.46)	2.44 (1.70-3.48)	2.33 (1.61-3.36)	2.47 (1.73-3.52)	N/A
Descriptive norm	N/A	2.83 (1.63-4.92)	2.83 (1.63-4.92)	2.82 (1.62-4.90)	2.84 (1.64-4.93)	N/A
Moral norm	N/A	7.97 (4.49-14.14)	7.97 (4.49-14.15)	8.38 (4.65-15.06)	7.92 (4.46-14.08)	N/A
Health literacy[d]	N/A	N/A	1.02 (0.58-1.81)	0.78 (0.43-1.43)	1.18 (0.66-2.12)	N/A
Deviance	316.78	358.11	358.10	357.48	357.80	N/A
Δ deviance		41.33	0.01	0.63	0.31	N/A
P value		<.001	.92	.43	.58	N/A

[a] TPB: Theory of Planned Behavior.

[b] Objective literacy could not be added to the regression model because of the lack of variability in the distribution.

[c] N/A: not applicable.

[d] Subjective numeracy: score≥ median versus score < median; subjective health literacy: adequate versus inadequate; objective numeracy: all correct answers versus one error or more.

Table 4. Significant beliefs of pregnant women (n=346).

Construct	Underlying belief	Descriptive analysis		Odds ratio (95% CI)
		Mean[a] (SD)	Median[a] (Q1-Q3)	
Attitude	Emotions: the use of a DA[b] would reassure pregnant women	3.85 (0.96)	4.00 (3.00-5.00)	2.55 (1.73-4.01)
	Advantages: the use of a DA would facilitate their reflection with their spouse	4.15 (0.91)	4.00 (4.00-5.00)	1.55 (1.05-2.29)
	Advantages: the use of a DA would let them know about the advantages of doing or not doing the prenatal screening test for DS[c]	4.28 (0.94)	4.00 (4.00-5.00)	1.53 (1.05-2.24)
Anticipated regret	N/A[d]	2.95 (1.04)	3.00 (2.00-4.00)	2.06 (1.47-2.88)
Descriptive norm	N/A	3.79 (0.80)	4.00 (3.33-4.33)	2.73 (1.62-4.58)
Moral norm	N/A	4.05 (0.87)	4.00 (3.67-5.00)	8.86 (5.19-15.14)

[a] Out of 5.

[b] DA: decision aid.

[c] DS: Down syndrome.

[d] N/A: not applicable.

Discussion

Principal Findings

In this theory-based Web survey, we sought to identify psychosocial factors influencing pregnant women's intention to use a DA for prenatal screening for Down syndrome and assessed whether health literacy added to the predictive power of this model. There are no data specifying the profile of pregnant women in the province of Quebec, but our sample compared well to that of women in the province overall, except for education and health literacy levels, which were higher in our sample [85-87]. Overall, we found that pregnant women showed high levels of intention to use a DA for prenatal screening for Down syndrome. Also, we observed that, in order of importance, attitude, moral and descriptive norms, and anticipated regret were the factors that explained most of their behavioral intention. In other words, the perception of the advantages of using a DA (attitude), the possible regret foreseen if the DA is not used (anticipated regret), the perception that it is a common practice (descriptive norm), and the feeling that using a DA for this decision would be in agreement with their moral values (moral norm) were significantly associated with a strong intention to use the DA. In addition, we identified 3 attitudinal beliefs significantly associated with women's intention: perceiving that using a DA (1) would reassure them, (2) would facilitate their reflection with their spouse, and (3) would let them know about the advantages of doing or not doing a prenatal screening test for Down syndrome. On the other hand, our findings showed that neither health literacy levels nor individual sociodemographic characteristics had any influence on the behavioral intention of interest, suggesting that, regardless of their health literacy levels and sociodemographic characteristics, all women are under the influence of the same sociocognitive factors regarding whether or not they intend to use a DA for prenatal screening for Down syndrome. These findings lead us to make 5 main points with regards to pregnant women's intention, the direct determinants of their intention, their underlying beliefs, the influence of health literacy, and the next steps.

Comparison With Prior Work

First, to the best of our knowledge, this study is among the first to adopt an all-encompassing theory-based approach to identifying factors, including health literacy, influencing the intention to use a DA in prenatal care. Our results support earlier research on SDM implementation indicating that women showed a strong intention to engage in SDM regarding prenatal screening for Down syndrome [26]. Moreover, this high level of intention may reflect a need felt by pregnant women facing prenatal screening choices to become more skilled in discussing screening tests with their health care provider, which is congruent with the literature on pregnant women's decision-making needs [4,6,9]. This strong intention suggests that future efforts to increase DA use and SDM among clinicians for prenatal screening for Down syndrome would find a favorable response in pregnant women.

Second, we observed that the following factors, in order of importance, influenced pregnant women's intention: attitude, moral norm, descriptive norm, and anticipated regret. These findings are congruent with earlier research on SDM implementation in this context [26], which showed that attitude, subjective norm, self-efficacy, and moral norm were determinants of pregnant women's intention to engage in SDM. Although the variables “descriptive norm” and “anticipated regret” were not investigated in the earlier study, the influence of social pressure came out through the subjective norm variable, which refers to the influence of significant individuals in women's entourage. Contrary to the findings of our study, and despite the similarity of the samples, however, the previous study showed self-efficacy as a determining factor among women without postsecondary education (although not among women with a higher level of education), whereas in our study sample perceived control was not a significant factor. Self-efficacy and perceived control are not the same constructs, but they are closely related as they both refer to a person's evaluation of the degree of difficulty of adopting a given behavior. This difference in findings could reflect the fact that the earlier study considered intention to *engage in SDM* while our study asked women about their intention to *use a DA*, a practice that constitutes one specific behavior in the overall SDM process. Pregnant women with low education could have more confidence (self-efficacy) about using a DA than about engaging in SDM in general, belying the common myth that the use of DAs is equivalent to the behavior of engaging in SDM [12,88].

Third, significant salient beliefs underlying attitude were, in order of importance, (1) the women's belief that the use of a DA would reassure them; (2) the belief that it would facilitate their reflection with their spouse; and (3) the belief that it would let them know about the advantages of doing or not doing the prenatal screening test for Down syndrome. These results are congruent with earlier research on decisional needs among pregnant women facing prenatal screening for Down syndrome, which showed that the main difficulties perceived by pregnant women were pressure from others, emotions, and lack of information [4]. Our findings provide information about modifiable attitudinal beliefs regarding DA use that could facilitate design of implementation strategies to increase their use by pregnant women in clinical practice. According to the Intervention Mapping approach, efficient interventions should “contain specific messages that target selected beliefs within the determinants of interest, and require specific translation to practical applications to reach optimal fit” [23]. In practice, a public health communication campaign combined with interventions mediated by health professionals could reinforce the influence of women's attitude to DA use by targeting its 3 identified underlying beliefs (reassurance, reflection with spouse, awareness of advantages of each choice). Key statements regarding these 3 salient beliefs could also be added to the DA to increase women's intention to use it and help clinicians to explain it.

Fourth, health literacy was not a factor that influenced women's intention in our study, although many studies have shown associations between health literacy and related notions, such as patient involvement in decision making [27,38,40-43,47,68]. Hence, a single population based DA implementation program would benefit any pregnant women in the province of Quebec to help them make informed values-congruent decision about prenatal screening for Down syndrome. To the best of our knowledge, this study is among the first to investigate the role of health literacy within the context of a theory-driven study using a behavior change model. Our findings suggest that regardless of their perceived or actual capacity to understand complex information, pregnant women would like to use a DA to decide about prenatal screening for Down syndrome. In addition, in our bivariate analyses we did identify some interesting associations between health literacy and perceived control. Although perceived control was not a predictive factor in our study, this association suggests that in contexts where it does play a predictive role, such as intention to engage in healthy eating behaviors [89], intention may be affected by health literacy. Similar studies that include populations with low health literacy should be conducted before decisive claims can be made. However, some have argued that it would be more efficient to work at clearer health communication and fostering participation among all patients rather than screening them for health literacy [90]. Our results should not be used to minimize the importance of improving patients' understanding. It is of primary importance to communicate clearly with every pregnant woman about Down syndrome screening and invite them to ask questions, whatever their health literacy level.

Finally, if the findings of this study are valid, identifying the 4 most significant determinants of pregnant women's intention to use a DA to decide about Down syndrome screening will be useful for the design of interventions to promote uptake. Each of the 4 determinants can be mapped to the Behavior Change Wheel [91], a method developed to inform the design of behavior change interventions. This generates a set of recommended interventions (such as education, training programs, persuasion, modelling, etc), each with its appropriate related methods. For example, clinicians could be trained to introduce the advantages of using the DA, and present the use of DAs as a common practice. Indeed, while it has been shown that lack of training was an important barrier to DA implementation [17], pregnant women indicated that clinicians had a key role in delivering such information [92]. An implementation intervention could also consist of a Web-based application coupled with a DA, which would enrich the current bank of online decision support tools [93]. In terms of moral norm, our findings confirm that there is a significant ethical dimension to the decision about prenatal screening [94-96]. No psychological techniques have yet been formally identified for considering the influence of the moral norm in an intervention [97]. Also, it has been shown that interventions that aim to manipulate moral norms can be counterproductive because of a "boomerang effect" that arises when a person perceives that his or her freedom is threatened by social pressure [98,99]. Health professionals could thus simply be invited to explain to women why moral values are at stake in the decision, so that they can subsequently discuss this and clarify the decision in light of the woman's moral principles.

Limitations

This study has limitations. First, although we suspected that the lack of variability in our health literacy findings could have been due to lack of scale discriminating capacity in our sample, except for the objective health literacy scale (S-TOFHLA), the administered scales covered many dimensions of health literacy and correlated together, indicating a convergence of the results (see Multimedia Appendix 7). In addition, this study will enable further validation of new French versions of the 3 scales.

Second, it is possible that the video used to present the behavior of using a DA mediated pregnant women's intent. However, we felt it was more important to ensure that respondents understood the nature of the behavior being studied than to avoid any risk of mediated intent by not using a video at all.

Third, use of the TPB framework could in itself have shaped our findings. For example, the assumption that agents and their actions are rational may neglect the role of nonrational factors (such as emotion or experience) in human action and reasoning. Also, the approach underestimates the singularity of each agent, as it considers that similar agents are influenced by similar factors [100]. Despite these theoretical limitations, from the wider perspective of developing potentially effective implementation strategies, a TPB-based approach promotes the collection of comprehensive, consistent and valid information, and is still one of the most frequently applied theories in the domain of behavior change.

Finally, we cannot assume that the results can be extrapolated widely without further research. Pregnant women in the sample were mostly white, with French as their mother tongue. This may weaken the external validity of our sample, but not with regards to the general population of the province of Quebec, which was the aim of this study. Because Canadian health care services are organized into 10 provincial and 3 territorial health care systems, each requires its own population-based prenatal screening program. Also, pregnant women in our sample were highly educated compared with women in the province of Quebec overall, where less than a quarter of women aged from 15 to 44 years old have a university education [87]. Likewise, health literacy levels were very high overall, far above that of the general population of the province of Quebec but also of the rest of Canada, where more than half the population has inadequate levels [85,86]. Pregnant women in our sample were recruited from a large Web panel and, as participants willingly subscribed to the panel, their literacy levels, including health literacy and eHealth literacy, might be higher than that of the general population [101]. Our study sample may thus lack representativeness with regard to vulnerable and less literate populations.

Our recruitment methods reflected our main objective (psychosocial determinants of women's intention), but methods in future studies looking at health literacy should be informed by the specificities of the studied population with respect to education levels, Internet use and eHealth literacy.

Conclusions

This study, based on a theoretical approach to behavior change, indicated which factors will need to be addressed to design an effective implementation intervention for the use of DAs in the context of prenatal screening for Down syndrome. Our findings indicate that women's intention to use a DA in this context was determined by the consequent pros and cons they perceived (attitude), its compatibility with their moral values (moral norm), their perception of how much other women use it (descriptive norm), and the regret they perceive they might feel if they do not use it (anticipated regret). This study provides valuable and specific guidance for designing an intervention to implement the use of a DA and ultimately to foster SDM in prenatal care.

Acknowledgments

Funding for the study was provided by Genome Canada's PEGASUS project, the Canadian Institutes of Health Research (CIHR), Genome Quebec, the Ministère de l'enseignement supérieur, de la recherche, de la science et de la technologie du Québec, Genome Alberta, and Genome British Columbia. Authors are very grateful to all consulted experts who helped us to improve our methods and our data analyses. We also thank Louisa Blair for her kind help with the writing, as well as all participating pregnant women.

Authors' Contributions

The study was led by FL, Chairholder of the Canada Research Chair in Shared Decision Making and Knowledge Translation. All authors contributed to the conception and writing of this study. AD, JL, and FL contributed to the study design. Data analyses were done by ST, AD, JL, and FL.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Online questionnaire.

[PDF File (Adobe PDF File), 1MB - jmir_v18i10e283_app1.pdf]

Multimedia Appendix 2

Decision aid for prenatal screening for Down syndrome.

[PDF File (Adobe PDF File), 2MB - jmir_v18i10e283_app2.pdf]

Multimedia Appendix 3

Socio-cognitive variables scores and correlations.

[PDF File (Adobe PDF File), 31KB - jmir_v18i10e283_app3.pdf]

Multimedia Appendix 4

Intention level by sociodemographic characteristics.

[PDF File (Adobe PDF File), 133KB - jmir_v18i10e283_app4.pdf]

Multimedia Appendix 5

Bivariate analysis of health literacy by intention category.

[PDF File (Adobe PDF File), 32KB - jmir_v18i10e283_app5.pdf]

Multimedia Appendix 6

Associations between health literacy scores and socio-cognitive factors.

[PDF File (Adobe PDF File), 42KB - jmir_v18i10e283_app6.pdf]

Multimedia Appendix 7

Health literacy measure correlations.

[PDF File (Adobe PDF File), 35KB - jmir_v18i10e283_app7.pdf]

References

1. Burke W, Tarini B, Press NA, Evans JP. Genetic screening. Epidemiol Rev 2011 Jun 27;33(1):148-164. [Medline: 21709145]

2. Asplin N, Wessel H, Marions L, Georgsson Öhman S. Pregnant women's experiences, needs, and preferences regarding information about malformations detected by ultrasound scan. Sex Reprod Healthc 2012 Jun;3(2):73-78. [doi: 10.1016/j.srhc.2011.12.002] [Medline: 22578754]
3. Legare F, O'Connor AC, Graham I, Saucier D, Cote L, Cauchon M, et al. Supporting patients facing difficult health care decisions: use of the Ottawa Decision Support Framework. Can Fam Physician 2006 Apr 10;52(4):476-477. [Medline: 17327891]
4. St-Jacques S, Grenier S, Charland M, Forest JC, Rousseau F, Légaré F. Decisional needs assessment regarding Down syndrome prenatal testing: a systematic review of the perceptions of women, their partners and health professionals. Prenat Diagn 2008 Dec;28(13):1183-1203. [doi: 10.1002/pd.2059] [Medline: 19097031]
5. Munthe C. A new ethical landscape of prenatal testing: individualizing choice to serve autonomy and promote public health: a radical proposal. Bioethics 2015 Jan;29(1):36-45. [doi: 10.1111/bioe.12126] [Medline: 25521972]
6. van Schendel RV, Dondorp WJ, Timmermans DR, van Hugte EJ, de Boer A, Pajkrt E, et al. NIPT-based screening for Down syndrome and beyond: what do pregnant women think? Prenat Diagn 2015 Jun;35(6):598-604. [doi: 10.1002/pd.4579] [Medline: 25693726]
7. Hewison J. Psychological aspects of individualized choice and reproductive autonomy in prenatal screening. Bioethics 2015 Jan;29(1):9-18. [doi: 10.1111/bioe.12124] [Medline: 25521969]
8. van Schendel RV, Kleinveld JH, Dondorp WJ, Pajkrt E, Timmermans DR, Holtkamp KC, et al. Attitudes of pregnant women and male partners towards non-invasive prenatal testing and widening the scope of prenatal screening. Eur J Hum Genet 2014 Dec;22(12):1345-1350 [FREE Full text] [doi: 10.1038/ejhg.2014.32] [Medline: 24642832]
9. Farrell RM, Agatisa PK, Nutter B. What women want: lead considerations for current and future applications of noninvasive prenatal testing in prenatal care. Birth 2014 Sep;41(3):276-282 [FREE Full text] [doi: 10.1111/birt.12113] [Medline: 24825739]
10. de Jong A, de Wert GM. Prenatal screening: an ethical agenda for the near future. Bioethics 2015 Jan;29(1):46-55. [doi: 10.1111/bioe.12122] [Medline: 25521973]
11. Marteau TM, Dormandy E, Michie S. A measure of informed choice. Health Expect 2001 Jun;4(2):99-108. [Medline: 11359540]
12. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev 2011(10):CD001431. [doi: 10.1002/14651858.CD001431.pub3] [Medline: 21975733]
13. Skjøth MM, Draborg E, Pedersen CD, Hansen HP, Lamont RF, Jørgensen JS. Providing information about prenatal screening for Down syndrome: a systematic review. Acta Obstet Gynecol Scand 2015 Feb;94(2):125-132. [doi: 10.1111/aogs.12543] [Medline: 25412186]
14. Vlemmix F, Warendorf JK, Rosman AN, Kok M, Mol BW, Morris JM, et al. Decision aids to improve informed decision-making in pregnancy care: a systematic review. BJOG 2013 Feb;120(3):257-266 [FREE Full text] [doi: 10.1111/1471-0528.12060] [Medline: 23145991]
15. van Agt HM, Korfage IJ, Essink-Bot ML. Interventions to enhance informed choices among invitees of screening programmes-a systematic review. Eur J Public Health 2014 Oct;24(5):789-801 [FREE Full text] [doi: 10.1093/eurpub/ckt205] [Medline: 24443115]
16. Leiva Portocarrero ME, Garvelink MM, Becerra Perez MM, Giguere A, Robitaille H, Wilson BJ, et al. Decision aids that support decisions about prenatal testing for Down syndrome: an environmental scan. BMC Med Inform Decis Mak 2015 Sep 24;15:76. [Medline: 26404088]
17. Elwyn G, Scholl I, Tietbohl C, Mann M, Edwards AG, Clay C, et al. “Many miles to go …”: a systematic review of the implementation of patient decision support interventions into routine clinical practice. BMC Med Inform Decis Mak 2013;13(Suppl 2):S14 [FREE Full text] [doi: 10.1186/1472-6947-13-S2-S14] [Medline: 24625083]
18. Légaré F, Ratté S, Gravel K, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. Patient Educ Couns 2008 Dec;73(3):526-535. [doi: 10.1016/j.pec.2008.07.018] [Medline: 18752915]
19. Lépine J, Leiva Portocarrero ME, Delanoë A, Robitaille H, Lévesque I, Rousseau F, et al. What factors influence health professionals to use decision aids for Down syndrome prenatal screening? BMC Pregnancy Childbirth 2016 Sep 5;16:262 [FREE Full text] [doi: 10.1186/s12884-016-1053-2] [Medline: 27596573]
20. Giguere A, Légaré F, Grad R, Pluye P, Haynes RB, Cauchon M, et al. Decision boxes for clinicians to support evidence-based practice and shared decision making: the user experience. Implement Sci 2012 Aug 03;7:72 [FREE Full text] [doi: 10.1186/1748-5908-7-72] [Medline: 22862935]
21. Giguere AM, Labrecque M, Haynes RB, Grad R, Pluye P, Légaré F, et al. Evidence summaries (decision boxes) to prepare clinicians for shared decision-making with patients: a mixed methods implementation study. Implement Sci 2014 Oct 05;9:144 [FREE Full text] [doi: 10.1186/s13012-014-0144-6] [Medline: 25280742]
22. Frosch DL, Légaré F, Mangione CM. Using decision aids in community-based primary care: a theory-driven evaluation with ethnically diverse patients. Patient Educ Couns 2008 Dec;73(3):490-496 [FREE Full text] [doi: 10.1016/j.pec.2008.07.040] [Medline: 18771875]

23. Kok G, Gottlieb NH, Peters GY, Mullen PD, Parcel GS, Ruiter RA, et al. A taxonomy of behaviour change methods: an Intervention Mapping approach. Health Psychol Rev 2016;10(3):297-312. [doi: 10.1080/17437199.2015.1077155] [Medline: 26262912]
24. Michie S, Johnston M, Abraham C, Lawton R, Parker D, Walker A, “Psychological Theory” Group. Making psychological theory useful for implementing evidence based practice: a consensus approach. Qual Saf Health Care 2005 Feb;14(1):26-33 [FREE Full text] [doi: 10.1136/qshc.2004.011155] [Medline: 15692000]
25. Ajzen I. The theory of planned behavior. Organ Behav Hum Decis Process 1991 Dec;50(2):179-211. [doi: 10.1016/0749-5978(91)90020-T]
26. Légaré F, St-Jacques S, Gagnon S, Njoya M, Brisson M, Frémont P, et al. Prenatal screening for Down syndrome: a survey of willingness in women and family physicians to engage in shared decision-making. Prenat Diagn 2011 Apr;31(4):319-326. [doi: 10.1002/pd.2624] [Medline: 21268046]
27. Malloy-Weir LJ, Charles C, Gafni A, Entwistle VA. Empirical relationships between health literacy and treatment decision making: a scoping review of the literature. Patient Educ Couns 2015 Mar;98(3):296-309. [doi: 10.1016/j.pec.2014.11.004] [Medline: 25535012]
28. Malloy-Weir LJ, Schwartz L, Yost J, McKibbon KA. Empirical relationships between numeracy and treatment decision making: A scoping review of the literature. Patient Educ Couns 2016 Mar;99(3):310-325. [doi: 10.1016/j.pec.2015.10.002] [Medline: 26519238]
29. van der Heide I, Uiters E, Jantine SA, Rademakers J, Fransen M. Health literacy and informed decision making regarding colorectal cancer screening: a systematic review. Eur J Public Health 2015 Aug;25(4):575-582. [doi: 10.1093/eurpub/ckv005] [Medline: 25733553]
30. McCaffery K, Sheridan S, Nutbeam D, Clayman M, Kelly-Blake K, Rovner D, et al. Addressing health literacy. International Patient Decision Aids Standards (IPDAS). 2012. URL: http://www.ipdas.ohri.ca/ [accessed 2016-10-24] [WebCite Cache ID 6lUj27qw3]
31. McCaffery KJ, Holmes-Rovner M, Smith SK, Rovner D, Nutbeam D, Clayman ML, et al. Addressing health literacy in patient decision aids. BMC Med Inform Decis Mak 2013;13(Suppl 2):S10 [FREE Full text] [doi: 10.1186/1472-6947-13-S2-S10] [Medline: 24624970]
32. Golbeck AL, Ahlers-Schmidt CR, Paschal AM, Dismuke SE. A definition and operational framework for health numeracy. Am J Prev Med 2005 Nov;29(4):375-376. [doi: 10.1016/j.amepre.2005.06.012] [Medline: 16242604]
33. Peters E, Hibbard J, Slovic P, Dieckmann N. Numeracy skill and the communication, comprehension, and use of risk-benefit information. Health Aff (Millwood) 2007;26(3):741-748 [FREE Full text] [doi: 10.1377/hlthaff.26.3.741] [Medline: 17485752]
34. Nutbeam D. The evolving concept of health literacy. Soc Sci Med 2008 Dec;67(12):2072-2078. [doi: 10.1016/j.socscimed.2008.09.050] [Medline: 18952344]
35. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, (HLS-EU) European Consortium Health Literacy Project. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health 2012 Jan 25;12:80 [FREE Full text] [doi: 10.1186/1471-2458-12-80] [Medline: 22276600]
36. Smith SG, Curtis LM, Wardle J, von WC, Wolf MS. Skill set or mind set? Associations between health literacy, patient activation and health. PLoS One 2013;8(9):e74373 [FREE Full text] [doi: 10.1371/journal.pone.0074373] [Medline: 24023942]
37. Fraenkel L, Cunningham M, Peters E. Subjective numeracy and preference to stay with the status quo. Med Decis Making 2015 Jan;35(1):6-11 [FREE Full text] [doi: 10.1177/0272989X14532531] [Medline: 24759686]
38. DeWalt DA, Boone RS, Pignone MP. Literacy and its relationship with self-efficacy, trust, and participation in medical decision making. Am J Health Behav 2007;31(Suppl 1):S27-S35. [doi: 10.5555/ajhb.2007.31.supp.S27] [Medline: 17931133]
39. Lillie SE, Brewer NT, O'Neill SC, Morrill EF, Dees EC, Carey LA, et al. Retention and use of breast cancer recurrence risk information from genomic tests: the role of health literacy. Cancer Epidemiol Biomarkers Prev 2007 Feb;16(2):249-255 [FREE Full text] [doi: 10.1158/1055-9965.EPI-06-0525] [Medline: 17267389]
40. Mancuso CA, Rincon M. Asthma patients' assessments of health care and medical decision making: the role of health literacy. J Asthma 2006 Jan;43(1):41-44. [doi: 10.1080/02770900500447052] [Medline: 16448964]
41. Naik AD, Street Jr RL, Castillo D, Abraham NS. Health literacy and decision making styles for complex antithrombotic therapy among older multimorbid adults. Patient Educ Couns 2011 Dec;85(3):499-504 [FREE Full text] [doi: 10.1016/j.pec.2010.12.015] [Medline: 21251788]
42. Yin HS, Dreyer BP, Vivar KL, MacFarland S, van Schaick L, Mendelsohn AL. Perceived barriers to care and attitudes towards shared decision-making among low socioeconomic status parents: role of health literacy. Acad Pediatr 2012 Mar;12(2):117-124 [FREE Full text] [doi: 10.1016/j.acap.2012.01.001] [Medline: 22321814]
43. Galesic M, Garcia-Retamero R. Do low-numeracy people avoid shared decision making? Health Psychol 2011 May;30(3):336-341. [doi: 10.1037/a0022723] [Medline: 21553977]
44. Seo J, Goodman MS, Politi M, Blanchard M, Kaphingst KA. Effect of health literacy on decision-making preferences among medically underserved patients. Med Decis Making 2016 May;36(4):550-556. [doi: 10.1177/0272989X16632197] [Medline: 26902737]

45. Ishikawa H, Yano E, Fujimori S, Kinoshita M, Yamanouchi T, Yoshikawa M, et al. Patient health literacy and patient-physician information exchange during a visit. Fam Pract 2009 Dec;26(6):517-523 [FREE Full text] [doi: 10.1093/fampra/cmp060] [Medline: 19812242]
46. Katz MG, Jacobson TA, Veledar E, Kripalani S. Patient literacy and question-asking behavior during the medical encounter: a mixed-methods analysis. J Gen Intern Med 2007 Jun;22(6):782-786 [FREE Full text] [doi: 10.1007/s11606-007-0184-6] [Medline: 17431697]
47. Smith SK, Dixon A, Trevena L, Nutbeam D, McCaffery KJ. Exploring patient involvement in healthcare decision making across different education and functional health literacy groups. Soc Sci Med 2009 Dec;69(12):1805-1812. [doi: 10.1016/j.socscimed.2009.09.056] [Medline: 19846245]
48. Fagerlin A, Ubel PA, Smith DM, Zikmund-Fisher BJ. Making numbers matter: present and future research in risk communication. Am J Health Behav 2007;31(Suppl 1):S47-S56. [doi: 10.5555/ajhb.2007.31.supp.S47] [Medline: 17931136]
49. Peters E, Västfjäll D, Slovic P, Mertz CK, Mazzocco K, Dickert S. Numeracy and decision making. Psychol Sci 2006 May;17(5):407-413. [doi: 10.1111/j.1467-9280.2006.01720.x] [Medline: 16683928]
50. Apter AJ, Paasche-Orlow MK, Remillard JT, Bennett IM, Ben-Joseph EP, Batista RM, et al. Numeracy and communication with patients: they are counting on us. J Gen Intern Med 2008 Dec;23(12):2117-2124 [FREE Full text] [doi: 10.1007/s11606-008-0803-x] [Medline: 18830764]
51. Lipkus IM, Samsa G, Rimer BK. General performance on a numeracy scale among highly educated samples. Med Decis Making 2001;21(1):37-44. [Medline: 11206945]
52. Veldwijk J, van der Heide I, Rademakers J, Schuit AJ, de Wit GA, Uiters E, et al. Preferences for vaccination: does health literacy make a difference? Med Decis Making 2015 Nov;35(8):948-958. [doi: 10.1177/0272989X15597225] [Medline: 26338176]
53. Lea DH, Kaphingst KA, Bowen D, Lipkus I, Hadley DW. Communicating genetic and genomic information: health literacy and numeracy considerations. Public Health Genomics 2011;14(4-5):279-289 [FREE Full text] [doi: 10.1159/000294191] [Medline: 20407217]
54. Zikmund-Fisher BJ, Exe NL, Witteman HO. Numeracy and literacy independently predict patients' ability to identify out-of-range test results. J Med Internet Res 2014;16(8):e187 [FREE Full text] [doi: 10.2196/jmir.3241] [Medline: 25135688]
55. Cho RN, Plunkett BA, Wolf MS, Simon CE, Grobman WA. Health literacy and patient understanding of screening tests for aneuploidy and neural tube defects. Prenat Diagn 2007 May;27(5):463-467. [doi: 10.1002/pd.1712] [Medline: 17345585]
56. Eccles M, Grimshaw J, Walker A, Johnston M, Pitts N. Changing the behavior of healthcare professionals: the use of theory in promoting the uptake of research findings. J Clin Epidemiol 2005 Feb;58(2):107-112. [doi: 10.1016/j.jclinepi.2004.09.002] [Medline: 15680740]
57. Frosch DL, Légaré F, Fishbein M, Elwyn G. Adjuncts or adversaries to shared decision-making? Applying the Integrative Model of behavior to the role and design of decision support interventions in healthcare interactions. Implement Sci 2009;4:73 [FREE Full text] [doi: 10.1186/1748-5908-4-73] [Medline: 19909547]
58. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). J Med Internet Res 2004 Sep 29;6(3):e34 [FREE Full text] [doi: 10.2196/jmir.6.3.e34] [Medline: 15471760]
59. Godin G, Bélanger-Gravel A, Eccles M, Grimshaw J. Healthcare professionals' intentions and behaviours: a systematic review of studies based on social cognitive theories. Implement Sci 2008;3:36 [FREE Full text] [doi: 10.1186/1748-5908-3-36] [Medline: 18631386]
60. Rivis A, Sheeran P. Descriptive norms as an additional predictor in the theory of planned behaviour: a meta-analysis. Curr Psychol 2003 Sep;22(3):218-233. [doi: 10.1007/s12144-003-1018-2]
61. Conner M, Armitage CJ. Extending the theory of planned behavior: a review and avenues for further research. J Appl Social Pyschol 1998 Aug;28(15):1429-1464. [doi: 10.1111/j.1559-1816.1998.tb01685.x]
62. Sandberg T, Conner M. Anticipated regret as an additional predictor in the theory of planned behaviour: a meta-analysis. Br J Soc Psychol 2008 Dec;47(Pt 4):589-606. [doi: 10.1348/014466607X258704] [Medline: 18039428]
63. Godin G. Les comportements dans le domaine de la santé. Montréal: Les Presses de l'Université de Montréal; Nov 2012.
64. Légaré F, Stacey D, Brière N, Fraser K, Desroches S, Dumont S, et al. Healthcare providers' intentions to engage in an interprofessional approach to shared decision-making in home care programs: a mixed methods study. J Interprof Care 2013 May;27(3):214-222 [FREE Full text] [doi: 10.3109/13561820.2013.763777] [Medline: 23394265]
65. Archambault P, Bilodeau A, Gagnon M, Aubin K, Lavoie A, Lapointe J, et al. Health care professionals' beliefs about using wiki-based reminders to promote best practices in trauma care. J Med Internet Res 2012;14(2):e49 [FREE Full text] [doi: 10.2196/jmir.1983] [Medline: 22515985]
66. Bandura A. Social learning theory. Englewood Cliffs, NJ: Prentice-Hall; 1977.
67. Stacey D, Brière N, Robitaille H, Fraser K, Desroches S, Légaré F. A systematic process for creating and appraising clinical vignettes to illustrate interprofessional shared decision making. J Interprof Care 2014 Sep;28(5):453-459. [doi: 10.3109/13561820.2014.911157] [Medline: 24766619]
68. Delanoë A, Lépine J, Leiva Portocarrero ME, Robitaille H, Turcotte S, Lévesque I, et al. Health literacy in pregnant women facing prenatal screening may explain their intention to use a patient decision aid: a short report. BMC Res Notes 2016;9(1):339 [FREE Full text] [doi: 10.1186/s13104-016-2141-0] [Medline: 27401163]

69. Ajzen I. Constructing a TPB questionnaire: Conceptual and methodological considerations. Umass. URL: https://people.umass.edu/aizen/pdf/tpb.measurement.pdf [accessed 2016-07-13] [WebCite Cache ID 6iyLukofx]
70. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. Am J Health Behav 2007;31(Suppl 1):S19-S26. [doi: 10.5555/ajhb.2007.31.supp.S19] [Medline: 17931132]
71. Altin SV, Finke I, Kautz-Freimuth S, Stock S. The evolution of health literacy assessment tools: a systematic review. BMC Public Health 2014 Nov 24;14:1207 [FREE Full text] [doi: 10.1186/1471-2458-14-1207] [Medline: 25418011]
72. Haun JN, Valerio MA, McCormack LA, Sørensen K, Paasche-Orlow MK. Health literacy measurement: an inventory and descriptive summary of 51 instruments. J Health Commun 2014;19(Suppl 2):302-333. [doi: 10.1080/10810730.2014.936571] [Medline: 25315600]
73. Mancuso JM. Response regarding the commentary of van der Ploeg W. Assessment and measurement of health literacy: An integrative review of the literature. Nursing & Health Sciences 2010; 12: 145-146. Nurs Health Sci 2010 Sep 1;12(3):304-305. [doi: 10.1111/j.1442-2018.2010.00540.x] [Medline: 20727080]
74. Collins SA, Currie LM, Bakken S, Vawdrey DK, Stone PW. Health literacy screening instruments for eHealth applications: a systematic review. J Biomed Inform 2012 Jun;45(3):598-607 [FREE Full text] [doi: 10.1016/j.jbi.2012.04.001] [Medline: 22521719]
75. Jordan JE, Osborne RH, Buchbinder R. Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses. J Clin Epidemiol 2011 Apr;64(4):366-379. [doi: 10.1016/j.jclinepi.2010.04.005] [Medline: 20638235]
76. Fagerlin A, Zikmund-Fisher BJ, Ubel PA, Jankovic A, Derry HA, Smith DM. Measuring numeracy without a math test: development of the Subjective Numeracy Scale. Med Decis Making 2007;27(5):672-680. [doi: 10.1177/0272989X07304449] [Medline: 17641137]
77. McNaughton C, Wallston KA, Rothman RL, Marcovitz DE, Storrow AB. Short, subjective measures of numeracy and general health literacy in an adult emergency department. Acad Emerg Med 2011 Nov;18(11):1148-1155 [FREE Full text] [doi: 10.1111/j.1553-2712.2011.01210.x] [Medline: 22092896]
78. Dolan JG, Cherkasky OA, Li Q, Chin N, Veazie PJ. Should health numeracy be assessed objectively or subjectively? Med Decis Making 2016 Oct;36(7):868-875. [doi: 10.1177/0272989X15584332] [Medline: 25948493]
79. Baker DW, Williams MV, Parker RM, Gazmararian JA, Nurss J. Development of a brief test to measure functional health literacy. Patient Educ Couns 1999 Sep;38(1):33-42. [Medline: 14528569]
80. Parker RM, Baker DW, Williams MV, Nurss JR. The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. J Gen Intern Med 1995 Oct;10(10):537-541. [Medline: 8576769]
81. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. Fam Med 2004 Sep;36(8):588-594 [FREE Full text] [Medline: 15343421]
82. Schwartz LM, Woloshin S, Black WC, Welch HG. The role of numeracy in understanding the benefit of screening mammography. Ann Intern Med 1997 Dec 1;127(11):966-972. [Medline: 9412301]
83. Peduzzi P, Concato J, Kemper E, Holford TR, Feinstein AR. A simulation study of the number of events per variable in logistic regression analysis. J Clin Epidemiol 1996 Dec;49(12):1373-1379. [Medline: 8970487]
84. Anderson BL, Obrecht NA, Chapman GB, Driscoll DA, Schulkin J. Physicians' communication of Down syndrome screening test results: the influence of physician numeracy. Genet Med 2011 Aug;13(8):744-749. [doi: 10.1097/GIM.0b013e31821a370f] [Medline: 21637105]
85. Murray S, Rudd R, Kirsch I, Yamamoto K, Grenier S. Phac-aspc. 2008. Ottawa: Conseil Canadien sur l'apprentissage. La littératie en santé au Canada. URL: http://www.phac-aspc.gc.ca/cd-mc/hl-ls/index-fra.php [accessed 2016-10-24] [WebCite Cache ID 6lUl0aNWm]
86. Bernèche F, Traoré I, Perron B. Littératie en santé : compétences, groupes cibles et facteurs favorables. Quebec: Institut de la statistique du Québec; Feb 2012.
87. Statistiques Canada. Statcan.: Quebec: adapté par l'Institut de la statistique du Québec; 2006. Enquête sur la population active, compilation spéciale. URL: http://www23.statcan.gc.ca/imdb/p2SV_f.pl?Function=getSurvey&SDDS=3701
88. Légaré F, Thompson-Leduc P. Twelve myths about shared decision making. Patient Educ Couns 2014 Sep;96(3):281-286 [FREE Full text] [doi: 10.1016/j.pec.2014.06.014] [Medline: 25034637]
89. Boucher D, Gagné C, Côté F. Determinants of the intention of post-secondary students to eat at least five servings of vegetables and fruit daily. Rev Epidemiol Sante Publique 2012 Apr;60(2):109-119. [doi: 10.1016/j.respe.2011.10.003] [Medline: 22386104]
90. Kronzer VL. Screening for health literacy is not the answer. BMJ 2016 Jul 05;354:i3699. [Medline: 27381740]
91. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. Implement Sci 2011 Apr 23;6:42 [FREE Full text] [doi: 10.1186/1748-5908-6-42] [Medline: 21513547]
92. Agatisa PK, Mercer MB, Leek AC, Smith MB, Philipson E, Farrell RM. A first look at women's perspectives on noninvasive prenatal testing to detect sex chromosome aneuploidies and microdeletion syndromes. Prenat Diagn 2015 Jul;35(7):692-698. [doi: 10.1002/pd.4594] [Medline: 25800864]

93. Skjøth MM, Hansen HP, Draborg E, Pedersen CD, Lamont RF, Jørgensen JS. Informed choice for participation in Down syndrome screening: development and content of a Web-based decision aid. JMIR Res Protoc 2015 Sep 21;4(3):e113 [FREE Full text] [doi: 10.2196/resprot.4291] [Medline: 26392319]
94. García E, Timmermans DR, van Leeuwen E. The impact of ethical beliefs on decisions about prenatal screening tests: searching for justification. Soc Sci Med 2008 Feb;66(3):753-764. [doi: 10.1016/j.socscimed.2007.10.010] [Medline: 17996350]
95. Williams C, Sandall J, Lewando-Hundt G, Heyman B, Spencer K, Grellier R. Women as moral pioneers? Experiences of first trimester antenatal screening. Soc Sci Med 2005 Nov;61(9):1983-1992. [doi: 10.1016/j.socscimed.2005.04.004] [Medline: 15899542]
96. Aune I, Möller A. “I want a choice, but I don't want to decide“–a qualitative study of pregnant women's experiences regarding early ultrasound risk assessment for chromosomal anomalies. Midwifery 2012 Feb;28(1):14-23. [doi: 10.1016/j.midw.2010.10.015] [Medline: 21130549]
97. Abraham C, Michie S. A taxonomy of behavior change techniques used in interventions. Health Psychol 2008 May;27(3):379-387. [doi: 10.1037/0278-6133.27.3.379] [Medline: 18624603]
98. Schwartz SH. Normative influences on altruism. Adv Exp Soc Psychol 1977;10:221-279. [doi: 10.1016/S0065-2601(08)60358-5]
99. Godin G, Bélanger-Gravel A, Vézina-Im LA, Amireault S, Bilodeau A. Question-behaviour effect: a randomised controlled trial of asking intention in the interrogative or declarative form. Psychol Health 2012;27(9):1086-1099. [doi: 10.1080/08870446.2012.671617] [Medline: 22471288]
100. Sniehotta FF, Presseau J, Araújo-Soares V. Time to retire the theory of planned behaviour. Health Psychol Rev 2014;8(1):1-7. [doi: 10.1080/17437199.2013.869710] [Medline: 25053004]
101. Rhodes SD, Bowie DA, Hergenrather KC. Collecting behavioural data using the world wide web: considerations for researchers. J Epidemiol Community Health 2003 Jan;57(1):68-73 [FREE Full text] [Medline: 12490652]

Abbreviations

CHERRIES: Checklist for Reporting Results of Internet E-Surveys
DA: decision aid
NIPT: noninvasive prenatal test
OR: odds ratio
PEGASUS: Personalized Genomics for Prenatal Aneuploidy Screening Using Maternal Blood
SDM: shared decision making
SNS: Subjective Numeracy Scale
S-TOFHLA: Short Test of Functional Health Literacy in Adults
3HLQ: 3 health literacy questions
3NQ: 3 numeracy questions
TPB: Theory of Planned Behavior

Edited by G Eysenbach; submitted 15.07.16; peer-reviewed by M Skjøth, D Peddie, C Lyles PhD; comments to author 18.08.16; revised version received 27.09.16; accepted 28.09.16; published 28.10.16.

Please cite as:
Delanoë A, Lépine J, Turcotte S, Leiva Portocarrero ME, Robitaille H, Giguère AMC, Wilson BJ, Witteman HO, Lévesque I, Guillaumie L, Légaré F
Role of Psychosocial Factors and Health Literacy in Pregnant Women’s Intention to Use a Decision Aid for Down Syndrome Screening: A Theory-Based Web Survey
J Med Internet Res 2016;18(10):e283
URL: http://www.jmir.org/2016/10/e283/
doi:10.2196/jmir.6362
PMID:27793792

Original Paper

"I Want to Keep the Personal Relationship With My Doctor": Understanding Barriers to Portal Use among African Americans and Latinos

Courtney Rees Lyles[1,2], PhD; Jill Y Allen[3], PhD; Dolly Poole[4], BA; Lina Tieu[1], MPH; Michael H Kanter[5,6], MD; Terhilda Garrido[7], MPH

[1]University of California San Francisco, San Francisco, CA, United States
[2]Kaiser Permanente Northern California Division of Research, Oakland, CA, United States
[3]Kaiser Permanente National Market Research, Oakland, CA, United States
[4]Kaiser Permanente Hospitals, Quality and Care Delivery Excellence, Oakland, CA, United States
[5]Kaiser Permanente Southern California Permanente Group, Pasadena, CA, United States
[6]The Permanente Federation, Oakland, CA, United States
[7]Kaiser Permanente Health Information Technology Transformation and Analytics, Oakland CA, United States. Terhilda Garrido is now with Camino Advisors, LLC, Oakland, CA, United States

Corresponding Author:
Courtney Rees Lyles, PhD
Kaiser Permanente Northern California Division of Research
2000 Broadway
Oakland, CA, 94607
United States
Phone: 1 4152066483
Fax: 1 4152065586
Email: Courtney.Lyles@ucsf.edu

Abstract

Background: Despite the widespread implementation of electronic health records (EHRs), there is growing evidence that racial/ethnic minority patients do not use portals as frequently as non-Hispanic whites to access their EHR information online. This differential portal use could be problematic for health care disparities since early evidence links portal use to better outcomes.

Objective: We sought to understand specific barriers to portal use among African American and Latino patients at Kaiser Permanente, which has had a portal in place for over a decade, and broad uptake among the patient population at large.

Methods: We conducted 10 focus groups with 87 participants in 2012 and 2013 among African American and Latino Kaiser Permanente members in the mid-Atlantic, Georgia, and Southern California regions. Members were eligible to participate if they were not registered for portal access. Focus groups were conducted within each racial/ethnic group, and each included individuals who were older, had a chronic disease, or were parents (as these are the three biggest users of the portal at Kaiser Permanente overall). We videotaped each focus group and transcribed the discussion for analysis. We used general inductive coding to develop themes for major barriers to portal use, overall and separately by racial/ethnic group.

Results: We found that lack of support was a key barrier to initiating portal use in our sample—both in terms of technical assistance as well as the fear of the portal eroding existing personal relationships with health care providers. This held true across a range of focus groups representing a mix of age, income, health conditions, and geographic regions.

Conclusions: Our study was among the first qualitative explorations of barriers to portal use among racial/ethnic subgroups. Our findings suggest that uniform adoption of portal use across diverse patient groups requires more usable and personalized websites, which may be particularly important for reducing health care disparities. This work is particularly important as all health care systems continue to offer and promote more health care features online via portals.

(J Med Internet Res 2016;18(10):e263) doi:10.2196/jmir.5910

KEYWORDS

electronic health record; African Americans; Hispanic Americans; qualitative research

Introduction

The US Health Information Technology for Economic and Clinical Health (HITECH) Act has provided more than US $25 billion in federal incentive dollars to implement electronic health records (EHRs) across health care clinics and systems across the United States. As we move forward with EHR implementation, there is increased emphasis on understanding patient needs and preferences for accessing portal websites that are linked to EHRs. This issue is particularly important given the growing evidence that patient access to and use of portals (which include viewing laboratory test results and visit summaries and allowing email communication between patients and health care providers) are linked to improved satisfaction [1] as well as better outcomes [2-4]. For example, several recent studies of systems that have had portals for over a decade (such as Kaiser Permanente) have shown that patient portal use is associated with better overall quality of care indicators [5].

Although portals are being widely implemented and may be contributing to improved health outcomes, there is evidence that they are not accessed equally across groups despite uniformly high patient interest in and enthusiasm for portals [6-8]. It is well documented that racial/ethnic minorities are significantly less likely to use portals in integrated delivery systems [9-11] as well as community-based clinics [12]. However, the differences in portal use are not fully understood and cannot be attributed to computer/Internet access alone [10]. Within the handful of studies examining adoption of portal use overall, there are several major barriers that have emerged. Some of the potential reasons previously cited for nonuse include lack of awareness [8,13], lack of sufficient computer skills [10,13,14], reduced ability to understand medical content or limited health literacy skills [8,15,16], poor usability of portal websites/interfaces [15,16], need for provider or system support [17], and concerns about security of information online [8,10].

There have been few qualitative studies to date that have specifically examined barriers to portal use by race/ethnicity, despite the documented findings of lower rates of portal use among racial/ethnic minority groups. Therefore, we designed a qualitative study of non-Hispanic African American and English-speaking Hispanic/Latino patients at Kaiser Permanente to explore this issue in depth. We hypothesized that the barriers to adoption of portal use would differ within the groups based on their interests, preferences, and concerns.

Methods

We conducted this qualitative study at Kaiser Permanente, which has offered a version of the patient portal in various regions of the United States since the mid-2000s. Collectively, this health care system serves 10 million patients, with well over half (5.5 million) already using the online patient portal website. Specifically, we recruited Kaiser Permanente members from the Mid-Atlantic, Georgia, and Southern California regions for this study to ensure geographic and racial/ethnic diversity in the patients sampled (explained more in depth below).

Recruitment and Focus Group Processes

We conducted 10 focus groups with Kaiser Permanente patients who were not registered for the online patient portal. The portal (also known as “kp.org”) allows patients access to several features:

(1) viewing medical history including visit summaries, immunizations, and allergies, (2) viewing laboratory results, (3) refilling medications, (4) making appointments, and (5) sending a secure message to a health care provider. All of these features were available on both a Web browser and a mobile app at the time of the study. The portal served as an alternative means to access these services, as they were often also available through in-person, mail, or phone platforms.

We limited our sample to individuals who were patients of Kaiser Permanente for at least 2 years and had visited a Kaiser Permanente facility in the past year, were English-speaking, were at least somewhat familiar with the patient portal, and used the Internet at least once a week (no other assessment of participants’ digital/computer literacy was collected). These recruitment criteria ensured that the sample was a stable group of Kaiser Permanente members who were capable of accessing the portal on their own. In particular, we understood that language barriers might be a particular barrier for Latino patients but believed that we could recruit only English speakers in this study since the portal was available only in English. The focus groups were also targeted to key groups that had health care coordination needs and therefore might be most inclined to use the portal for specific tasks.

In October 2012, we conducted six of the focus groups specifically with African American patients, holding two focus groups each in three Kaiser Permanente regions nationwide (Mid-Atlantic, Georgia, and Southern California). This included two focus groups with older adults, two focus groups with patients with chronic illness, and two focus groups with parents of young children (Table 1). Focus groups were also additionally stratified by income level (based on categories that reflected the income distributions of Kaiser Permanente patients) and age when possible to increase variation in the participants across the groups. Finally, within each focus group we ensured a mix of gender, employment status, education, and marital status during recruitment. In December 2013, we used the same process to conduct four additional focus groups with Latino patients, all conducted in Southern California (Table 2). This included two focus groups with parents and two focus groups with patients with chronic illness.

Table 1. African American focus groups.

	Group 1, n=9	Group 2, n=9	Group 3, n=10	Group 4, n=5	Group 5, n=10	Group 6, n=9
Location	Mid-Atlantic	Mid-Atlantic	Georgia	Georgia	Southern California	Southern California
Demographic/ Health focus	Older adults	Chronic illness	Chronic illness	Parents	Older adults	Parents
Household income, US $	Any	≤$40K or $41-80K	$41-80K or ≥$81K	≤$40K or $41-80K	Any	$41-80K or ≥$81K
Age, years	55+	35-59	35-59	30-44	60+	30-54

Table 2. English-speaking Latino focus groups in Southern California.

	Group A, n=10	Group B, n=9	Group C, n=8	Group D, n=8
Demographic/Health focus	Chronic illness	Parents	Chronic illness (2 or more)	Parents
Household income, US $	Any	$41-80K or ≥$81K	Any	≤$40K
Age, years	35-59	24-34	35-54	24-39
Older adults	Mix	No	Mix	No

The focus groups were led by 2 experienced moderators who were racially/ethnically concordant with the study sample. All focus groups were held in independent market research facilities and lasted approximately 2 hours. Each group consisted of 8-10 participants (with the exception of one focus group with only 5 participants), and participants received a US $100 incentive for participation. All sessions were videotaped and the conversations were later transcribed for analysis. The study was approved by the Kaiser Permanente Southern California Institutional Review Board.

The discussions focused on (1) current health status and relationship with health care providers, (2) current Internet/technology use, (3) knowledge of Kaiser Permanente and the patient portal, (4) review of the health care services and health content available online, and (5) barriers and facilitators to adoption of the patient portal. The full discussion guide is included in Multimedia Appendix 1.

Analysis

Our qualitative analysis began with open coding of all the transcripts, focusing in on portions of the conversations that raised potential barriers and facilitators to use [18]. One member of the team (CRL) created the initial codebook, based on the discussion guide questions and a review of the previous qualitative literature documenting barriers to portal use in the general patient population. Then, at least 2 researchers read each transcript and coded using both the original codebook and open coding whenever necessary. The entire team met regularly to review the approach, edit the codes (collapsing or creating new codes as needed), and come to consensus on the themes and their interpretation as they emerged [19]. We also compared the coded segments within each theme to one another in a spreadsheet, which allowed us to identify and report on the richest information rather than quantifying the number and type of barrier categories. Overall, this process allowed for several checks on the validity of the final results by making sense of ambivalent and contradictory statements and articulating themes that were common across key informant interviews.

The primary themes presented here were fully saturated among both African Americans and Latinos and are therefore presented combined. When subsequently stratifying the analysis by race/ethnicity, we also identified one additional theme that was specific to each group.

Results

Sample Demographics

Overall, there were 87 individuals who attended the focus groups (Table 3). The sample was 60% female (52/87), 45% (39/87) low-income (≤US$40,000 annual household income), and 54% (47/87) aged 45 or older. In addition, 30% (26/87) of respondents had diabetes and 30% (26/87) had hypertension. The African American focus groups were slightly more female (69%, 36/52) versus Latinos (46%, 16/35), older (68%, 35/52 aged 45 or older) compared to Latinos (32%, 11/35), with a higher proportion of respondents with hypertension (40%, 21/52) versus Latinos (20%, 7/35), and a lower proportion who were low-income (37%, 19/52) compared to Latinos (57%, 20/35).

Table 3. Participant demographics.

		African American, n=52	Latino, n=35	Total, n=87
Age (years), %				
	24-39	21	57	35
	40-49	23	28	25
	50-74	56	15	40
Gender, %				
	Male	31	54	40
	Female	69	46	60
Income (USD), %				
	≤$40K	37	57	45
	$41-80	54	43	49
	≥$81K	10	0	6
Education (highest level completed), %				
	Less than high school	2	6	3
	High school degree	26	54	38
	Some college or 2-year college degree	46	37	43
	4-year college degree	13	3	9
	Postgraduate degree	12	0	7
Chronic condition, %				
	Hypertension	40	20	30
	Diabetes	23	40	30
	Asthma	17	0	10
	Cancer	4	0	2

Technological Proficiency

Although all participants were current Internet users based on the inclusion criteria of the study, the focus group discussions among participants uncovered a mix of technological skills. The patients who were younger tended to be the most Internet-savvy, but even a substantial proportion of the older participants/chronic illness patients could perform sophisticated tasks online, including researching medical treatments and conducting banking transactions: “I’ve had health questions that I’ve gotten online to find out cures, and alternative medicine, and things like that” (African American female, focus group 5 with older adults) and “If you’re on your smartphone it’s so much easier, with one click you have everything you need” (Latina female, focus group B with parents). However, older adults and those with chronic illness (who were also older on average) tended to make most of the comments related to limited computer proficiency: “And I tell myself, I see some seniors out there and they’re texting and they’re going online and I say if they can do that, I can do it and it isn’t that difficult. So like it’s a challenge for me” (African American female, focus group 5 with older adults).

Major Reasons for Portal Nonuse

Our detailed coding and analytic process revealed several primary barriers to use of the patient portal, all outlined in Table 4. Four of the themes were directly linked to the need for feeling supported and/or connected, either from health care providers or from the health care system: all of which are explored in depth below.

Table 4. Additional themes outlining barriers to portal use.

Theme	Latino/Hispanic	No. of comments	Black/African American	No. of comments
Not technically savvy	Compared to some of these kids, and all they do is live out of their computer, I don't. I'm barely learning. (focus group C, Male)	9	Then you've got 100 passwords – you've got one for the bank, for the school, you've got the ABT, and you've got to be remembering all of this. (focus group 1, Female)	15
			For me it's taking the time to get into all this new technology. I'm old school. I'm not used to all that. (focus group 3, Male)	
	I'm old school. I'm very computer illiterate. Somebody at work tells me "You have to do..." I'm like "Oh, can you do it for me? I don't know what to do." When it comes to sitting in front of a computer, I sit in front of a computer all day, but I just do input. (focus group A, Female)		I don't go on the Internet. I don't look for any medical anything on the Internet. (focus group 5, Male)	
Concern portal would interfere with personal relationships	When you're talking to a person, you can tell if that person cares about what you're talking about. (focus group C, Male)	11	Let's have something personal with the doctor. Everything else is automated and animated. (focus group 1, Male)	16
	[On why it's better to get results from doctor vs online:] He [my doctor] would explain it to me more in detail, and he keeps telling me over and over, every single visit, how I'm doing this bad. (focus group C, Male)		The trust factor is really important. (Female, focus group 5)	
			That [secure messaging] is not going to sub for having him [my doctor] look at me. (focus group 1, Female)	
Prefer talking to live person	I tried to use it to find things out, but at the same time, to me I feel like I need to talk to people. I can't deal with computers, or stuff like that, because you're not talking to a human person that can answer to you right there and things like that. (focus group C, Female)	28	I'd rather be called in for everything good or bad because if the only time you're calling me in, is if something is wrong, I don't really want to go. I'd rather go in for everything. (focus group 1, Male)	34
	I just like a live person…Yes. A live person. Computers only do so much, and I like a live person just in case I have a question. Especially, like he said, you look at your results, what the hell do they mean? (focus group C, Male)		I want to hear the voice and know that they care. When you get test results, if there's nothing wrong with you, they'll be a letter. (focus group 4, Female)	
Need help to register	When I went to the website, I was trying to sign in to all the process but for some reason it didn't work. I gave up, I just contacted them. (focus group B, Male)	14	I didn't understand anything [on kp.org]. They said put your name and your zip code – it was too much. (focus group 1, Female)	11
Think existing systems are working fine	Certain people, like myself, you stick to ways that work for you. (focus group B, Female)	3	I never have a problem with them. I don't get sick that often, so I really don't know if it works or it doesn't work to be online or not. I don't know if it would be a convenience for me or not. (focus group 4, Female)	23
kp.org needs to be simple to understand/use	If you go to kp.org there is information for either view, basic information, health information but I think what it is it's a lot of reading and it's overwhelming. (focus group A, Female)	12	[If I saw a lab result online I didn't understand,] I'd pick up the phone and call them asking what it means. (focus group 4, Female)	8
Concerns about security	They can hack into phones, they can steal my information. I wouldn't use it. I only use it for music and calls. That's it. (focus group D, Male)	3	There are hackers out to get you…We're paranoid scared about who is looking in our stuff. (focus group 1, Female)	26

Concern Online Tools Would Diminish Personal Relationships With Health Care Providers

A main theme of the discussions was the need to protect or establish interpersonal relationships with health care providers. Many participants stated that they knew their health care provider was invested in them when he or she took time to talk about their health and wellness during visits or followed up with them personally via phone calls after visits: "When I do go in there with a long list of certain things going on with me, he answers. He gives me more than 15 minutes. He calls me by name" (African American female, focus group 1 with older adults).

> *That's one thing I liked about my Doctor, Dr. X. He wanted to know what was happening in your life. It wasn't just because your test was wrong or low or whatever. It's like, let's see what's happening in your life, to see what's contributing to your health problems.* [Latino male, focus group C with 2 or more chronic conditions]

Because of this high level of importance on the patient-provider relationship, it was clear that several participants were skeptical of portals supporting their relationships. Some even expressed concern that portals would decrease their existing quality of care or be used to replace face-to-face visits altogether: "I really don't want to get into it [the portal]. I don't want them to get used to me going to kp.org. I want to keep the personal relationship with my doctor" (African American male, focus group 6 with parents).

> *I really have concerns about the email. The doctor ratio patient, per email, if he has 500 patients and I'm just saying hypothetically. He receives 200 directly from patients, plus the nurses typing, the respond time, the time for him seeing his patients, if everybody joined this and started texting all kinds of stuff, what care are these physicians now going to provide? Seriously, it concerns me.* [African American female, focus group 2 with chronic illness]

These comments collectively suggest participants' worry that portals would interfere with existing visits. This was true regardless of the status of the participant's existing relationship with their health care provider: those with negative relationships felt the portal could block the ability to establish an interpersonal relationship, and those with positive relationships often stated that portals could threaten their personal connection.

Stated Preferences for In-Person Communication

Because there was such as strong emphasis on relationships with health care providers, this was naturally directly related to many stated preferences for face-to-face or phone communication. This was the case overall (ie, being the type of person who liked in-person communication throughout all aspects of life) and particularly true for health-related communication because of the importance of the discussion content: "When you have something that's wrong with you, like diabetes, I think that's when you would want a little bit more personal" (Latina female, focus group A with chronic illness), "I want to look at you and I want to talk to you. I want you to see me" (African American female, focus group 1 with older adults), and "I'm not a big email person and I just feel like, especially when it comes to my health, I would prefer to be face to face with my doctor" (African American female, focus group 3 with chronic illness).

However, when exploring this preference more in-depth, more nuance emerged. Some of the comments about preferring in-person communication could be additionally interpreted as a need for personal reassurance or verification. That is, these individuals did not feel as though they could comprehend the provided information sufficiently through online communication alone, or were worried they would not be sufficiently understood: "I like also to confirm when I am speaking to a live person. I like to confirm that I spoke to somebody" (Latino male, focus group D with parents) and "I can deal with the phone, but I really don't like talking to anybody over the phone because I had a bad experience with someone on the phone, he couldn't understand what I was saying, but when you're in their presence it's different" (African American male, focus group 4 with parents).

Taken together, these comments about preferring in-person communication reflected a mix of personal values and confidence in the health care system (often based on previous experiences at Kaiser or other health care institutions). Face-to-face communication was critical to assure patients that they understood health care information correctly and that the health care provider/system was not making a mistake in some way—that is, a safeguard to ensure the highest quality of care possible.

Portal Not Easy/Simple Enough to Use

There was also a sentiment that many participants needed more concrete support and/or technical assistance for portal use. This was the case regardless of existing computer use since all participants had to be weekly Internet users to be included in our final sample. In addition, this theme emerged in focus groups regardless of whether they predominantly comprised low-income patients, older adults, or with those with chronic illness. First, there were some general comments about trying to navigate more sophisticated websites: "I think a lot of it is just the simplicity to get into it…The simpler it is, the easier to get into it, to look at it. If it's complex—I'm not going to look at it" (Latino male, focus group C with 2 or more chronic conditions) and "It's just I know I can blame myself for it but I'm just like, I'm very forgetful with passwords. I know, it's like every 3 or 4 months, I'll probably forget my password. I know I can write it down, but most people don't" (Latino male, focus group D with parents).

In addition, this was especially true for the portal registration process. While all participants were *not* portal users based on the inclusion criteria for the study, some had previously (but unsuccessfully) attempted to register for portal use: "When I heard about it [the portal], I went on it, and when it asked me for the password and wouldn't give it, I said 'Forget it. I don't know how to do it.'" (Latina female, focus group A with chronic illness), "When I went to the website, I was trying to sign in to all the process but for some reason it didn't work. I gave up, I just contacted them" (Latino male, focus group B with parents), and "It was too difficult when I tried it…It said to create a password. It took you through a whole bunch of stuff, and I finally got frustrated and stopped" (African American male, focus group 1 with older adults).

Because of the perceived difficulties in using the website, there were also several comments about needing more training or one-on-one support from the health care system to be able to access the portal: "Maybe Kaiser can provide some kind of guidance to help you use it, and what you can find, and how you can do things through them, and be able to get that information available, and it's easier" (Latina female, focus group C with 2 or more chronic conditions).

> *I'm going to do it [use the portal] only when I can do it for myself. I don't need anybody to do it for me. When I can walk in, fire up the computer, and do everything that I'm supposed to do for myself…This is what I'm saying. When I can just walk in and do it for myself. I don't have to ask for help, I'd consider that then.* [African American male, focus group 1 with older adults]

Portal Content Is Often Too Complex

Finally, some participants noted that, beyond basic functionality, the website content could also be challenging. This was strongly related to the ability to interpret the medical information provided: "If you go to kp.org, there is information for either view, basic information, health information. But I think what it is it's a lot of reading and it's overwhelming" (Latina female, focus group A with chronic illness) and "Is it user friendly? Is it terms that we can understand, laymen's terms?" (African American female, focus group 2 with chronic illness).

> *If I have a question because sometimes when you get these lab results with all these medical terms, they don't break it down into what they really mean, so sometimes I have to call my doctor and say, "What is this about, what does it mean, what do these numbers represent?"* [African American male, focus group 5 with older adults]

Specific Themes for African Americans and Latinos

We sought to explore whether there were differences in barriers to portal use for African Americans compared to Latinos; however, most of the themes from the focus groups were similar in both groups. There were two exceptions to note. First, African American respondents appeared to be more concerned about the security/privacy of their information online: "If you can crack the Pentagon and the White House and all that, first of all, they didn't even ask if they could put my medical records online" (female, focus group 5 with older adults).

> *Because my medical history and my medical business is my business, and when you have hackers and all kinds of foolishness going on in the Internet that may go into somebody else's spam folder and that's my medical history. I'm not comfortable with that.* [female, focus group 3 with chronic illness]

Second, Latino respondents were more consistent in their comments about using the mobile phone app to access the site, as they felt strongly this would be more usable than a website: "A website might be much more complicated but the app is broken down to very simple. It's on your phone, there's not so much you can do" (female, focus group B with parents) and "If I had an app on my phone, then I could just know...I don't have to look for it through the internet, I could just click on it and there it is, and just sign in, and make it easier" (male, focus group C with 2 or more chronic conditions)

Discussion

Principal Findings

Our study was among the first to specifically examine barriers to portal use among African American and Latino patients. Among a national sample of Kaiser Permanente patients, we found that lack of support was a primary barrier in using the online patient portal. More specifically, participants wanted both additional technical assistance in using the portal and expressed worry that the portal could undermine their existing in-person relationships with their health care providers. This held true across a range of focus groups representing a mix of age, income, health conditions, and geographic region. These findings are particularly important because of the well-documented lower portal use within these two racial/ethnic groups across health care systems.

Comparison to Previous Work

Our findings are consistent with previous literature on this topic, which suggests that the categories of barriers for racial/ethnic minority groups may not be substantially different from those seen in the overall patient population. For example, as stated above, previous studies have also found that connections with health care providers and comfort with using computers were challenges in using portal websites [13,14,17]. However, our findings go deeper on many of the themes than the previous literature was able to do. For example, participants expressed not just a desire for closer relationships with their provider, but the need to protect in-person visits from the "threat" of online communication, indicating anxiety about portal use replacing the interpersonal aspects of their existing relationships. In addition, our findings indicate a multifaceted perspective on preferences for in-person communication that might be more prevalent than in the dominant culture. This may include stronger cultural value placed on face-to-face communication or utilizing in-person communication as a coping strategy to ensure that the patient is receiving the highest quality of care possible. It is also important to note in our other national market research (results available among request), mainstream Kaiser Permanente portal users reported feeling very differently from the participants in this study: that the portal strengthened their relationships with health care providers.

Furthermore, it is clear from our study that basics of website usability, such as simplicity in design and content delivery, are also barriers to portal use. A large proportion of individuals in our study, even those who used the computer or mobile phone for other tasks, reported that the portal seemed too complex to access. This is consistent with previous evidence that documented lower usability of portal websites among racial/ethnic minority patients as well as those with limited health literacy [20,21]. Moreover, the need for health literacy training or support was also evident, such as the lack of confidence in being able to independently interpret medical content presented on a portal without one-on-one assistance, which is also consistent with other health technology work [22,23]. While literacy and socioeconomic status can trend together, the health literacy needs noted in this study were not confined to those from lower socioeconomic status alone.

Because portals display patient-specific medical content from the EHR that is meant for provider use, there is ongoing work that needs to be done to ensure that portals are accessible and usable.

With respect to the subgroup-specific theme related to security and privacy of information online, we found that African Americans expressed more concerns about portals compared to Latinos. This might be related to age [24], as the Latino focus groups were slightly younger than the African American focus groups, or broader cultural mistrust of the health care system based in the unique historical context for this racial/ethnic group, such as the unethical treatment in the Tuskegee Syphilis Experiment [25,26]. However, it is important to note that in the overall Kaiser Permanente population, older adults have the highest rate of portal registration and use. This suggests that patient education/communication about the security measures taken to protect portal websites (including the limits to that security) should be well developed, potentially targeted to older patient groups first, and should be clear about the specific contexts of use (eg, who is viewing the information and for what purpose [27]).

Limitations

Our study has some limitations to note. First of all, our sample included only Kaiser Permanente patients, and so the barriers to portal use in this integrated delivery system may not be comparable to other health care settings or insurance types. However, it is important to note that Kaiser Permanente cares for patients from all sociodemographic groups and multiple private and public insurer types, making it an extremely heterogeneous patient population overall. In addition, while we did include African American patients from across the country, the Latino patients were all residents of Southern California. We did not include patients from other races/ethnicities, which would allow for more comparisons between racial/ethnic groups, including direct comparisons to white and East Asian patients at Kaiser Permanente who use the portal at the highest rates in this health care setting. Finally, we focused only on portal nonusers and therefore developed a more detailed understanding of barriers (rather than facilitators) to use.

Conclusions

Moving forward, our findings have implications for clinical practice. One of the key messages of this study is that personal relationships can substantially support and encourage use. This is particularly important with respect to having clear expectations about what types of communication are best delivered through in-person versus online channels, which might help to assure patients that interpersonal aspects of communication will be prioritized and preserved. In addition, this study suggests that additional support or training for digital and health literacy skills might enhance portal use for some patient subgroups.

At a system level, there are a number of targeted strategies already underway to address some additional barriers identified in this study. For example, the Kaiser Permanente portal registration process continues to be enhanced to simplify and streamline the experience for patients. In addition, a TRUSTe security seal was added to the homepage of the portal to assure visitors of their privacy when they interact with the Kaiser Permanente website. Also, the marketing messages for patients are being refreshed to promote the availability of the mobile app and to reinforce that the portal is a convenient way for patients to have more personalized contact with their health care providers. Future studies should examine the effectiveness of these system-level efforts in ultimately increasing portal use rates across racial/ethnic groups.

In conclusion, our study identified the need for personalized and technical support to encourage African American and Latino patients to use portals for their health care management. As the United States continues to shift toward patient engagement and patient-centered care, it is critical to ensure that health technologies like portals are usable for all patient groups. Portals are a platform through which many health care systems plan to integrate additional mobile health technologies, such as uploading patient-generated sensor or mobile phone app data into the EHR. As health care systems move to collecting and sending more electronic data to and from patients, it is critical that this process addresses broad barriers to use and reduces the possibilities of exacerbating existing health care disparities.

Acknowledgments

This work was funded by the Kaiser Foundation Health Plan, Program Office as a quality improvement initiative. CRL is supported by a career development award from Agency for Healthcare Research and Quality (R00HS022408).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Focus Group Discussion Guide.

[PDF File (Adobe PDF File), 118KB - jmir_v18i10e263_app1.pdf]

References

1. Ralston JD, Carrell D, Reid R, Anderson M, Moran M, Hereford J. Patient web services integrated with a shared medical record: patient use and satisfaction. J Am Med Inform Assoc 2007;14(6):798-806 [FREE Full text] [doi: 10.1197/jamia.M2302] [Medline: 17712090]
2. Harris LT, Koepsell TD, Haneuse SJ, Martin DP, Ralston JD. Glycemic control associated with secure patient-provider messaging within a shared electronic medical record: a longitudinal analysis. Diabetes Care 2013 Sep;36(9):2726-2733 [FREE Full text] [doi: 10.2337/dc12-2003] [Medline: 23628618]
3. Sarkar U, Lyles CR, Parker MM, Allen J, Nguyen R, Moffet HH, et al. Use of the refill function through an online patient portal is associated with improved adherence to statins in an integrated health system. Med Care 2014 Mar;52(3):194-201 [FREE Full text] [doi: 10.1097/MLR.0000000000000069] [Medline: 24374412]
4. Tenforde M, Nowacki A, Jain A, Hickner J. The association between personal health record use and diabetes quality measures. J Gen Intern Med 2012 Apr;27(4):420-424 [FREE Full text] [doi: 10.1007/s11606-011-1889-0] [Medline: 22005937]
5. Zhou YY, Kanter MH, Wang JJ, Garrido T. Improved quality at Kaiser Permanente through e-mail between physicians and patients. Health Aff (Millwood) 2010 Jul;29(7):1370-1375 [FREE Full text] [doi: 10.1377/hlthaff.2010.0048] [Medline: 20606190]
6. Zarcadoolas C, Vaughon WL, Czaja SJ, Levy J, Rockoff ML. Consumers' perceptions of patient-accessible electronic medical records. J Med Internet Res 2013;15(8):e168 [FREE Full text] [doi: 10.2196/jmir.2507] [Medline: 23978618]
7. Schickedanz A, Huang D, Lopez A, Cheung E, Lyles CR, Bodenheimer T, et al. Access, interest, and attitudes toward electronic communication for health care among patients in the medical safety net. J Gen Intern Med 2013 Jul;28(7):914-920 [FREE Full text] [doi: 10.1007/s11606-012-2329-5] [Medline: 23423453]
8. Dhanireddy S, Walker J, Reisch L, Oster N, Delbanco T, Elmore JG. The urban underserved: attitudes towards gaining full access to electronic medical records. Health Expect 2014 Oct;17(5):724-732. [doi: 10.1111/j.1369-7625.2012.00799.x] [Medline: 22738155]
9. Sarkar U, Karter AJ, Liu JY, Adler NE, Nguyen R, López A, et al. Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. J Am Med Inform Assoc 2011 May 1;18(3):318-321 [FREE Full text] [doi: 10.1136/jamia.2010.006015] [Medline: 21262921]
10. Lyles CR, Harris LT, Jordan L, Grothaus L, Wehnes L, Reid RJ, et al. Patient race/ethnicity and shared medical record use among diabetes patients. Med Care 2012 May;50(5):434-440. [doi: 10.1097/MLR.0b013e318249d81b] [Medline: 22354209]
11. Garrido T, Kanter M, Meng D, Turley M, Wang J, Sue V, et al. Race/ethnicity, personal health record access, and quality of care. Am J Manag Care 2015 Feb;21(2):e103-e113 [FREE Full text] [Medline: 25880485]
12. Goel MS, Brown TL, Williams A, Hasnain-Wynia R, Thompson JA, Baker DW. Disparities in enrollment and use of an electronic patient portal. J Gen Intern Med 2011 Oct;26(10):1112-1116 [FREE Full text] [doi: 10.1007/s11606-011-1728-3] [Medline: 21538166]
13. Osborn CY, Mayberry LS, Wallston KA, Johnson KB, Elasy TA. Understanding patient portal use: implications for medication management. J Med Internet Res 2013;15(7):e133 [FREE Full text] [doi: 10.2196/jmir.2589] [Medline: 23823974]
14. Kim E, Stolyar A, Lober WB, Herbaugh AL, Shinstrom SE, Zierler BK, et al. Challenges to using an electronic personal health record by a low-income elderly population. J Med Internet Res 2009;11(4):e44 [FREE Full text] [doi: 10.2196/jmir.1256] [Medline: 19861298]
15. Tieu L, Schillinger D, Sarkar U, Hoskote M, Hahn KJ, Ratanawongsa N, et al. Online patient websites for electronic health record access among vulnerable populations: portals to nowhere? J Am Med Inform Assoc 2016 Jul 8. [doi: 10.1093/jamia/ocw098] [Medline: 27402138]
16. Czaja SJ, Zarcadoolas C, Vaughon WL, Lee CC, Rockoff ML, Levy J. The usability of electronic personal health record systems for an underserved adult population. Hum Factors 2015 May;57(3):491-506. [doi: 10.1177/0018720814549238] [Medline: 25875437]
17. Winkelman WJ, Leonard KJ, Rossos PG. Patient-perceived usefulness of online electronic medical records: employing grounded theory in the development of information and communication technologies for use by patients living with chronic illness. J Am Med Inform Assoc 2005;12(3):306-314 [FREE Full text] [doi: 10.1197/jamia.M1712] [Medline: 15684128]
18. Richards L, Morse J. User's Guide to Qualitative Methods. 2nd edition. Thousand Oaks, CA: Sage Publications; 2007.
19. Miles M, Huberman M. Qualitative Data Analysis: An Expanded Sourcebook. Thousand Oaks, CA: Sage Publications; 1994.
20. Lyles CR, Sarkar U, Osborn CY. Getting a technology-based diabetes intervention ready for prime time: a review of usability testing studies. Curr Diab Rep 2014 Oct;14(10):534. [doi: 10.1007/s11892-014-0534-9] [Medline: 25173689]
21. Lyles CR, Sarkar U. Health literacy, vulnerable patients, and health information technology use: where do we go from here? J Gen Intern Med 2015 Mar;30(3):271-272 [FREE Full text] [doi: 10.1007/s11606-014-3166-5] [Medline: 25588688]
22. Bickmore TW, Paasche-Orlow MK. The role of information technology in health literacy research. J Health Commun 2012;17 Suppl 3:23-29. [doi: 10.1080/10810730.2012.712626] [Medline: 23030559]
23. Chakkalakal RJ, Kripalani S, Schlundt DG, Elasy TA, Osborn CY. Disparities in using technology to access health information: race versus health literacy. Diabetes Care 2014;37(3):e53-e54 [FREE Full text] [doi: 10.2337/dc13-1984] [Medline: 24558085]

24. Hoofnagle C, King J, Li S, Turow J. How Different are Young Adults from Older Adults When it Comes to Information Privacy Attitudes and Policies?. 2010. URL: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1589864 [accessed 2016-09-26] [WebCite Cache ID 6koYPEbac]
25. Benkert R, Peters RM, Clark R, Keves-Foster K. Effects of perceived racism, cultural mistrust and trust in providers on satisfaction with care. J Natl Med Assoc 2006 Sep;98(9):1532-1540. [Medline: 17019925]
26. Corbie-Smith G, Thomas SB, Williams MV, Moody-Ayers S. Attitudes and beliefs of African Americans toward participation in medical research. J Gen Intern Med 1999 Sep;14(9):537-546 [FREE Full text] [Medline: 10491242]
27. Atienza AA, Zarcadoolas C, Vaughon W, Hughes P, Patel V, Chou WS, et al. Consumer Attitudes and Perceptions on mHealth Privacy and Security: Findings From a Mixed-Methods Study. J Health Commun 2015;20(6):673-679. [doi: 10.1080/10810730.2015.1018560] [Medline: 25868685]

Abbreviations

EHR: electronic health record

Edited by G Eysenbach; submitted 26.04.16; peer-reviewed by S Shimada, C Zarcadoolas; comments to author 25.07.16; revised version received 19.08.16; accepted 07.09.16; published 03.10.16.

Please cite as:
Lyles CR, Allen JY, Poole D, Tieu L, Kanter MH, Garrido T
“I Want to Keep the Personal Relationship With My Doctor”: Understanding Barriers to Portal Use among African Americans and Latinos
J Med Internet Res 2016;18(10):e263
URL: http://www.jmir.org/2016/10/e263/
doi:10.2196/jmir.5910
PMID:27697748

Original Paper

A Multimedia Child Developmental Screening Checklist: Design and Validation

Hsin-Yi Kathy Cheng[1,2], PhD; Li-Ying Chen[1], MS; Chih-Hsiu Cheng[2,3], PhD; Yan-Ying Ju[4], PhD; Chia-Ling Chen[1,2], MD, PhD; Kevin C Tseng[2,5], PhD

[1]Graduate Institute of Early Intervention, College of Medicine, Chang Gung University, TaoYuan, Taiwan
[2]Department of Physical Medicine and Rehabilitation, Chang Gung Memorial Hospital, TaoYuan, Taiwan
[3]Department of Physical Therapy and Graduate Institute of Rehabilitation Science, College of Medicine, Chang Gung University, TaoYuan, Taiwan
[4]Department of Adapted Physical Education, College of Physical Education, National Taiwan Sport University, TaoYuan, Taiwan
[5]Department of Industrial Design, College of Management, Chang Gung University, TaoYuan, Taiwan

Corresponding Author:
Kevin C Tseng, PhD
Department of Industrial Design
College of Management
Chang Gung University
259 Wen-Hua 1st Rd
Kwei-Shan
TaoYuan, 333
Taiwan
Phone: 886 32118800 ext 3509
Fax: 886 2118800
Email: ktseng@pddlab.org

Abstract

Background: Identifying disability early in life confers long-term benefits for children. The Taipei City Child Development Screening tool, second version (Taipei II) provides checklists for 13 child age groups from 4 months to 6 years. However, the usability of a text-based screening tool largely depends on the literacy level and logical reasoning ability of the caregivers, as well as language barriers caused by increasing numbers of immigrants.

Objective: The objectives of this study were to (1) design and develop a Web-based multimedia version of the current Taipei II developmental screening tool, and (2) investigate the measurement equivalence of this multimedia version to the original paper-based version.

Methods: To develop the multimedia version of Taipei II, a team of experts created illustrations, translations, and dubbing of the original checklists. The developmental screening test was administered to a total of 390 primary caregivers of children aged between 4 months and 6 years.

Results: Psychometric testing revealed excellent agreement between the paper and multimedia versions of Taipei II. Good to excellent reliabilities were demonstrated for all age groups for both the cross-mode similarity (mode intraclass correlation range 0.85-0.96) and the test-retest reliability (r=.93). Regarding the usability, the mean score was 4.80 (SD 0.03), indicating that users were satisfied with their multimedia website experience.

Conclusions: The multimedia tool produced essentially equivalent results to the paper-based tool. In addition, it had numerous advantages, such as it can facilitate active participation and promote early screening of target populations.

ClinicalTrial: Clinicaltrials.gov NCT02359591; https://clinicaltrials.gov/ct2/show/NCT02359591 (Archived by WebCite at http://www.webcitation.org/6l21mmdNn)

(J Med Internet Res 2016;18(10):e277) doi:10.2196/jmir.6249

KEYWORDS

child development; multimedia; screening; usability; Web-based; disability

Introduction

Identifying disability early in life confers long-term benefits for children, particularly those with special needs. To detect those who need help early, judicious use of practical and reliable standardized screening tools is of great importance. Most children who are diagnosed with disabilities are not identified before entering school [1,2]. Their developmental problems are often associated with poor health, low school performance, high in-grade retention, and special education placement [3]. Early intervention for children not only enhances child developmental outcomes, but also improves parents' ability to care for their children and increase family quality of life [4].

Clinically, disorders such as cerebral palsy and profound intellectual disability are clearly recognizable. However, subtle disabilities, such as mild intellectual disability and learning disabilities, can often escape detection in the early years of life despite frequent well-child visits [5,6]. Physicians generally acknowledge the importance of screening for developmental disabilities, but most of them rely on clinical judgment and milestones instead of standardized screening instruments [3]. A survey study conducted in 2011 reported that among 1821 pediatricians, less than half screened patients younger than 36 months with formal screening tools [7]. The main barriers cited in preventing the use of such tools included time limitations, lack of staff to perform screening, and inadequate reimbursement. Conducting formal neurodevelopmental assessments by using standardized tests presents numerous operational difficulties.

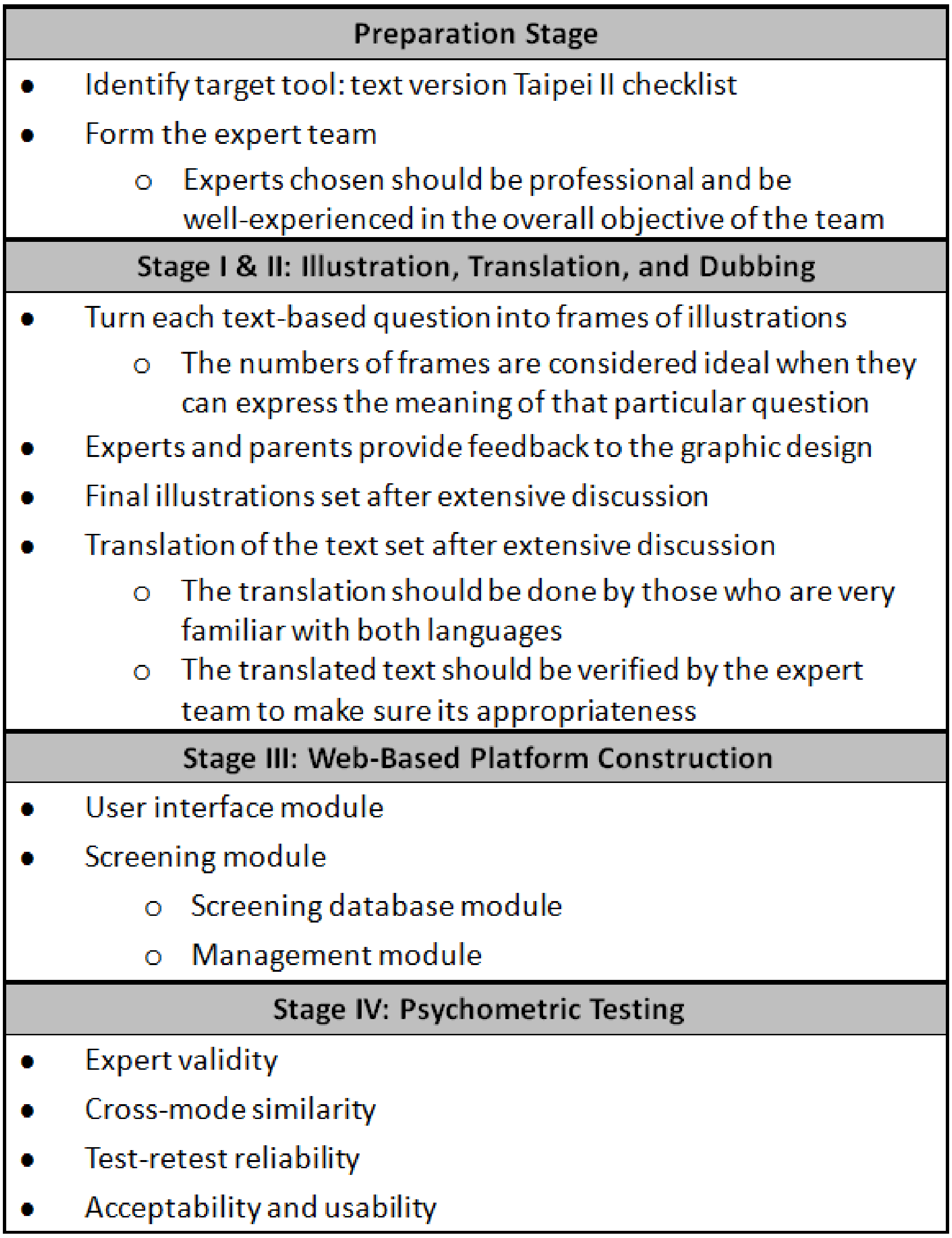
Therefore, researchers have searched for alternatives, such as using parent-reported data [8]. Primary caregivers typically know their children better than their physicians and are able to identify most developmental problems. The Taipei City Child Development Screening tool, second version (Taipei II) is a valid screening tool that was developed and funded by the Taiwan health authority. It provides checklists for 13 child age groups from 4 months to 6 years (4, 6, 9, 12, 15, 18, 24, 30, 36, 42, 48, 60, and 72 months), with 11 to 13 behavior/skill items related to gross/fine motor, cognition, language/communication, and emotion/social areas easily observed or elicited by the child's caregiver. Methodology research testing the reliability and validity of the Taipei II, using a sample of 506 children aged 5.5 to 35.5 months, was performed. To simulate the clinical situation for validity analysis, the Taipei II checklist was filled out by one parent or a main caregiver at clinics after explaining the purpose of this study and the rating principles. The results revealed that the sensitivity ranged from 0.85 to 1.00 and the specificity ranged from 0.82 to 1.00 if the cutoff was set at "failure to pass more than one item." For test-retest reliability, the data of the Taipei II were collected twice within a time interval of 1 week. Significant reliability coefficient of the total score was reported. In addition, the checklist also demonstrated a significant and moderate-to-high screening accuracy ($P<.05$) for each age-appropriate checklist via the receiver operating characteristics curve [9]. Taipei II is typically delivered to caregivers during well-child visits, which is passive and often fails to deliver if the caregivers miss the visit. In addition, Taipei II is text-based, and the usability of a text-based screening tool largely depends on the literacy level and logical reasoning ability of the caregivers, as well as language barriers because of increasing numbers of immigrants [10].

To help caregivers comprehend textual information, illustrated medical instructions and education tools have been increasingly used in recent years [11,12]. Illustrations have various functions: they support comprehension of textual content, provide a clear structural framework, help to clarify difficult passages, direct users' attention to the material, and enhance enjoyment [13]. Recently, multimedia has been considered to more effectively exert vision-mediated effects; hence, it has also become a trend in promoting learning and comprehension [14,15], including a mixture of static or dynamic illustrations and sound effects, particularly with computers. Use of computers and mobile phones is now widespread and users can access information actively and easily by using these devices. Therefore, a Web-based multimedia system would facilitate active participation and assist in comprehension of the target contents. The purposes of this study were to (1) design and develop a Web-based multimedia version of the Taipei II developmental screening tool and (2) investigate the psychometric properties of this multimedia mode compared to the original text version.

Methods

This study was conducted in four stages: the first stage involved illustrating each text-based question, the second stage was the translation and dubbing, the third stage was the Web-based system construction, and the fourth stage was testing the psychometric properties of the final multimedia system and comparing them with the original paper version (Figure 1). These four stages also represented the key processes when turning a paper-and-pencil checklist to a multimedia Web-based format. Other detailed considerations, such as the ideal amount of illustrations and the particular backgrounds of the experts, were case-specific.

Figure 1. Flowchart depicting the design stages of the multimedia system.



Preparation Stage

- Identify target tool: text version Taipei II checklist
- Form the expert team
  - Experts chosen should be professional and be well-experienced in the overall objective of the team

Stage I & II: Illustration, Translation, and Dubbing

- Turn each text-based question into frames of illustrations
  - The numbers of frames are considered ideal when they can express the meaning of that particular question
- Experts and parents provide feedback to the graphic design
- Final illustrations set after extensive discussion
- Translation of the text set after extensive discussion
  - The translation should be done by those who are very familiar with both languages
  - The translated text should be verified by the expert team to make sure its appropriateness

Stage III: Web-Based Platform Construction

- User interface module
- Screening module
  - Screening database module
  - Management module

Stage IV: Psychometric Testing

- Expert validity
- Cross-mode similarity
- Test-retest reliability
- Acceptability and usability

Participants

This study involved clinics and communities located in different areas of Northern Taiwan, representing the social and cultural contexts in the region. Three pediatric and family physician clinics participated. Participants recruited through communities were referred from six local public health centers. Primary caregivers of children aged between 4 months and 6 years were included to perform the developmental screening test. Considering that one of the primary goals of this study was the validation of a multimedia version of Taipei II, participants were excluded if they had any visual, auditory, or other deficits that would hinder them in operating the Web-based computer interface. No other exclusion criteria were applied. A total of 390 participants (104 men, 286 women) with a mean age of 33.35 (SD 6.71, range 23-70) years joined this study. Each age group consisted of 30 participants. The mean ages of their children were 29.8 (SD 20.6, range 4-84) months.

Design Stages

Preparation Stage

Taipei II was identified as the target tool to transform. A task force of experts was responsible for the developmental process. The task force primarily consisted of child development, rehabilitation, and graphic/Web design professionals, reflecting a broad array of backgrounds, perspectives, and expertise that enriched the study (Table 1). The developmental process of the multimedia version of Taipei II lasted approximately 10 months.

Table 1. Details of the expert team.

Member ID	Profession	Years of experience	Role on the team
1	Child development; rehabilitation; evidence-based research	22	Multimedia system design and validation; website conceptualization and design; coordinated and supervised study progress; supervised data collection at clinical sites; data analysis
2	Child development; nursing	5	Multimedia system design; website conceptualization and design; coordinated and supervised study progress; data collection and analysis
3	Child development; rehabilitation	21	Website conceptualization and design; system validation
4	Child development; physical therapy	16	System validation
5	Child development; physical therapy	12	System validation
6	Pediatrics; rehabilitation	20	System validation
7	Graphic design; Web design	20	Multimedia system design; website conceptualization and design; coordinated and supervised study progress
8	Graphic design; Web design	6	Multimedia system design; website conceptualization and design; character design and drawing
9	Graphic design	5	Character design and drawing
10	Graphic design	19	Character design and drawing

Stages I and II: Illustration, Translation, and Dubbing

The goal of this stage was to turn each text-based question into at least four illustrations to be displayed in sequence on the screen of a mobile device or computer. A subset of the task force members formed a discussion group that prepared subsequent iterations of the design, including illustrations and translations, and distributed them to the full task force for review and feedback. Because this screening tool is applied to children with a wide age range, and children of different ages differ in appearance, the graphic designer was first provided with pictures of children for each age group. Thus, the designer knew what the characters should look like at different developmental stages. Efforts were then made to ensure that the graphic designer understood the meanings of the questions to assist in composing the illustrations. Two experts were in charge of this process. The translation and voice recordings for dubbing were also checked extensively.

During this period, drafts of each illustrated checklist were distributed to volunteer parent groups. These parents provided feedback regarding the illustrations and indicated whether they were clear and attractive. The illustrations were then modified accordingly. This version was reevaluated by the task force. The translations were also checked by the task force through extensive discussion before dubbing. The final illustrations were dubbed in both English and Chinese.

Stage III: Web-Based Platform Construction

The proposed system is a Web-based system that fulfills the needs of early childhood developmental screening by involving caregivers, clinical professionals, and government officials over the Internet. It is a professional child screening system presented in a playful style. In total, 144 checklists were developed for 13 different age groups (4, 6, 9, 12, 15, 18, 24, 30, 36, 42, 48, 60, and 72 months). The overall flow of this multimedia system is shown in Figure 2. It represents the interface of the website. Level I consists of information regarding child development and related resources. If the “rapid screening” or “developmental screening” icon is clicked or touched, the user enters Level II, where the screening takes place. Once done with the screening process, the user enters Level III for screening results. The user can also choose whether to retake the test or upload the result to the cloud for data storage and/or warning the administrator.

The child developmental screening system framework is depicted in Figure 3. The Web-based system can be used with Hypertext Transfer Protocol online encryption to enhance information safety. In addition, the back-end system enables government officials to monitor data such as users’ health-related information and their screening results.

The system contains four major modules:

1. User interface module: this module provides a Web-based interface for users to use the child screening service on different devices, such as mobile phones or PCs, provided that Internet access is available.

2. Screening module: this module contains the front-end webpage of the child developmental screening system. A server that included information such as Web interface data, user interaction data, and health information browsing history was linked to this screening module. It also analyzes the screening results collected from the users. When users take the screening test on the system, it automatically processes the input data and determines whether the child passes the test for his or her developmental age. The analyzed data are then saved in the screening database for future search and use.

3. Screening database module: this module preserves data collected from users’ screening tests. The screening results can

also be transmitted to the Department of Health of the Taipei City Government or exported in .csv format for future use.

4. Management module: the government database manager receives users' screening results from the back-end system management platform. Experts can interpret the screening results and provide relevant suggestions or assistance.

The service engine of the system platform can be widely applied to all organizations and users. In addition, the complete multimedia checklists were provided on the Internet and can be used in various browsers. The front-end webpage includes not only the developmental checklists, but also reference sources and information regarding healthy child development, general health information for children, and early intervention and education resources. The back-end control panel can be accessed by registered health care consultants. When a positive screening result raises an alarm, attention can be focused on the child and the consultants can make further contact with the caregivers of that child by phone or mail. Follow-up, such as at-home interviews or physician visits, should be provided on the basis of the initial screening results in addition to the phone conservation, if possible.

Figure 2. The website interface of the child developmental screening system.

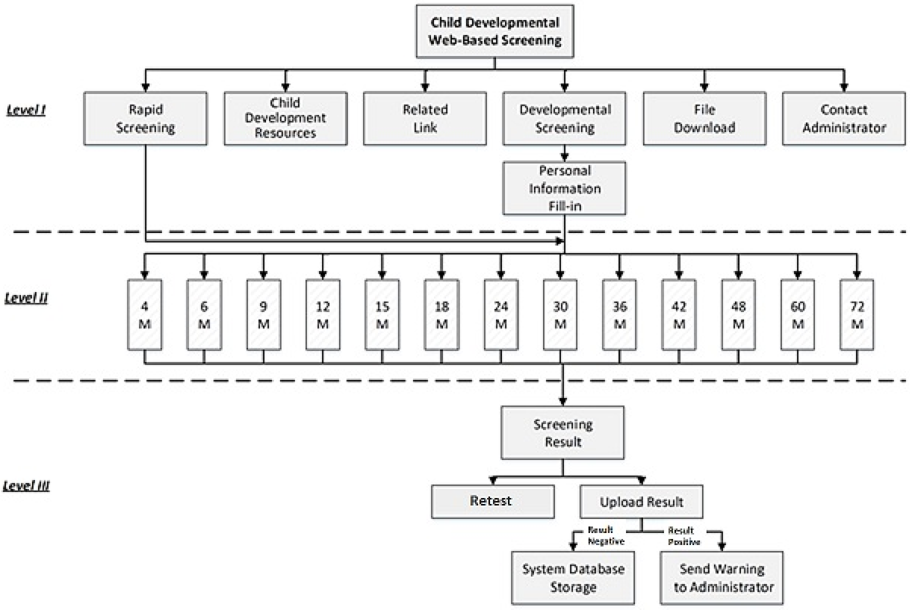
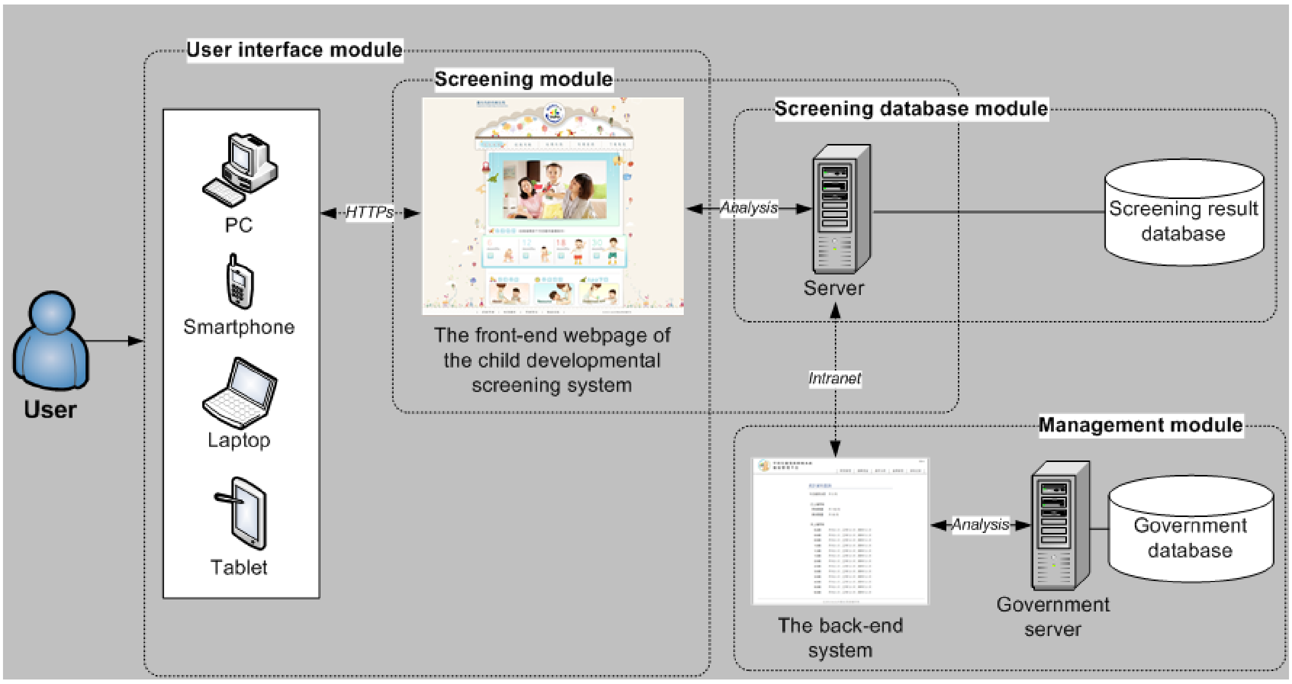


Figure 3. System framework.



Stage IV: Psychometric Testing

Expert Validity

The complete multimedia version of Taipei II was checked for measurement equivalence to the text-based paper-and-pencil version by calculating expert validity. Task force agreement was measured using a four-point Likert-type rating scale [16] (1=not relevant, 2=somewhat relevant, 3=quite relevant, and 4=very relevant). This proportional agreement procedure, calculated using a content validity index (CVI), allows two or more raters to independently review and evaluate the relevance of the illustrations and original text. Multiple iterations of illustration, translation, and dubbing were obtained. The stability of their agreements was determined on the basis of these results.

The final multimedia version was used for cross-mode similarity, test-retest reliability, acceptability, and usability tests. The study protocol was explained to the participants and they were asked to provide informed consent. They were also informed that the data might be made available to government officials. Baseline demographics of the participants and their children were collected to ensure their eligibility. The participants were asked to complete the developmental checklists that matched the age of their children. This study protocol was approved by the Institutional Review Board of Chang Gung Medical Hospital, TaoYuan, Taiwan.

Cross-Mode Similarity

To determine the measurement equivalence between the two versions, a crossover design was implemented. Participants were randomly assigned to complete either the paper version or the multimedia version of Taipei II for the first administration, and the other version for the second administration. A 2-week washout period was enforced between administrations to minimize the carryover effects from the first administration. The cross-mode similarities between checklists for the different age groups were calculated as: ([test number]–[the number of differences])×100%.

Test-Retest Reliability

The test-retest reproducibility was determined for both the paper and multimedia versions. Two weeks after the end of the previously mentioned crossover study, the participants again completed the same version of the developmental checklist they completed in the second administration during the crossover period. The authors tallied the participants’ responses and calculated the similarity for each age group.

Usability and Acceptability of the Web-Based Platform

Combined quantitative and qualitative methods were used to evaluate the usability and acceptability of the Web-based multimedia platform. A five-point Likert scale was used to measure the usability of this multimedia system. The testing items included the screen layout, information displayed on the screen, arrangement of information on the screen, clarity of the expression, ease of navigation, and overall experience with the website. A score of 5 meant most comfortable or extremely satisfied for that particular item. The mean score for the usability items was calculated. Acceptability was assessed using quantitative data regarding whether the participants preferred the Web-based multimedia checklists or the paper-and-pencil checklists or had no specific preference based on its usefulness. The Web-based method was considered acceptable if more than 50% of the parents preferred it to the paper instrument or had no preference [17]. Qualitatively, a semistructured interview was administered. The interviewer asked the parents’ opinions regarding the operation of the website, the quality and layout of the pictorial designs, any improvement needed, or suggestions they had for the multimedia version. The postsurvey interview took no more than 5 minutes.

Results

Throughout the developmental process, there were multiple iterations of illustrations, translation, and dubbing, and the expert validities were obtained twice: the first and the last iterations. The calculated content validities for the two major revisions for each age group are listed in Table 2 for both illustrations and translation/dubbing. The experts achieved a consensus for the final revision. For the overall cross-mode similarity, the mean score for the paper and the multimedia version was 0.94 (Table 2). For test-retest reliability, the mean score was high (r=.93) (Table 2).

Table 2. Expert validity for the first and final iterations, cross-mode similarity for the paper and the multimedia version, and test-retest reliability for the multimedia version.

Psychometrics	Overall	Child age (months)												
		4	6	9	12	15	18	24	30	36	42	48	60	72
Expert validity, CVI														
First iteration		0.97	0.95	0.99	0.69	0.95	0.85	0.96	0.85	0.90	0.81	0.90	0.86	0.86
Final iteration		1.00	1.00	1.00	0.95	1.00	0.91	1.00	0.92	1.00	1.00	1.00	1.00	1.00
Cross-mode similarity, mode intraclass correlation	0.94	0.94	0.88	0.89	0.85	0.89	0.95	0.89	0.96	0.95	0.96	0.92	0.94	0.96
Test-retest reliability, *r*	.93	.95	.89	.90	.87	.91	.95	.91	.96	.95	.96	.92	.95	.97

Table 3. Usability test for the multimedia website (N=390).

Usability items	Score, n					Usability score, mean (SD)
	1	2	3	4	5	
Screen layout	0	0	1	58	331	4.85 (0.37)
Information displayed on the screen	0	0	2	88	300	4.76 (0.44)
Arrangement of information on the screen	0	0	2	87	301	4.77 (0.44)
Ease of navigation	0	0	0	75	315	4.81 (0.39)
Overall experience with the website	0	0	0	77	313	4.80 (0.40)
Mean usability score for all items						4.80 (0.03)

Usability and Acceptability of the Web-Based Multimedia Platform

Quantitatively, the mean usability score for all the test items was 4.80 (SD 0.03), indicating that users were satisfied with their multimedia website experience. The individual scores for testing items are depicted in Table 3. In addition, 97.9% (382/390) of participants preferred the Web-based multimedia version to the paper version, less than 0.8% (3/390) preferred the paper version, and 1.3% (5/390) expressed no preference. In total, 99.2% (387/390) preferred the Web-based multimedia version or had no preference, strongly supporting its acceptability. Qualitatively, participants suggested adding more illustrations or even animation to certain questions to make the checklist clearer and more attractive.

Discussion

Early identification of developmental delays is essential for optimal early intervention. Children with subtle developmental problems often remain unidentified as such; therefore, regular screening is of great importance. Typical text-based screening can overlook respondents with low literacy and those whose first language differs from the text. In addition, text-based screening tools lose users' attention easily. This study successfully transformed the text-based Taipei II into a multimedia version, and the two modes of administration produced essentially equivalent results. Based on feedback from the participants, the Web-based multimedia mode demonstrated higher acceptability and accessibility than the original version.

Compared with text-based instructions, illustrations and spoken information promote clearer understanding, particularly among people with limited literacy skills or cognitive impairment [11,12]. They promote text comprehension through two effects: increasing motivation and deepening elaboration [11]. Research on learning with text and pictures has yielded numerous recommendations on how to design effective multimedia instruction [14]. It has been proposed that adding visualizations to text (ie, the multimedia principle), using spoken rather than written text to accompany visualizations (ie, the modality principle), and using spoken rather than written and spoken text (ie, the redundancy principle) aid learning. These principles also reflected the needs of our parent groups. Parents' concerns and suggestions included the attractiveness of the designed characters, the clearness of the dubbing contents, and whether the contents were easy to comprehend. Our multimedia developmental screening system consisted of illustrations and dubbings that were evaluated by both the expert teams and the intended users, thereby facilitating clearer understanding for the caregivers.

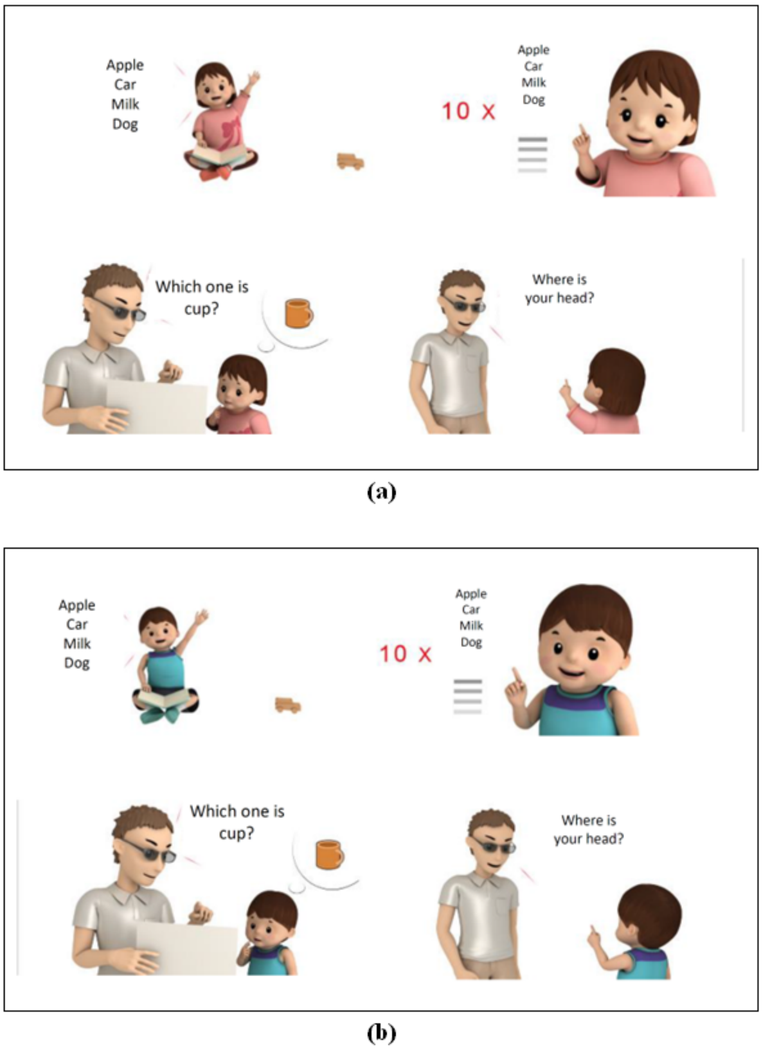
Our results revealed a satisfactory overall similarity of 0.94 between the two versions. This result was achieved through close cooperation among the experts. During the developmental process, the expert team strived to make the presentation of the multimedia system vivid and lively. Research has indicated that positive emotional feelings play a critical role in multimedia learning and should be considered when designing multimedia materials [18]. Therefore, the graphic designers used warm colors and smooth shapes for the child characters (eg, a pink dress for girls and a blue shirt for boys) and their surrounding environment (Figure 4). Age-appropriate appearance (eg, younger children with proportionally larger heads) was also considered during the illustration process. In addition, sound has also been demonstrated to affect comprehension [19]. The team chose a calm female voice to dub each item in the checklists. All these efforts were intended to accurately convey the meaning of the original text-based version and to maintain caregivers' attention.

Physicians generally acknowledge that screening for developmental disabilities is crucial; however, because they are often overwhelmed with patients and constrained for time, few use standardized screening instruments [5,6]. With the current Web-based multimedia screening tool, children can be evaluated by their caregivers. Coupled with the clinical judgment of physicians, this screening tool can considerably improve the rates of appropriate screening and time to diagnosis of children with developmental delay. Hence, such children can be directed to appropriate early intervention services in a timely manner. Still, necessary cautions should be made when using this promising multimedia screening tool. Future studies can focus on other types of reliability tests, such as the stability (ie, the performance agreement over months or years) and other types of validity tests, such as the accuracy of this multimedia system. Alternative screening with proven accuracy, such as Bayley Scales or Vineland Adaptive Behavior Scales, can also be used for developmental screening and their multimedia version can be built in reference to the current process.

The complete developmental process of this multimedia system can be modeled when one is intended to design an effective multimedia tool. The methods and considerations within the four stages in this study (ie, the design of illustration, the translation and dubbing, the Web-based system construction, and the psychometric properties evaluation) can serve as guidelines during the construction of many multimedia system platforms.

In summary, the results indicate that the Web-based multimedia checklists successfully retain the psychometric properties of the original paper-based tool. These findings also support the usefulness of Web-based multimedia checklists as an appropriate development screening tool for children aged between 4 months and 6 years. With the added illustrations and dubbing, the checklists became clearer and more attractive. Moreover, the Web-based tool is easily accessed, facilitating active participation. The team’s next step is promoting this multimedia checklist through the broadcasting media or advertisements in health care agencies, pediatric clinics, public areas, and other related organizations.

Figure 4. Screening checklists for age 24 months (questions 3-5): (a) girl’s version, (b) boy’s version.



(a)

(b)

Acknowledgments

The authors would like to thank all the caregivers and the clinical staffs who participated in this study. This study was supported by the Department of Health, Taipei City Government (GMRPD1C0071), and by Chang Gung Memorial Hospital (CMRPD1E0511). The funding organization had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data or preparation; review; or approval of the manuscript.

Authors' Contributions

HYKC conceptualized and designed the study, designed and validated the multimedia system, designed the data collection instruments, coordinated and supervised data collection at clinical sites, and wrote the manuscript. LYC contributed to the design of the multimedia graphics, designed the data collection instruments, performed the data collection, carried out the statistical analyses, and drafted the manuscript. CHC contributed to the study conceptualization and design, and designed the data collection instruments. YYJ conceptualized and designed the study protocol, and designed the data collection instruments. CLC conceptualized the study protocol, and coordinated and supervised data collection at clinical sites. KCT conceptualized and designed the multimedia system, coordinated the development of the multimedia system, and critically reviewed the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Developmental e-screening leaflet.

[PDF File (Adobe PDF File), 1MB - jmir_v18i10e277_app1.pdf]

References

1. Dearlove J, Kearney D. How good is general practice developmental screening? BMJ 1990 May 5;300(6733):1177-1180 [FREE Full text] [Medline: 1693300]
2. Palfrey J, Singer J, Walker D, Butler J. Early identification of children's special needs: a study in five metropolitan communities. J Pediatr 1987 Nov;111(5):651-659. [Medline: 2444688]
3. Hamilton S. Screening for developmental delay: reliable, easy-to-use tools. J Fam Pract 2006 May;55(5):415-422. [Medline: 16670037]
4. Ziviani J, Darlington Y, Feeney R, Rodger S, Watter P. Early intervention services of children with physical disabilities: complexity of child and family needs. Aust Occup Ther J 2014;61(2):67-75. [Medline: 24689917]
5. Sices L, Feudtner C, McLaughlin J, Drotar D, Williams M. How do primary care physicians identify young children with developmental delays? A national survey. J Dev Behav Pediatr 2003 Dec;24(6):409-417. [Medline: 14671474]
6. Halfon N, Olson L, Inkelas M, Mistry R, Sareen H, Lange L. Summary statistics from the National Survey of Early Childhood Health, 2000. Vital Health Stat 2002;15(3):1-34 [FREE Full text]
7. Radecki L, Sand-Loud N, O'Connor K, Sharp S, Olson L. Trends in the use of standardized tools for developmental screening in early childhood: 2002-2009. Pediatrics 2011 Jul;128(1):14-19. [doi: 10.1542/peds.2010-2180] [Medline: 21708798]
8. Martin AJ, Darlow BA, Salt A, Hague W, Sebastian L, Mann K, Inis Trial Collaborative Group. Identification of infants with major cognitive delay using parental report. Dev Med Child Neurol 2012 Mar;54(3):254-259 [FREE Full text] [doi: 10.1111/j.1469-8749.2011.04161.x] [Medline: 22188172]
9. Liao H, Yao G, Chien C, Cheng L, Hsieh W. Likelihood ratios of multiple cutoff points of the Taipei City Developmental Checklist for Preschoolers, 2nd version. J Formos Med Assoc 2014 Mar;113(3):179-186 [FREE Full text] [doi: 10.1016/j.jfma.2011.10.005] [Medline: 24630036]
10. Carroll A, Bauer N, Dugan T, Anand V, Saha C, Downs S. Use of a computerized decision aid for developmental surveillance and screening: a randomized clinical trial. JAMA Pediatr 2014 Sep;168(9):815-821. [doi: 10.1001/jamapediatrics.2014.464] [Medline: 25022724]
11. Shimada H, Kitajima M. Why do illustrations promote comprehension of manuals? Jpn J of Educ Psychol 2008;56(4):474-486. [doi: 10.5926/jjep1953.56.4_474]
12. Kripalani S, Robertson R, Love-Ghaffari MH, Henderson LE, Praska J, Strawder A, et al. Development of an illustrated medication schedule as a low-literacy patient education tool. Patient Educ Couns 2007 Jun;66(3):368-377. [doi: 10.1016/j.pec.2007.01.020] [Medline: 17344015]
13. Magner U, Schwonke R, Aleven V, Popescu O, Renkl A. Triggering situational interest by decorative illustrations both fosters and hinders learning in computer-based learning environments. Learn Instruct 2014;29:141-152. [doi: 10.1016/j.learninstruc.2012.07.002]
14. Scheiter K, Schüler A, Gerjets P, Huk T, Hesse F. Extending multimedia research: how do prerequisite knowledge and reading comprehension affect learning from text and pictures. Comput Hum Behav 2014 Feb;31(1):73-84. [doi: 10.1016/j.chb.2013.09.022]
15. Höffler T, Leutner D. Instructional animation versus static pictures: a meta-analysis. Learn Instruct 2007 Dec;17(6):722-738. [doi: 10.1016/j.learninstruc.2007.09.013]
16. Wynd CA, Schmidt B, Schaefer MA. Two quantitative approaches for estimating content validity. West J Nurs Res 2003 Aug;25(5):508-518. [Medline: 12955968]
17. Pyke-Grimm KA, Kelly KP, Stewart JL, Meza J. Feasibility, acceptability, and usability of web-based data collection in parents of children with cancer. Oncol Nurs Forum 2011 Jul;38(4):428-435. [doi: 10.1188/11.ONF.428-435] [Medline: 21708533]
18. Plass J, Heidig S, Hayward E, Homer B, Um E. Emotional design in multimedia learning: effects of shape and color on affect and learning. Learn Instruct 2014 Feb;29:128-140. [doi: 10.1016/j.learninstruc.2013.02.006]
19. Moreno R, Mayer R. A coherence effect in multimedia learning: the case for minimizing irrelevant sounds in the design of multimedia instructional messages. J Educ Psychol 2000;92(1):117-125. [doi: 10.1037/0022-0663.92.1.117]

Abbreviations

CVI: content validity index
Taipei II: Taipei City Child Development Screening tool, second version

---

Edited by G Eysenbach; submitted 26.06.16; peer-reviewed by J Hamid, FP Glascoe, A Paglialonga; comments to author 28.07.16; revised version received 26.08.16; accepted 27.09.16; published 24.10.16.

Please cite as:
Cheng HYK, Chen LY, Cheng CH, Ju YY, Chen CL, Tseng KC
A Multimedia Child Developmental Screening Checklist: Design and Validation
J Med Internet Res 2016;18(10):e277
URL: http://www.jmir.org/2016/10/e277/
doi:10.2196/jmir.6249
PMID:27777218

Original Paper

The Narrative Impact of Active Video Games on Physical Activity Among Children: A Feasibility Study

Amy Shirong Lu[1,2], PhD; Tom Baranowski[3], PhD; S Lee Hong[4], PhD; Richard Buday[5], FAIA; Debbe Thompson[3], PhD; Alicia Beltran[3], MSc; Hafza Razak Dadabhoy[3], RN, MS; Tzu-An Chen[6], PhD

[1]College of Arts, Media & Design, Department of Communication Studies, Northeastern University, Boston, MA, United States
[2]Bouvé College of Health Sciences, Department of Health Sciences, Northeastern University, Boston, MA, United States
[3]USDA/ARS Children's Nutrition Research Center, Department of Pediatrics, Baylor College of Medicine, Houston, TX, United States
[4]Information Control Company, Columbus, OH, United States
[5]Archimage Inc, Houston, TX, United States
[6]McGovern Medical School, The University of Texas Health Science Center at Houston, Houston, TX, United States

Corresponding Author:
Amy Shirong Lu, PhD
College of Arts, Media & Design
Department of Communication Studies
Northeastern University
360 Huntington Ave
204 Lake Hall
Boston, MA, 02115
United States
Phone: 1 6173737839
Fax: 1 6173738533
Email: a.lu@northeastern.edu

Abstract

Background: Active video games (AVGs) capable of inducing physical activity offer an innovative approach to combating childhood obesity. Unfortunately, children's AVG game play decreases quickly, underscoring the need to identify novel methods for player engagement. Narratives have been demonstrated to influence behaviors.

Objective: The objective of this study was to test the hypothesis that a narrative would motivate increased AVG play, though a feasibility study that investigated the motivational effect of adding a previously developed narrative cutscene to an originally nonnarrative AVG, *Nintendo Wii Sports Resort: Swordplay Showdown*.

Methods: A total of 40 overweight and obese 8- to 11-year-olds equally divided by sex played the AVG. Half (n=20) were randomly assigned to a narrative group that watched the narrative cutscene before game play. The other half played the game without watching it.

Results: Children in the narrative group had significantly ($P<.05$) more steps per 10-second period (mean 3.2, SD 0.7) and overall (mean 523, SD 203) during game play compared with the nonnarrative group (10-second period: mean 2.7, SD 0.7; overall: mean 366, SD 172).

Conclusions: The AVG with narrative induced increased physical activity. Additional research is needed to understand the mechanisms through which narrative increases physical activity during AVG game play.

(J Med Internet Res 2016;18(10):e272) doi:10.2196/jmir.6538

KEYWORDS

video games; narration; behavior; child health; child obesity; motivation

Introduction

Background and Theory

Children in the United States spend more time with electronic media than any other activity except sleep [1]. Their daily video game play has tripled over the past decade [1]. Traditional video games are sedentary [2] and the likelihood of getting physical activity from health education games is low [3]. Active video games (AVGs), or "interactive video or electronic games that feature player movement, such as would occur in 'real-life' exercise participation" [4], capable of inducing moderate physical activity levels may be a method for increasing youth physical activity [5-7].

A critical issue for AVG interventions, however, is that players typically do not play them for sufficiently long durations [8]. Innovative approaches to promote continued game play are needed to address this problem. A possible solution is the telling of narratives, or stories, one of the most distinctive characteristics of human social groups [9]. Narratives may have a crucial role in motivating increased game play in AVGs through their immersive properties, resulting in increased engagement, but their role has not been systematically investigated [10].

To our knowledge, this is the first feasibility study to systematically investigate the effect of narrative on children's AVG play, testing the hypothesis that narratives will increase physical activity during AVG play. A professionally developed narrative cutscene was developed (ie, a brief, animated movie clip) for an existing AVG requiring trunk movement at a moderate level of physical activity. Children aged 8-11 years played either the narrative or the nonnarrative version of the game by either watching or not watching the narrative cutscene before game play.

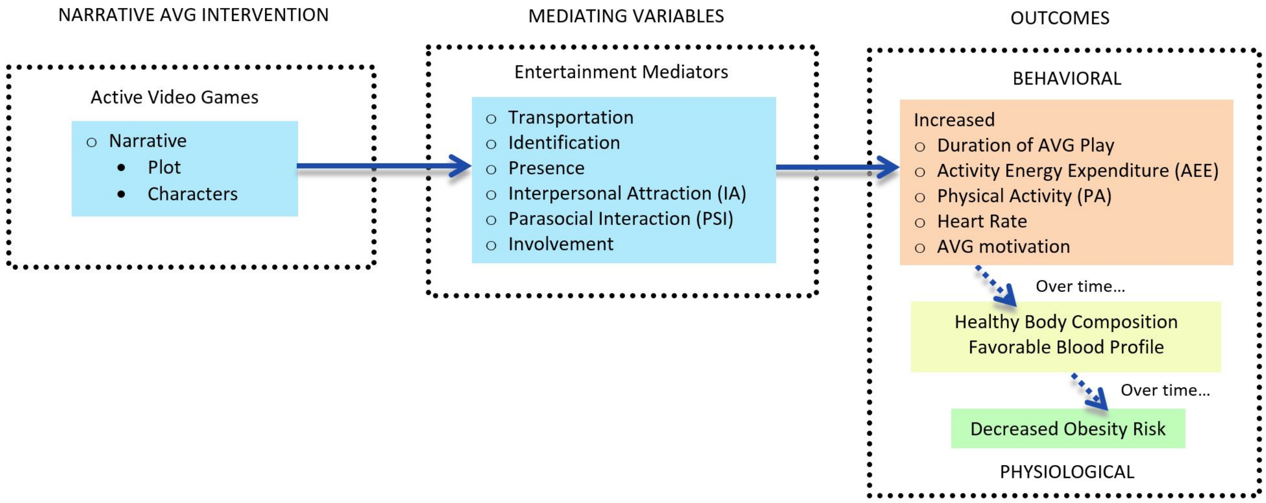
Childhood obesity is a worldwide problem [11], which increases the risk of certain cancers [12-14], shortens life span [15], impedes functional ability [15], diminishes quality of life [15], and tracks into adulthood [16]. Physical activity is critical to preventing childhood obesity [17,18]. US physical activity guidelines recommend 60+ minutes of age-appropriate, enjoyable, mostly moderate or vigorous daily physical activity for children [17]. Yet few children meet these guidelines [18]. Most physical activity interventions have not achieved these effects; lack of access and motivation were identified as key challenges [19-21].

Active video games could provide an innovative method of increasing physical activity with promising health outcomes for many children [22]. As of 2014, an average US household owned at least one dedicated gaming device [23]. All major game console manufacturers offer controllers that can be used as exercise equipment [24]. In 2015, a typical child in the United States aged 8-12 years spent 1.33 hours/day playing video games and 81% of them had a video game console at home [25]. Access to these types of equipment may encourage physical activity among children who live in unsafe neighborhoods that lack accessible outdoor alternatives [4,26,27]. Replacing sedentary activities (eg, entertainment-oriented video games) with AVG play may increase physical activity, thus reducing obesity risk [28].

While AVGs may prevent childhood obesity by increasing physical activity levels, reported AVG play duration varies. One study found that a quarter of young players played AVGs for 2 days a week in bouts of 50 minutes on average [29], whereas another showed that the daily average time spent playing AVGs was only 5 minutes (SD 13.1) for adults and 8 minutes (SD 14.7) for children [30]. Despite game companies' continued high level of investment in "AAA" games, that is, games with the highest development budgets, quality, and levels of promotion [31], most players did not play one game completely before starting a new one [8]. The obesity-combating potential of AVG cannot be realized if players do not play in sufficient dosage [32-34].

Approaches are needed to enhance physical activity resulting from AVG play. Narratives possess unique motivational properties that may encourage AVG play [10]. Although narratives appear in some health video games [35], most were simply used as background context at the beginning of a game and not well adapted throughout the game play. Few AVGs capable of achieving a moderate physical activity level have incorporated narratives [36]. One of the most basic forms of human communication [37], a narrative can be defined as any two or more events arranged in a chronological or causal order [38]. The ability to enjoy narratives is universal [39]. On the psychological level, narratives have a significant impact on cognition, affect, and, potentially, health behavior [40] through transportation, a unique immersive quality that enables suspension of disbelief [41], instills vivid personal experiences [42,43], and helps create deep affection for the characters [44]. The addition of compelling narratives to AVGs could foster strong intrinsic motivation, defined as motivation that comes from inside an individual rather than from outside, to play by reducing cognitive load [45]; engendering arousal and attention [46]; eliciting character identification [47]; and absorbing players in an immersive fictional world [48] that promotes physical activity as necessary and fun [49]. Narratives also encourage players in their role as characters to enhance and maintain their physical activity [50]. On the behavioral level, AVGs with well-constructed stories may elicit desirable behavioral consequences, such as a higher level of physical activity than that elicited by nonnarrative AVGs. Figure 1 illustrates the conceptual model of the potential mechanism for narrative effects. A more detailed explanation of this conceptual model can be found elsewhere [10]. As part of the initial approach in addressing this gap in scientific understanding, this feasibility study tested the hypothesis that a child-friendly narrative would increase physical activity during AVG play.

Figure 1. Conceptual model of the mechanisms for narrative effects. AVG: active video game.



Hypothesis

The narrative version of the AVG will result in a higher level of physical activity measured by steps/second count, total steps count, play duration, and total energy expenditure than the nonnarrative version.

Methods

Design

This study used a 2-arm randomized controlled design with assessments of children's AVG play during and after the sessions. Children were randomly assigned to narrative (n=20) or nonnarrative (n=20) groups.

Sample

Inclusion criteria were as follows: age 8-12 years, between the 85th and 99th percentiles for body mass index (BMI), ability to speak and understand English, and physically able to play the selected AVG. This group was targeted because (1) obese children in this age group are highly likely to become obese young adults [51] and interventions have had effects primarily among the overweight and obese [52,53]; (2) children younger than 8 years have cognitive limitations in responding to questionnaires [54], while children older than 12 years have entered early adolescence and may require different intervention strategies [55]; (3) English is a commonly taught language among children, including migrant children living in the study region; and (4) higher BMI percentile could prevent them from playing the AVG safely. Exclusionary criteria were not speaking or understanding English, having medical or physical problems that prevented AVG game play (eg, epilepsy, using orthopedic devices), or morbid obesity (BMI percentile ≥ 99). Special attention was given to recruiting African American and Hispanic children, the racial and ethnic groups linked to higher rates of obesity [11].

The Institutional Review Boards of Northwestern University and the Baylor College of Medicine approved the research protocols. Children were recruited from mostly lower-income public schools in Chicago and a participant database in Houston. Parents provided written informed consent and children provided written informed assent.

Intervention: Narrative Development and Format

Prior research has used both quantitative and qualitative methods (surveys and cognitive interviews) to explore child preferences for the type of narrative genres (eg, adventure, fable, mystery, comedy) and story plots. A total of 4 plots were developed to presage the selected AVG, *Swordplay: Showdown* (Nintendo Co, Ltd, Kyoto, Japan), by a professional media production company. *Swordplay: Showdown* requires players to wave a remote game controller as a sword to knock out enemies coming at them in different environments (eg, bridge, mountain, ruins). Because the essential movement was to wield a sword, "sword fighting" became the theme of the 4 narratives. An earlier formative observational study suggested that children playing this game were more likely to engage in trunk movement instead of just moving their arms or wrists.

A total of 20 children were recruited from the Chicago metro area. Of the 4 narrative plots, *The Door* was the children's preferred story line. *The Door* tells the story of an ordinary child mysteriously absorbed into a strange world full of cartoon stickmen carrying swords. Results of cutscene testing and development are reported elsewhere [56]. To ensure the narrative would appeal to a diverse audience, character race and ethnic background as well as the plot and background cues were made racially and ethnically ambiguous [57-59].

The selected plot was fully developed and entitled *The Door*. *The Door* included information about the health benefits of physical activity, delivered in a narrative format through character dialogue. To ensure narrative was an optimal message format for health information delivery, a nonnarrative cutscene of comparable character and background setting containing the same type of information about the health benefits of physical activity was produced as a control condition. In the narrative version, when stickmen started to attack the player, they explained the benefits of physical activity and encouraged the player to stay physically active. In the nonnarrative version, stickmen communicated to the player the same information. More details about the conditions can be found elsewhere [60].

Another 20 children from the Houston metro area were recruited to evaluate the narrative and nonnarrative cutscenes. Results indicated that children preferred the narrative cutscene over the nonnarrative cutscene [60]. The narrative version of *The Door* was burned onto a digital video disc (DVD) for use in the study.

Implementation

A total of 40 children from the Houston metro area were recruited. Of these children, 8 participated in a pilot-testing session and 32 participated in the main study. The research protocol did not change between the pilot testing and main study. Thus, results were combined. Children were brought to the Metabolic Research Unit (MRU) of the Children's Nutrition Research Center located in the Texas Medical Center in Houston, Texas. The MRU consisted of a private, semiopen space simulating a modern-day living room with home furniture and household electronics (eg, television) with a separate waiting room attached. Children played the AVG inside the room, while their parents stayed in the waiting room.

After consent and assent and facility orientation, children were randomly assigned to 1 of 2 conditions (narrative or nonnarrative) with 2 physical activity measurement instruments attached by a trained research associate. Those in the narrative condition first watched *The Door* (3 minutes in length) on a large LCD (liquid crystal display) television. The research associate then remotely switched the display from the DVD player to a Wii console preloaded with the *Swordplay: Showdown* AVG. The child was instructed to play the game for as long as he or she desired, up to a maximum playtime of 30 minutes. The research associate exited the room during AVG play to avoid social facilitation and observed the child play from a hidden monitor. The research protocol for those in the nonnarrative condition was identical, except that the children did not view the narrative cutscene before playing the AVG.

Incentives

Each of the 40 children participating in the AVG play study session received a US $25 gift card.

Measures

Children's BMI was calculated as weight in kilograms divided by height in meters squared [61]. Children's height and weight were measured twice by a research associate. A portable stadiometer (Shorr Height Measuring Board, Weigh and Measure, LLC, Olney, MD, USA) was used to measure height to the nearest 0.1 cm. Children's weight was measured to the nearest 0.1 kg using a calibrated scale (Seca 813 digital floor scale, Seca GmbH & Co KG, Hamburg, Germany). The mean of the 2 recordings was recorded. A third measurement was taken in the event of a >0.2 cm or >0.2 kg difference between the first 2 measurements; the mean of these 3 measurements was taken. Each child's age- and sex-specific BMI percentile was obtained from the Centers for Disease Control and Prevention manual [61].

Traditionally, activity sensors have been worn on the hip or arm areas for physical activity assessment. To measure physical activity during children's AVG play, a Sensewear Pro Armband [62] (Sensewear, Jawbone, San Francisco, CA, USA) and ActiGraph GT3X+ triaxial accelerometer [63] (ActiGraph, ActiGraph, LLC, Pensacola, FL, USA) were attached to children (Sensewear Pro on their upper arms and ActiGraph on their hips). The devices were synchronized to ensure they recorded similar time intervals. The research associate documented the duration of the children's AVG play time with a stopwatch. Step data were obtained from both the Sensewear Pro Armband and the ActiGraph accelerometer. Energy expenditure in joules was tracked through the Sensewear Pro Armband.

Social desirability of responses was assessed with the Revised Children's Manifest Anxiety Scale (Sample item: I never say things I shouldn't.) [64]. The questions were collected via a touch-screen tablet.

Statistical Analysis

Independent *t* tests were performed to detect between-group differences in demographic information and BMI. For physical activity measurement, 2 phases were adopted for inferential statistical comparisons of the between-group difference using 2-sample *t* tests assuming unequal variances. Step 1 tested for significant differences in demographic (eg, age) and anthropometric (eg, BMI) measures to determine if the randomization process resulted in any biases in group physical characteristics. Step 2 compared play characteristics in terms of play duration, number of steps, and energy expenditure.

Power analysis showed that with 40 participants (20 per randomized sequence) and an alpha of .05, a 2-sided independent *t* test of the between-group narrative effect had 80% power to detect a large effect size of 0.91 SD units between means of the 2 conditions (narrative vs nonnarrative).

Independent 2-sample *t* tests and chi-square tests showed no between-group differences regarding demographic and baseline anthropometric measures of height, weight, BMI, BMI percentile, or social desirability. Because there was no group bias in participant height, weight, or demographics, covariance analysis was not conducted.

To test whether the narrative cutscene resulted in a more even distribution of activity over the play period, information entropy was used to analyze the probability distribution of the activity monitor data. Higher entropy indicates that the data are more evenly distributed, whereas lower entropy values indicate that activity was clustered around a narrow activity range.

Results

The demographic information for the 40 children can be found in Table 1. The children were on average 9.6 years old and were evenly distributed on the basis of sex. They were from diverse backgrounds, with an overrepresentation of African and Hispanic American children (31/40, 78%). All children were overweight or obese (BMI = 27.2, BMI percentile = 94.3). Most parents (31/40, 78%) had attended some college or beyond. Children primarily resided in single-family homes (35/40, 88%) and lived with 2 or more adults in the household (34/40, 85%). When asked how they liked being in this project at the end of game play, all expressed that participating in the project was a positive experience and that they would like to participate in similar projects in the future.

Table 1. Children’s demographic and weight information (N=40).

Measure	Count, n	% or mean (SD)
Sex (%)		
Female	20	50
Male	20	50
Race (%)		
Asian	2	5
African American	14	35
White American	6	15
Hispanic American	17	43
Multiracial	1	2
Age in years, mean (SD)	N/A[a]	9.6 (1.2)
BMI[b] in kg/m^2, mean (SD)	N/A	27.2 (11.9)
BMI percentile, mean (SD)	N/A	94.3 (12)
Parent education (%)		
Eighth grade or less	1	2
Some high school	1	2
High school	4	10
Technical school	3	8
Some college	9	22
College	11	28
Postgraduate	11	28
Annual income in US $ (%)		
< 20,000	5	12
20,000-39,999	7	17
40,000-59,999	12	30
60,000-79,999	5	13
80,000-100,000	5	13
>100,000	6	15
Type of residence (%)		
Single-family house	35	88
Apartment	3	7
Other	2	5
Number of adults living in the household (%)		
1	6	15
2	27	68
3	7	17

[a] N/A: not applicable.

[b] BMI: Body mass index.

Table 2. Children's physical activity levels during game play (N=40).

Device	Variable	Narrative (n=20), mean (SD)	Nonnarrative (n=20), mean (SD)	t_{19}	*P* value
Stopwatch	Playing duration	17.6 (3.9)	16.2 (4.1)	1.14	.26
ActiGraph	Mean steps/10 seconds[a]	3.2 (0.7)	2.7 (0.7)	2.22	.03
	Total steps[a]	523.0 (203.3)	366.4 (172.0)	2.63	.01

[a] *P*<.05.

We found that the Sensewear Pro Armband significantly overestimated physical activity (ie, total energy expenditure was more than 500 kcal for a 20-minute AVG play) and that the step count correlations between the Sensewear and ActiGraph were inconsistent for the steps per 10 seconds (*r*=.39) and total steps (*r*=.32). Thus, data from Sensewear were discarded for further analysis.

ActiGraph more accurately assessed trunk movement. This is important because many children jumped around when playing with the Wii Remotes [65]. According to Table 2, when physical activity was measured with the ActiGraph accelerometer, children in the narrative group had significantly (*P*<.05) more steps during AVG play in terms of the average number of steps per 10-second period (mean 3.2, SD 0.7) and overall (mean 523, SD 203) when compared with the nonnarrative group (10-second period: mean 2.7, SD 0.7; overall: mean 366, SD 172).

Children in the narrative group had significantly lower entropy (mean 0.77, SD 0.14) than the nonnarrative group (mean 0.88, SD 0.15) according to the ActiGraph measurement (*P*=.01 measured by bits of information), that is, the narrative group's physical activity data were clustered around fewer physical activity levels, indicating more consistent physical activity or play at a steadier pace. The standard deviation and coefficient of variation of the physical activity were not significantly different (*P*=.8 and *P*=.13, respectively). These results indicated that the participants' activity patterns were not normally distributed. Thus the entropy analysis was warranted as a measure of variability.

Differences in average play duration (narrative: mean 17.6, SD 3.9 vs nonnarrative: mean 16.2, SD 4.1) and total energy expenditure (narrative: mean 566.9, SD 215.3 vs nonnarrative: mean 495.8, SD 190.7) were not statistically significant between the narrative and nonnarrative groups.

Discussion

Principal Findings

To the best of our knowledge, this is the first feasibility study of the influence of a narrative on physical activity during AVG play among overweight and obese children. Participants were from diverse backgrounds in an urban area and responded well to the project. The narrative was carefully developed with multiple empirical tests to ensure that plot and characters were closely related to the AVG and were positively received by the diverse child participants. Compared with the original nonnarrative AVG, the addition of a 3-minute narrative cutscene at the beginning of the game play session increased physical activity in children's AVG play, as evidenced by increased average number of steps per 10 seconds and the total step counts. Our findings suggest that the participants in the narrative group were more physically active during game play and more effectively engaging their bodies in swordplay movements than those in the nonnarrative group, who played the original version of the AVG without a narrative cutscene. These findings provide preliminary evidence that an engaging narrative may influence child physical activity during AVG game play.

Children are imaginative beings who could be positively influenced by a make-believe world when a compelling narrative has been developed to meet their developmental, emotional, and recreational needs [66]. To respond to their needs, the research group conducted extensive formative work to ensure children were involved in narrative development, that character and plot design were child-friendly, and that the narrative was appealing. Thus, when a narrative cutscene corresponds to the original AVG and is engaging, children could be motivated to mentally incorporate the narrative into their active play. Future studies should investigate psychobehavioral mechanisms behind such an effect with the goal of maximizing narrative's impact.

There are several limitations to this study. The scale of this study was small, with a small sample of children playing a single AVG session using multiple measurement devices attached to their body after watching just a 3-minute narrative cutscene in a research laboratory. Because of the feasibility nature of the study, the sample of 40 in this study was initially powered to detect a large difference; future studies should be powered to detect smaller differences. Measurement device placements and the laboratory setting may have caused participants to shorten their natural AVG play time, which could have reduced our ability to detect differences in energy expenditure and AVG play motivation between the conditions. Other studies have found similar unreliable measurement results by Sensewear Armbands among overweight and obese children [67,68], possibly because children tend to have a higher body temperature than adults and that changes in skin temperature are central to Sensewear Armbands' energy expenditure calculation. These results suggested that measurement devices should be coordinated to accommodate specific physical activity measurement scenarios and should be able to accurately track physical activity among children. Having heard the story once, the attractiveness of the story may decrease for children who would like to play the game a second time. This may suggest branching narratives or randomized multiple plotlines. In addition, performance-based narrative development may motivate children to repeat AVG game play. Future studies should try measuring participants' physical activity level in a more natural setting for elongated and multiple repeated study sessions and for increased frequency of each play session.

Conclusions

This is the first feasibility study to systematically vary and test the effect of narrative on children's physical activity during AVG play. Narrative increased physical activity during AVG game play among overweight and obese children as evidenced by more steps per 10-second period and total steps overall. Future research is needed to identify the underlying mechanisms through which this occurs.

Acknowledgments

Leia Butler, Leopoldo Castillo, Robert Dolezal, Sakina Kazmi, and Kimberlyn Shirrels helped with data collection in the narrative development stage. This project was funded by a grant from the National Cancer Institute (1R21CA158917-01A1), "The Narrative Impact of Active Video Games on Physical Activity," and federal funds from the US Department of Agriculture's Agricultural Research Service under Cooperative Agreement No. 58-6250-0-008.

Conflicts of Interest

No financial interests were reported from the authors except RB, who is president of Archimage, Inc, the company that created the narrative cutscene for the project.

References

1. Kaiser Family Foundation. KFF. 2010. Generation M2: Media in the Lives of 8- to 18-Year-Olds URL: http://kff.org/other/poll-finding/report-generation-m2-media-in-the-lives/ [accessed 2016-08-24] [WebCite Cache ID 6jzZFrQG0]
2. Vandewater EA, Shim M, Caplovitz AG. Linking obesity and activity level with children's television and video game use. J Adolesc 2004 Feb;27(1):71-85. [doi: 10.1016/j.adolescence.2003.10.003] [Medline: 15013261]
3. Baranowski T, Baranowski J, Thompson D, Buday R, Jago R, Griffith MJ, et al. Video game play, child diet, and physical activity behavior change a randomized clinical trial. Am J Prev Med 2011 Jan;40(1):33-38 [FREE Full text] [doi: 10.1016/j.amepre.2010.09.029] [Medline: 21146765]
4. Bailey BW, McInnis K. Energy cost of exergaming: a comparison of the energy cost of 6 forms of exergaming. Arch Pediatr Adolesc Med 2011 Jul;165(7):597-602. [doi: 10.1001/archpediatrics.2011.15] [Medline: 21383255]
5. Biddiss E, Irwin J. Active video games to promote physical activity in children and youth: a systematic review. Arch Pediatr Adolesc Med 2010 Jul;164(7):664-672. [doi: 10.1001/archpediatrics.2010.104] [Medline: 20603468]
6. Graf DL, Pratt LV, Hester CN, Short KR. Playing active video games increases energy expenditure in children. Pediatrics 2009 Aug;124(2):534-540. [doi: 10.1542/peds.2008-2851] [Medline: 19596737]
7. Foley L, Maddison R. Use of active video games to increase physical activity in children: a (virtual) reality? Pediatr Exerc Sci 2010 Feb;22(1):7-20. [Medline: 20332536]
8. Abernathy T, Rouse R. GDC Vault. 2014. Death to the three-act structure: Toward a unique structure for game narratives URL: http://www.gdcvault.com/play/1020050/Death-to-the-Three-Act [accessed 2016-08-24] [WebCite Cache ID 6jzZXiTMa]
9. Jameson F. The political unconscious: narrative as a socially symbolic act. Ithaca, NY: Cornell University Press; 1981.
10. Lu AS. Narrative in Exergames: Thoughts on Procedure, Mechanism, and Others. Games Health J 2015 Feb;4(1):19-24 [FREE Full text] [doi: 10.1089/g4h.2014.0090] [Medline: 26181676]
11. Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of childhood and adult obesity in the United States, 2011-2012. JAMA 2014 Feb 26;311(8):806-814. [doi: 10.1001/jama.2014.732] [Medline: 24570244]
12. Steinbeck KS. The importance of physical activity in the prevention of overweight and obesity in childhood: a review and an opinion. Obes Rev 2001 May;2(2):117-130. [Medline: 12119663]
13. National Cancer Institute. NCI. 2010. Obesity and Cancer Risk URL: http://www.cancer.gov/about-cancer/causes-prevention/risk/obesity/obesity-fact-sheet [accessed 2016-08-24] [WebCite Cache ID 6jzZgWJxl]
14. McTiernan A. Cancer Prevention and Management through Exercise and Weight Control. Boca Raton, FL: Taylor & Francis; 2006.
15. Danaei G, Ding EL, Mozaffarian D, Taylor B, Rehm J, Murray CJ, et al. The preventable causes of death in the United States: comparative risk assessment of dietary, lifestyle, and metabolic risk factors. PLoS Med 2009 Apr 28;6(4):e1000058 [FREE Full text] [doi: 10.1371/journal.pmed.1000058] [Medline: 19399161]
16. Freedman DS, Khan LK, Dietz WH, Srinivasan SR, Berenson GS. Relationship of childhood obesity to coronary heart disease risk factors in adulthood: the Bogalusa Heart Study. Pediatrics 2001 Sep;108(3):712-718. [Medline: 11533341]
17. U.S. Department of Health and Human Services. Health.gov. 2016. Physical Activity Guidelines for Americans URL: https://health.gov/paguidelines/guidelines/ [accessed 2016-08-24] [WebCite Cache ID 6jzZovaVe]
18. National Physical Activity Plan. Physicalactivityplan. 2016. The 2014 United States Report Card on Physical Activity for Children & Youth URL: http://www.physicalactivityplan.org/reportcard/NationalReportCard_longform_final%20for%20web.pdf [accessed 2016-08-24] [WebCite Cache ID 6jzZykDze]

19. Shaya FT, Flores D, Gbarayor CM, Wang J. School-based obesity interventions: a literature review. J Sch Health 2008 Apr;78(4):189-196. [doi: 10.1111/j.1746-1561.2008.00285.x] [Medline: 18336677]
20. Brown T, Summerbell C. Systematic review of school-based interventions that focus on changing dietary intake and physical activity levels to prevent childhood obesity: an update to the obesity guidance produced by the National Institute for Health and Clinical Excellence. Obes Rev 2009 Jan;10(1):110-141. [doi: 10.1111/j.1467-789X.2008.00515.x] [Medline: 18673306]
21. Salmon J, Booth ML, Phongsavan P, Murphy N, Timperio A. Promoting physical activity participation among children and adolescents. Epidemiol Rev 2007;29:144-159. [doi: 10.1093/epirev/mxm010] [Medline: 17556765]
22. Biddiss E, Irwin J. Active video games to promote physical activity in children and youth: a systematic review. Arch Pediatr Adolesc Med 2010 Jul;164(7):664-672. [doi: 10.1001/archpediatrics.2010.104] [Medline: 20603468]
23. Theesa. 2014. Essential Facts About the Computer and Video Game Industry URL: http://www.theesa.com/wp-content/uploads/2014/10/ESA_EF_2014.pdf [accessed 2016-08-24] [WebCite Cache ID 6jza4JbG8]
24. Greenwald W. PC Magazine. 2013. Xbox One, PS4, and Wii U: Welcome to the WAFT Generation URL: http://www.pcmag.com/article2/0,2817,2419456,00.asp [accessed 2016-08-24] [WebCite Cache ID 6jza9O9ZJ]
25. Rideout V. Commonsensemedia. 2015. The Common Sense Census: Media Use by Tweens and Teens URL: https://www.commonsensemedia.org/research/the-common-sense-census-media-use-by-tweens-and-teens [accessed 2016-10-04] [WebCite Cache ID 6l06UVIRy]
26. Miles R. Neighborhood disorder, perceived safety, and readiness to encourage use of local playgrounds. Am J Prev Med 2008 Apr;34(4):275-281. [doi: 10.1016/j.amepre.2008.01.007] [Medline: 18374240]
27. Weir LA, Etelson D, Brand DA. Parents' perceptions of neighborhood safety and children's physical activity. Prev Med 2006 Sep;43(3):212-217. [doi: 10.1016/j.ypmed.2006.03.024] [Medline: 16712912]
28. Maddison R, Foley L, Ni MC, Jiang Y, Jull A, Prapavessis H, et al. Effects of active video games on body composition: a randomized controlled trial. Am J Clin Nutr 2011 Jul;94(1):156-163 [FREE Full text] [doi: 10.3945/ajcn.110.009142] [Medline: 21562081]
29. O'Loughlin EK, Dugas EN, Sabiston CM, O'Loughlin JL. Prevalence and correlates of exergaming in youth. Pediatrics 2012 Nov;130(5):806-814 [FREE Full text] [doi: 10.1542/peds.2012-0391] [Medline: 23027171]
30. Fullerton S, Taylor AW, Dal GE, Berry N. Measuring physical inactivity: do current measures provide an accurate view of “sedentary” video game time? J Obes 2014;2014:287013 [FREE Full text] [doi: 10.1155/2014/287013] [Medline: 25002974]
31. DeMaria R, Wilson J. High score! the illustrated history of electronic games. Berkeley, CA: McGraw-Hill/Osborne; 2002.
32. Chin A Paw MJ, Jacobs WM, Vaessen EP, Titze S, van M. The motivation of children to play an active video game. J Sci Med Sport 2008 Apr;11(2):163-166. [doi: 10.1016/j.jsams.2007.06.001] [Medline: 17706461]
33. Madsen KA, Yen S, Wlasiuk L, Newman TB, Lustig R. Feasibility of a dance videogame to promote weight loss among overweight children and adolescents. Arch Pediatr Adolesc Med 2007 Jan;161(1):105-107. [doi: 10.1001/archpedi.161.1.105-c] [Medline: 17199076]
34. Graves LE, Ridgers ND, Atkinson G, Stratton G. The effect of active video gaming on children's physical activity, behavior preferences and body composition. Pediatr Exerc Sci 2010 Nov;22(4):535-546. [Medline: 21242603]
35. Kharrazi H, Lu AS, Gharghabi F, Coleman W. A Scoping Review of Health Game Research: Past, Present, and Future. Games Health J 2012 Apr 18;1(2):153-164 [FREE Full text] [doi: 10.1089/g4h.2012.0011] [Medline: 24416638]
36. Lu AS, Kharrazi H, Gharghabi F, Thompson D. A Systematic Review of Health Videogames on Childhood Obesity Prevention and Intervention. Games Health J 2013 Jun;2(3):131-141 [FREE Full text] [doi: 10.1089/g4h.2013.0025] [Medline: 24353906]
37. Fisher W. The Narrative Paradigm: In the Beginning. J Communication 1985 Dec;35(4):74-89. [doi: 10.1111/j.1460-2466.1985.tb02974.x]
38. Rimmon-Kenan S. Narrative Fiction: Contemporary Poetics. London: Routledge; 2002.
39. Cosmides L, Tooby J. Evolutionary psychologythe emotions. In: Lewis M, Haviland-Jones JM, editors. Handbook of Emotions. New York, NY: Guilford; 2000:91-115.
40. Kreuter MW, Green MC, Cappella JN, Slater MD, Wise ME, Storey D, et al. Narrative communication in cancer prevention and control: a framework to guide research and application. Ann Behav Med 2007 Jun;33(3):221-235. [doi: 10.1080/08836610701357922] [Medline: 17600449]
41. Green MC, Garst J, Brock TC. The power of fiction: Determinants and boundaries. In: Shrum LJ, editor. The Psychology of Entertainment Media: Blurring the Lines between Entertainment and Persuasion. Mahwah, NJ: Lawrence Erlbaum Associates; 2004:161-176.
42. Fazio R, Zanna M. Direct experience and attitude-behavior consistency. In: Berkowitz L, editor. Advances in Experimental Social Psychology. New York, NY: Academic Press; 1981:161-202.
43. Epstein S. Cognitive-experiential self-theory. In: Barone DF, Hersen M, Van Hasselt VB, editors. Advanced personality. New York, NY: Plenum Press; 1998:211-238.
44. Oatley K. Emotions and the story worlds of fiction. In: Green MC, Strange JJ, Brock TC, editors. Narrative Impact: Social and Cognitive Foundations. Mahwah, NJ: Lawrence Erlbaum Associates; 2002:39-69.

45. Pillay H. An investigation of cognitive processes engaged in by recreational computer game players: Implications for skills of the future. Journal of Research on Technology in Education 2002;34(3):336-350.
46. Slater M. Entertainment education and the persuasive impact of narratives. In: Green MC, Strange JJ, Brock TC, editors. Narrative Impact: Social and Cognitive Foundations. Mahwah, NJ: Lawrence Erlbaum Associates; 2002:157-182.
47. Cohen J. Defining identification: A theoretical look at the identification of audiences with media characters. Mass Communication & Society 2001;4(3):245-264.
48. McLellan H. Hypertextual Talestory Models for Hypertext Design. Journal of Educational Multimedia and Hypermedia 1993;2(3):239-260.
49. Laurillard D. Multimedia and the learner's experience of narrative. Computers and Education 1998;31(2):229-242.
50. Bielenberg D, Carpenter-Smith T. Efficacy of story in multimedia training. Journal of Network and Computer Applications 1997;20(2):151-159.
51. Whitaker RC, Wright JA, Pepe MS, Seidel KD, Dietz WH. Predicting obesity in young adulthood from childhood and parental obesity. N Engl J Med 1997 Sep 25;337(13):869-873. [doi: 10.1056/NEJM199709253371301] [Medline: 9302300]
52. Gutin B, Islam S, Treiber F, Smith C, Manos T. Fasting insulin concentration is related to cardiovascular reactivity to exercise in children. Pediatrics 1995 Dec;96(6):1123-1125. [Medline: 7491233]
53. McMurray RG, Bauman MJ, Harrell JS, Brown S, Bangdiwala SI. Effects of improvement in aerobic power on resting insulin and glucose concentrations in children. Eur J Appl Physiol 2000 Jan;81(1-2):132-139. [doi: 10.1007/PL00013786] [Medline: 10552278]
54. Borgers N, de Leeuw E, Hox J. Children as Respondents in Survey Research: Cognitive Development and Response Quality 1. Bulletin de Méthodologie Sociologique 2000 Apr 01;66(1):60-75. [doi: 10.1177/075910630006600106]
55. CDC. 2011. Child Development URL: http://www.cdc.gov/ncbddd/child/earlyadolescence.htm [accessed 2016-08-24] [WebCite Cache ID 6jzaKLpjP]
56. Lu AS, Buday R, Thompson D, Baranowski T. What type of narrative do children prefer in active video games? An exploratory study of cognitive and emotional responses. In: Tettegah SY, Huang WD, editors. Emotions, Technology, and Digital Games. London: Elsevier Publications; 2015:137-155.
57. Lu AS. What Race Do They Represent and Does Mine Have Anything to Do with It? Perceived Racial Categories of Anime Characters. Animation 2009 Jul 21;4(2):169-190. [doi: 10.1177/1746847709104647]
58. Lu AS, Thompson D, Baranowski J, Buday R, Baranowski T. Story Immersion in a Health Videogame for Childhood Obesity Prevention. Games Health J 2012 Feb 15;1(1):37-44 [FREE Full text] [doi: 10.1089/g4h.2011.0011] [Medline: 24066276]
59. Thompson D, Baranowski T, Buday R, Baranowski J, Thompson V, Jago R, et al. Serious Video Games for Health How Behavioral Science Guided the Development of a Serious Video Game. Simul Gaming 2010 Aug 1;41(4):587-606 [FREE Full text] [doi: 10.1177/1046878108328087] [Medline: 20711522]
60. Fernandes DV, Mafra R, Beltran A, Baranowski T, Lu AS. Children's Cognitive and Affective Responses About a Narrative Versus a Non-Narrative Cartoon Designed for an Active Videogame. Games Health J 2016 Apr;5(2):114-119. [doi: 10.1089/g4h.2015.0019] [Medline: 26881473]
61. CDC. 2011. Healthy Weight URL: http://www.cdc.gov/healthyweight/assessing/bmi/ [accessed 2016-08-24] [WebCite Cache ID 6jzaQaXhc]
62. Jawbone. 2010. Jawbone URL: https://jawbone.com/?rf=bodymedia [accessed 2016-08-24] [WebCite Cache ID 6jzaafh81]
63. ActiGraph. Actigraphcorp. 2011. ActiGraph Research Database URL: http://actigraphcorp.com/resources/research-database/ [accessed 2016-08-24] [WebCite Cache ID 6jzanad9L]
64. Reynolds C, Paget K. National normative and reliability data for the Revised Children's Manifest Anxiety Scale. School Psychology Review 1983;12:324-336.
65. Ward DS, Evenson KR, Vaughn A, Rodgers AB, Troiano RP. Accelerometer use in physical activity: best practices and research recommendations. Med Sci Sports Exerc 2005 Nov;37(11 Suppl):S582-S588. [Medline: 16294121]
66. Nicolopoulou A. Children and narratives: Toward an interpretive and sociocultural approach. In: Bamberg M, editor. Narrative Development: Six Approaches. Hillsdale, NJ: Lawrence Erlbaum Associates; 1997:179-215.
67. Dorminy CA, Choi L, Akohoue SA, Chen KY, Buchowski MS. Validity of a multisensor armband in estimating 24-h energy expenditure in children. Med Sci Sports Exerc 2008 Apr;40(4):699-706 [FREE Full text] [doi: 10.1249/MSS.0b013e318161ea8f] [Medline: 18317374]
68. Predieri B, Bruzzi P, Lami F, Vellani G, Malavolti M, Battistini NC, et al. Accuracy of SenseWear Pro2 Armband to predict resting energy expenditure in childhood obesity. Obesity (Silver Spring) 2013 Dec;21(12):2465-2470 [FREE Full text] [doi: 10.1002/oby.20427] [Medline: 23512749]

Abbreviations

AVG: active video game
BMI: body mass index
DVD: digital video disc

MRU: Metabolic Research Unit

Edited by G Eysenbach; submitted 24.08.16; peer-reviewed by E Lyons, D Castelli, V Fernandes Davies, F Gharghabi, J Meng; comments to author 14.09.16; revised version received 21.09.16; accepted 22.09.16; published 14.10.16.

Please cite as:
Lu AS, Baranowski T, Hong SL, Buday R, Thompson D, Beltran A, Dadabhoy HR, Chen TA
The Narrative Impact of Active Video Games on Physical Activity Among Children: A Feasibility Study
J Med Internet Res 2016;18(10):e272
URL: http://www.jmir.org/2016/10/e272/
doi:10.2196/jmir.6538
PMID:27742605

Original Paper

“I Always Vet Things”: Navigating Privacy and the Presentation of Self on Health Discussion Boards Among Individuals with Long-Term Conditions

Ellen Brady[1], PhD; Julia Segar[1], PhD; Caroline Sanders[2], PhD

[1]Centre for Primary Care, University of Manchester, Manchester, United Kingdom

[2]NIHR School for Primary Care Research, Manchester Academic Health Sciences Centre, University of Manchester, Manchester, United Kingdom

Corresponding Author:
Ellen Brady, PhD
Centre for Primary Care
University of Manchester
Williamson Building
Oxford Road
Manchester, M13 9PL
United Kingdom
Phone: +44 (0) 161 306 6000
Email: ellen.brady1987@gmail.com

Abstract

Background: The ethics of research into online communities is a long-debated issue, with many researchers arguing that open-access discussion groups are publically accessible data and do not require informed consent from participants for their use for research purposes. However, it has been suggested that there is a discrepancy between the perceived and actual privacy of user-generated online content by community members.

Objective: There has been very little research regarding how privacy is experienced and enacted online. The objective of this study is to address this gap by qualitatively exploring the expectations of privacy on Internet forums among individuals with long-term conditions.

Methods: Semistructured interviews were conducted with 20 participants with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and 21 participants with type 1 and 2 diabetes mellitus, and were analyzed using thematic analysis. Participants were recruited via online and offline routes, namely forums, email lists, newsletters, and face-to-face support groups.

Results: The findings indicate that privacy online is a nebulous concept. Rather than individuals drawing a clear-cut distinction between what they would and would not be comfortable sharing online, it was evident that these situations were contextually dependent and related to a number of unique and individual factors.

Conclusions: Interviewees were seen to carefully manage how they presented themselves on forums, filtering and selecting the information that they shared about themselves in order to develop and maintain a particular online persona, while maintaining and preserving an acceptable level of privacy.

(J Med Internet Res 2016;18(10):e274) doi:10.2196/jmir.6019

KEYWORDS

privacy; ethics; research ethics; informed consent; patients; social support

Introduction

Rapid advances in technology and Internet use have led to an increasingly evolving body of research and practice in the area of eHealth. In particular, there has been a wealth of patient-centered systems and services, such as the growth of informal support systems via online patient communities [1,2]. In line with this growth, there has been an equivalent focus on these online communities by researchers. However, despite the growing use of user-generated content as data by researchers, less attention has been paid to the ethical considerations surrounding this research. This paper aims to contribute to discussions in this area by exploring the notions of “public” and “private” spaces among individuals with long-term conditions.

The ethics surrounding the study of Web-based interactions is a long-debated issue. For example, King [3] argues that it is unnecessary to receive permission from a virtual community to conduct research based on messages generated in publicly available spaces, as long as certain criteria surrounding privacy are adhered to, for example, removing all references to the name and type of the groups. Similarly, Reid [4] mentions that once participants in a multi-user dungeon (MUD), a type of Internet forum, learned the nature of her research, they began to "manufacture quotable quotes" (p 171), leading her to conclude that nondisclosure of her research was not only justified but also essential.

In addition, many researchers make distinctions between degrees of public and private spaces online. Many of the forums used in health care research do not require any subscription or registration in order to access the messages; thus, it has been suggested that members of such forums are not likely to view the discussion boards as a "private place" online [5]. For example, Elwell [6], in studying forums used by adolescents with cancer, justified the lack of informed consent from forum participants on this basis, saying:

> *Ethical issues associated with the present project include the issue of informed consent, as the adolescents who posted messages to the computer-mediated support group are not aware that their messages are being used for research purposes, so thus have not formally consented. However, in the present study an online support group was chosen that did not require subscription or registration in order to access the messages, thus it is argued that messages posted to the computer-mediated social support group are indeed accessible to the public and thus informed consent from the adolescents in this instance is not required.* [p 239]

Although this argument is frequently made in the study of online forums [7-9], ethical concerns continue to be extensively discussed, reflecting a common discomfort with observational research online [10]. Some early attempts were made to establish a series of ethical guidelines around the Internet as a source of data, notably the 2002 recommendations from the Association of Internet Researchers (AoIR). These guidelines were updated in 2012 to acknowledge the evolving field of Internet ethics. As the guidelines themselves acknowledge, rather than representing a strict code of behavior, they merely serve to "emphasize processes for decision making and questions that can be applied to ever-changing technological contexts" [11]. The recommendations cover a number of topics that are beyond the scope of this paper, but of key relevance to the present research is that they highlight the nebulous notion of privacy. In particular, they outline how social, academic, and regulatory distinctions between public and private are not likely to be applicable in the context of the Internet and social media.

Public and Private Spaces Online

It is first necessary to consider what current research exists on these topics. The AoIR recommendations highlight the potential for discrepancies to exist between the actual privacy and the perceived privacy of online content. For example, despite forum content being publically accessible and available to anyone with a Web connection, it is possible that the creators of the content may perceive that the information, experiences, and opinions that they share online are being disseminated in a private space. This may have particular resonance for health-related forums, where the topics under discussion may have a particular emotive significance [12]. As Daker-White et al [12] highlight, the knowledge that their words and experience could potentially be shared and disseminated could have an impact on participants' posting style or even discourage them from posting.

The potential contradictions between notions of public and private are covered at length by boyd and Marwick [13]. In this article, they describe a scenario where images from teenagers' Facebook pages were used in an educational lecture on Internet safety by educators and law enforcement officials in the United States. Despite students being aware that the information and pictures that they shared on Facebook were public or relatively public, their expectations of privacy included an expectation that their profiles would not be accessed and shared without their prior knowledge and consent. Students reacted angrily, describing the lecture as "a violation of privacy" (p 6).

The authors argue that rather than representing a contradictory stance, this perception is in line with typical social norms around public engagement [13]. They suggest that expectations of privacy online mirror expectations of privacy offline—one would not expect a conversation held in a public restaurant to be overheard and broadcast, despite the knowledge that the conversation *can* be overheard [14]. Indeed, early research into computer-mediated communication indicated that individuals often self-disclose very personal information online that they would not be willing to reveal offline, known as the "online disinhibition effect" [15].

Supporting this notion, other researchers have pointed to apparent discrepancies in Internet users' perceptions and expectations of privacy. Bassett and O'Riordan [16] highlight an example in which lesbian, gay, bisexual, and transgender forum users' constructions of privacy online, and their expected levels of confidentiality, safety, and freedom, were sharply divergent from both the actual levels of privacy and access and the description of the site and forum provided by the website owners. This indicates that despite signals to the contrary, individuals involved in online discussion groups may view the spaces that they occupy online as safe spaces, unlikely to be accessed or disseminated by outsiders.

As Hogan [17] indicates, expectations of privacy online do not necessarily indicate that individuals are sharing information that they wish to remain hidden. Rather it suggests that, when information is shared, the people with whom the information has been explicitly shared (ie, forum users, Facebook friends, members of an email list) are considered to be contextually appropriate for the specific information [18]. This notion of contextual integrity [18,19] holds that conceptions of privacy are shaped by the norms of the contexts in which the information is shared. Instead of utilizing a strict public/private dichotomy, Nissenbaum [18,19] proposes that individuals exist in a plurality of realms, each with different guidelines outlining how to act and interact. Privacy is considered to be violated when norms specific to a particular context are violated, such as norms about what information is appropriate to divulge in a given situation or how it is appropriate for that information to be distributed [18].

For example, within a health care consultation, it is considered appropriate for an individual to share information about his or her physical condition with a doctor. However, if the doctor were to reciprocate by divulging information about his or her own physical state, that would not be seen as appropriate. Similarly, although an individual may expect a doctor to share information about his or her condition with a practice nurse, if required, it is likely that distributing that same information to the doctor’s family and friends would be receive an extremely negative reaction from the patient [19]. Although the information being shared in all cases may be virtually identical, the alterations in context and audience result in privacy norms being violated.

However, as Marwick and boyd [20] point out, this model presumes that the individual at the center of the scenario is fully aware of the social context surrounding their disclosure. In order to navigate privacy online, individuals must have the technological expertise to operate their medium of sharing information, as well as the knowledge and skills to influence how information flows in an online context and how it is interpreted within that context. Instead, they propose a model of networked privacy, which draws on social media research to argue that information norms are co-constructed by participants and are constantly shifting due to variations in social norms and technological skills among individuals. This further highlights the complexities of privacy online, and suggests that a blanket approach toward particular media as “public spaces” or “private spaces” may be problematic.

From a research perspective, Hudson and Bruckman [21] reported that many of the chat rooms they entered as part of their study responded negatively to the presence of researchers. In the majority of cases, the researchers were “kicked out” or banned from participating in the space. Comments from some groups indicated that they viewed the publically accessible chat rooms as private spaces and were unwilling to tolerate the use of the content for research purposes. Although this is in line with findings from boyd and Marwick [13] and Bassett and O’Riordan [16], it does have potential implications for the use of user-generated content and particularly forum content as data. Specifically, it contradicts the assumption that publically accessible spaces online are seen as public spaces by participants [5,6] and, therefore, do not require informed consent from users.

There has been a growing use of forums in research, particularly health research and, to a lesser extent, debate and dialog around the ethical implications of this practice [22-24], but there has been a dearth of research directly exploring forum participants’ perceptions and expectations of public and private spaces online. Bond et al [10] interviewed users of online diabetes discussion boards. Although the participants were generally supportive of the use of forum data for research purposes, citing the need for the voices of individuals with diabetes to be heard, there was less of a consensus about the specifics of using the data.

Despite many participants acknowledging that their posts were publically available and, therefore, ultimately in the public domain, a number were uncomfortable with their words being used without their consent. In particular, the use of direct quotes was controversial, with interviewees expressing concern that they may be identifiable from the quotes [10]. Although these findings provide some insight into the views and perceptions of forum users, the brief nature of the research offers little clarity around the topic and indicates the need for further research.

Given this, it seems particularly important to give consideration to concepts of public and private spaces within Internet forums, specifically within health-related discussion forums. As the AoIR guidelines suggest, this will by no means result in a strictly defined delineation between the two concepts. Factors such as the level of access available, the number of forum users, and individual forum guidelines and norms will all likely play a role in establishing the boundaries between public and private spaces [5]. Nevertheless, an exploration of these concepts within specific conditions may provide a useful case study of the notions of “public” and “private” in practice.

In this paper, perceptions of privacy on Internet forums are explored by drawing on analysis of qualitative data gathered as part of a broader study into the use of online discussion boards by individuals with long-term conditions. To do this, semistructured qualitative interviews were conducted with UK-based individuals recruited from two population groups. One sample consisted of individuals with type 1 and 2 diabetes mellitus. Diabetes affects more than 5% of the British population and has been highlighted by the National Health Service as a key focus of the effort to improve chronic disease management in the United Kingdom [25]. The other sample consisted of individuals with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), which is characterized by fatigue, pain, and impaired cognitive functioning, and affects up to 100,000 people per year in the United Kingdom [26].

Methods

A qualitative approach was selected as it allowed for an exploration of the opinions and perspectives of individuals with long-term conditions. A broad interview schedule was developed, which explored the role and nature of online support for those with long-term conditions. Interviewees were given space to express their own opinions and ideas; in many cases, their responses shaped the order and structure of the interview [27]. In addition to the broader health-related questions, interviewees were asked about their views of online support groups as public or private spaces and their concepts of audience when sharing and receiving information and experiences online. This was also explored via a vignette (seen in Textbox 1), which was adapted from existing forum data. It was intended that the use of a vignette would enable participants to consider themselves in the place of the character [28].

Textbox 1. Vignette used during the interview process.

> Rachel has ME/CFS and regularly posts in a forum used by other people with similar symptoms. She is concerned that the forum can be viewed by anyone, not just the people who contribute to it. She starts a thread on the forum to discuss this and to see if other people feel the same way.
>
> **Rachel:**
>
> *"Some people are revealing some quite intimate info, and I myself often forget that the forum is open to outsiders to view."*
>
> Here are some of the responses that Rachel receives.
>
> **Sarah:**
>
> *"Not too bothered by this as I have never said anything that I would not be prepared to share with the whole world. I tend to think that the more people that know of the devastation that is caused by this illness, the better. I would like to think that some of the stuff is read by the medical profession—though I think not!!!"*
>
> **Jane:**
>
> *"Hi, I've just seen this thread and am rather concerned and wondering whether not to post anymore, to be honest. That's not just this forum but a lot of open forums too.*
>
> *People need to realize that as we all get so very down, we may say things on here that we wouldn't say to family and friends and maybe it's rather personal.*
>
> *"I shall be having a think as to whether I shall post on here for a while now."*
>
> What do you think about what people have said to Rachel?
>
> What would you say to Rachel?
>
> Do you have anything else to add?

Participants

A total of 41 participants completed interviews, 20 with ME/CFS, 12 with type 1 diabetes, and nine with type 2 diabetes. Interviewees were drawn from across the United Kingdom and the majority of the respondents were female (n=28), with a mean age of 50 (range 18-82) years. To ensure that a range of perspectives were considered, recruitment took place both online and offline. Interviewees were recruited through online and offline sites, such as Internet forums, face-to-face support groups, email lists, and research networks.

Participants were offered the option of face-to-face or phone interviews with the researcher; many (n=29) chose to participate by phone. All interviewees described themselves as white. Notably, the majority of participants (71%, 29/41) had completed at least a higher education degree or equivalent. The latest census data suggested that in 2011, just 27% of the population of England and Wales had received a degree or higher [29], indicating that participants in this study were educated to a higher level than the general British population.

Data Analysis

Interviews were recorded and transcribed verbatim, including participants' responses to the vignette. The anonymized interview transcripts were imported into a qualitative data analysis computer software package (ATLAS.ti version 7) in order to carry out the analysis. It should be noted that the use of a software package merely provided a tool to organize and review the data during the analysis process, rather than offering an objective method of analysis [30]. Each transcript was read through several times and notes were made in order to make note of preliminary connections between interviewees.

A thematic method of analysis was employed, with a view to examining comparisons and contrasts across participants and within cases. Thematic analysis was chosen because it provided a flexible approach to analyzing qualitative data and involves identifying themes in a body of data [31]. Themes were considered to capture something important about the data and to represent a level of patterned response or meaning within a dataset. This process allows the development of a conceptual scheme, which enables further interrogation of the data [32].

The analysis followed an iterative process. A coding frame was devised comprising the initial themes identified within the data. Following this, the data were coded according to these themes. Initially, these codes were broadly descriptive, and related directly to the content of interviewees' transcripts, rather than subtle nuances within the data. For example, references to an interviewee's family were coded as "family" and so on. As coding continued, categories were further refined into subcategories or aggregated to form higher-level categories because the initial coding frame did not sufficiently capture the complexities of the data. The coding frame was continually revised and transcripts were reviewed on an ongoing basis to ensure that additional codes were applied.

Ethics

Ethical approval was granted by the University of Manchester research ethics committee. Any identifying information was removed from the interview transcripts and all participants were assigned pseudonyms. Each participant was provided with an information sheet and encouraged to contact the researcher with any questions both before and after the interview. Signed consent was received from all participants; for telephone interviews, the consent form was mailed in advance along with a stamped addressed envelope to return the signed form to the researcher.

Results

Participants experienced privacy online as a complex and nuanced process. Interviewees were seen to carefully manage how they presented themselves on forums, selecting the information that they shared about themselves and where this information was shared in order to develop and maintain a particular online persona, while preserving their privacy. The context in which information was shared influenced users' decisions about what to disclose and not to disclose online, with individuals adapting what they shared online in order to ensure it was appropriate for the broadest possible audience. In addition, the value of sharing personal information online for fellow patients and health care professionals was consistently highlighted by participants. The process of navigating privacy online is outlined in the following sections.

Presentation of Self Online

For many participants, maintaining their anonymity online was a pivotal aspect of their usage of forums. As "Gemma" (type 2 diabetes, 31-35 years) described it, the diabetes forum she used was "my place and that's my space to talk about things." Although both her parents had been diagnosed with diabetes, she had not told them about her own diagnosis. In addition, she had been extremely reluctant to share that information with family and friends: "The only people that know that I'm diabetic is my husband and my best friend, I haven't told my family and friends, even though my family are, even though my parents are diabetic, I haven't told them." As a result, her diabetes was an intensely personal experience, shared with the forum and a select few acquaintances in real life. This meant that anonymity was a pivotal aspect of her condition ("It would really, really bother me if people found that information, if by googling my name, it came up with all this information, I would be devastated really") and she was unwilling to disclose information about her diabetes to her real-life acquaintances ("I would stop using it").

This suggests that, for some individuals, online discussion groups provide them with a "safe space" in which they could access support away from their real-life support networks [33,34]. For these interviewees, however, the safety of the space was tempered by the awareness that their words may be disseminated among a wider audience than they intended. For others, having an identifiable online presence was something that they had consciously chosen, rather than attempting to remain anonymous online. This was the case for "Louise" (type 1 diabetes, 31-35 years), who regularly blogged about her experiences with type 1 diabetes. She described how she had decided to blog as herself rather than an anonymous individual because she had already been active in the diabetes community for a number of years and, as a result, had a "good network" of peers. By naming herself on her blog, she felt that she was able to "talk freely" about herself, and describe her own situation and experiences, rather than hiding behind an "anonymous persona." However, she acknowledged the impact that this lack of anonymity had had on her online communications. She described how having her words linked to her offline identity made her consider how they were likely to be viewed by an audience, such as a potential employer: "I always vet things with the idea of, OK, would I be happy to discuss this in an interview."

Despite Louise's willingness to identify herself online, her reference to her employer indicates that she was managing her performance and persona online. As research on social media suggests [17,35,36], individuals will adapt the information that they share online in order to cater to the "lowest common denominator" (ie, cater to the broadest audience possible). As a result, Louise, Gemma, and many other interviewees took care to ensure that only certain aspects of themselves were represented online [36]. This self-censorship extended beyond forum participants to members of their social networks. Interviewees spoke about how, while they were happy to share their own experiences online, they avoided sharing personal information about their children or other family members. Participants were conscious that although they could control the level of information that they provided about themselves online, others may not be happy to have information shared about them:

> *When I mentioned about my son going through a difficult time...I don't mean, I don't mention him, what I mean is, I don't mention the difficulties he went through and what it was to do with or anything.* [Joan, ME/CFS, 56-60 years]

This sentiment was echoed by Louise. Although she frequently blogged about her experiences with diabetes, she made a decision not to disclose her experiences with fertility treatments. She was conscious that sharing information and experiences regarding in vitro fertilization (IVF) and diabetes could be of value to others, she felt that the information was "too personal, too vulnerable" to share, despite the potential benefits. Interestingly, she later wrote about her experiences with IVF after she became pregnant, indicating that her desire for privacy was shaped by the need to control the context in which the information was shared rather than the information itself [18-20,35]:

> *That was quite a tough decision because in a way I wanted to share what we were going through because no one writes anything about IVF and diabetes, that's such a niche problem. It's very hard to find good information about it. But I just didn't feel I could expose that kind of thing to the Internet. That was too personal, too vulnerable, especially when we were in the middle of it. Now, I have written some stuff about it looking back, so it's interesting. I don't censor much of what I put online, but there are bits that I do.* [Louise, type 1 diabetes, 31-35 years]

The Value of Sharing Information Online

Despite participants' perceptions of forums as public spaces, or perhaps because of these perceptions, many interviewees reported that they saw a value in sharing their experiences within a public arena. Although participants acknowledged that their words could be accessed by those outside of the immediate audience, this was seen as a pivotal aspect of sharing experiences online. This was particularly prevalent among those with

ME/CFS, many of whom felt that the Internet and Internet forums enabled individuals to describe the daily realities of living with ME/CFS. “Michelle” (ME/CFS, 41-45 years) reported that she shared experiences online in order to address those who may have family or friends with ME/CFS. By sharing her own experiences online, she attempted to legitimize the experiences of others by validating their feelings and symptoms:

> *If you have the partners, or the family watching this kind of website to understand better, if they can see that something their daughters, or whoever, told them about and they can see it said by someone else, maybe they will understand better.* [Michelle, ME/CFS, 41-45 years]

For other participants, the notion that sharing information and experiences online could be of value to health care professionals was highlighted. In response to the vignette, “Nicole” (ME/CFS, 26-30 years) suggested that medical professionals accessing Internet forums could increase their understanding around ME/CFS, which could translate into improved health care for patients: “Sometimes I would like some people from the medical profession to read it and to understand, because the understanding around chronic fatigue is terrible.” This was of similar importance to “Mark” (type 1 diabetes, 41-45 years), who felt that medical professionals accessing Internet forums for individuals with diabetes would not only lead to increased understanding around diabetes, but would also illustrate to professionals the potential benefits to individuals accessing online support: “I think there needs to be a bit of a sea change in some minds of health care professionals, that it’s not actually all bad but that it is a positive experience and it can really help.” Indeed, this echoes recent trends among clinicians, with suggestions that the “cloud of patient experience” online may provide valuable insights into care unfiltered by health care professionals, researchers, or academics [37,38].

Curating the Information Shared Online

In addition to individuals filtering what information they shared online in order to manage their online persona [36,39], interviewees also described how they drew distinctions between where to share their experiences, advice, and information with peers and where not to share this information. The “permanent” nature of Internet forums, some of which did not allow users to delete their posts after a certain period of time, was discussed by many participants, with some reporting that this made them less likely to discuss particular topics in this arena. This led to forum members utilizing other methods of communication, such as live chat, instant messaging, emails, or private messages. Rather than making a blanket distinction about what personal information or data to share and not share online, participants instead considered the context in which information was shared and who was likely to access this information [18-20,35].

For participants, this often meant seeking out spaces online, which were not fully open or publically accessible in order to share information that they considered to be very personal. For example, “Lesley” (type 2 diabetes, 56-60 years) described how she used the live chat on the diabetes forum that she was a member of, which enabled her to exchange instant messages with other forum members. Crucially, using live chat meant that the conversation was not stored afterward and was not publically accessible, even by those who were registered forum members: “If you go on live chat, it’s there, and then when you go off, it’s gone, if you know what I mean, it’s not stored anywhere for anyone else to come and read.” She used this option to talk regularly to other forum members who she considered to be friends, sharing information about their day-to-day experiences with diabetes: “You know, ‘oh, my blood sugar’s up today,’ ‘oh, I’ve had such a thing for my tea and I shouldn’t have done,’ and you know, things like that, what we’ve eaten, the nitty-gritty bits, that’s what we tend to do.” And they also shared more personal information that may not be appropriate for discussion on the forum: “And then we talk personally, you know, how’s it going at home, are you OK, you know, have you been to work today, things like that that you wouldn’t put on the forum because that’s very personal.”

Despite valuing the privacy that this medium afforded her, Lesley still used the forum to discuss “major problems” about her diabetes over the live chat. She recognized the impact that sharing experiences openly had on other people, and wanted to be able to offer that support to others: “The point of the forum, I think, is to help other people who might be like I was doing and just reading, and don’t want to join, and they want to gain something from your experience.” This emphasizes the value of sharing information online, as discussed previously.

It is important to acknowledge the educational backgrounds of the participants in this study and to consider how this may have influenced individuals’ perceptions of privacy online. Many drew explicitly and implicitly on their level of education or work experience in describing how they navigated Internet forums. Indeed, Papacharissi and Gibson [35] describe privacy online as a form of “luxury commodity” (p 85), arguing that the level of computer literacy required to acquire it is inaccessible to many. For example, “Karen” (ME/CFS, 41-45 years) had a degree in information technology and she felt that this background gave her an advantage when it came to deciding what information to share and what not to share online. Like many other interviewees, she viewed the Internet and Internet forums as public spaces, and this influenced how she interacted with others online: “It’s permanent, it don’t matter what you do with it, it’s up there. So I wouldn’t put anything up there that I wouldn’t want a stranger [to read], do you know what I mean?” She drew a distinction between her experiences and those of her husband, who did not have the same educational background and, as a result, struggled to utilize the Internet in the same way:

> *I’m lucky in the sense that I’ve actually studied the Internet and I’ve studied computing, so I have a bit more information than maybe say, like, my husband doesn’t have that much information or nous about the Internet, so he’d be likely to worry about things like that more than me and he’d ask me and I’d say, well, you’re alright to do that but not that.* [Karen, ME/CFS, 41-45 years]

Online Audiences

Given that the majority of interviewees viewed forums as public rather than private spaces, it is necessary to examine whom they felt they were sharing information with online. Nissenbaum

[18,19] suggests that the context in which information is shared influences users' expectations around privacy. In particular, the people with whom information has been shared have been considered appropriate recipients for the specific information. For some of the interviewees recruited via offline sources, the public nature of forums was a barrier to them utilizing forums to share personal information online. In line with the expectation that forums were public spaces, for many individuals, their concept of audience extended outside the members who were actively participating in the forum. For example, interviewees spoke about sharing information online in light of the possibility that their words could be accessed by family and friends.

Illustrating the concept of the lowest common denominator [17], Michelle described how she considered the perspectives of her husband and parents in her interactions online. Although she did not think it was likely that they would access an Internet forum, the awareness that they had the ability to read what she wrote meant that she ensured that she could "justify" what she said to them:

> *I don't think my husband is reading it, but maybe he is...I think, yeah, he wasn't supportive, or anything, I would put it in writing if it were true and if he knows about it, because I've talked about it with him.* [Michelle, ME/CFS, 41-45 years]

For other participants, their concept of audience extended outside their family and friends to include outside parties. This was illustrated by "Susan" (ME/CFS, no age given), who blogged about her experiences with ME/CFS. She was particularly concerned about protecting her identity online because she worried that her online activity would be seen as evidence that she was fit for work by the Department of Work and Pensions (DWP) and would have an impact on the benefits and allowances to which she was currently entitled:

> *I've not actually put my name on the blog...that's because really of potential criticism from somebody like the DWP, because, you know, if they see I've written that blog and I've got that amount of information on it. They'll turn around and say, well, crikey, you're fit to work.* [Susan, ME/CFS, no age given]

However, it should be noted that this awareness of external audiences was not present throughout the entire sample. Some interviewees held a different perception of forums, viewing them as a more private and personal space. Like Karen, many participants expressed concerns that although they were aware of the public nature of Internet forums, others may not be as savvy as them and, as a result, may experience difficulties navigating concerns around privacy and anonymity online. For example, "Michael" (ME/CFS, 66-70 years) described how he had encountered a number of people who had shared information online that he felt was inappropriate:

> *I'm all for frankness and openness but some of the things that I had read I was surprised that people would have put that information in that domain when you think of who could actually see that and that just concerned me a bit.* [Michael, ME/CFS, 66-70 years]

Illustrating this, "Jennifer" (ME/CFS, 36-40 years) drew a comparison between sites online where "anyone could read it and anyone could respond" (eg, comments on the BBC website) and ME/CFS forums. By contrast, forums were seen as less of an unknown quantity, with the expectation that there was a mutual understanding and respect among members: "If it was an ME forum, then, yeah, I think it's nice to know that you can walk into to a space that you've chosen to and that you know what you're walking into." Despite the fact that both spaces were open-access, online public arenas, Jennifer perceived that discussion boards had a deeper level of privacy.

This suggests support for Nissenbaum's notion of contextual integrity [18,19]. Although the majority of interviewees viewed open forums as public spaces, there were exceptions to this. Rather than a strict delineation between public and private spaces online, the context in which the information was shared—in this case, a health-related Internet forum—influenced users' expectations of who could access their words. Participants raised concerns about the supportive nature of online discussion groups and cognitive impairments associated with ME/CFS that could encourage forum users to share information that may be inappropriate or potentially identifying:

> *People in desperation reach out and other people who've been in this cozy environment, this kind of warm room full of friends sharing things openly, forgetting that complete strangers can then just look and read.* [Mark, type 1 diabetes, 41-45 years]
>
> *People with ME, because of the tiredness, etc—I do things now that I wouldn't dream of doing, just by mistake, I wouldn't dream of doing when I was well.* [Nicole, ME/CFS, 26-30 years]

As a result, it is possible that the online context in which individuals perceive they are interacting may not accurately reflect the reality of the situation.

Discussion

The findings support the notion that privacy online is a nebulous concept. For participants, online discussion boards enabled them to reveal information that was intensely personal and private and that they did not feel comfortable sharing in an offline setting, such as with their family and friends. This suggests that, for some individuals, the forums provided them with a safe space in which they could access support away from their real-life support networks [33,34]. However, this does not mean that the information shared on forums represents an unfiltered expression of forum members' thoughts and feelings. In keeping with Goffman's [40] dramaturgical work on identity, participants described a degree of impression management, where they filtered and adapted the information that they shared online in order to create a particular identity for themselves. For many individuals, their adopted online persona was an anonymous one and they spent time censoring and editing what they shared to ensure that their online and offline identities remained separate.

In this way, the findings of this study support previous social media research on the notion of the lowest common denominator, in which individuals adapted what they shared online to ensure it was appropriate for the broadest possible audience [17,35,36]. Interviewees described scrutinizing and modifying their online communications in light of the audiences that they felt could access their words, such as employers, family members, journalists, or government agencies.

In order to remain anonymous online, this self-censorship involved avoiding revealing identifying information such as an individual's place of home or work. For the majority of interviewees, remaining anonymous online was desirable, supporting previous research that indicated that being able to contact peers anonymously is an important aspect of individuals accessing and receiving support online, particularly for health-related queries [33,41]. Even for individuals who did not maintain an anonymous persona online, there was still a sense of managing and monitoring the words and information that they shared. This suggests that maintaining an identifiable online persona is not merely a direct replication of one's offline identity. Rather, only some aspects of oneself are presented online. However, as highlighted by Bullingham and Vasconcelos [36], this can be a two-way process. Although some individuals may carefully share aspects of themselves online in order to present a delicately constructed persona, others may in fact offer their "true selves" online, in cases in which their offline self is influenced by societal or family pressure. Within this study, forum users often utilized both aspects of this presentation simultaneously, describing how they took care to present an anonymous online persona, while at the same time sharing their true feelings and experiences with their condition that they would not feel safe or comfortable sharing with their family and friends. In this way, forums provided a space for posters to perform aspects of their identity unconstrained by offline relationships [34,36].

Despite this, there were concerns from participants that certain forum members were not engaged in a sufficient level of identity management online, leading to ineffective attempts at safeguarding privacy. Although all interviewees felt that they themselves were in control of the information that they disclosed and were capable of navigating and negating any privacy concerns online, some expressed doubts that other Internet users were as competent at these tasks. Returning to the notion of the lowest common denominator, participants suggested that for some forum users, their version of the lowest common denominator was an unrealistic one that did not account for the public nature of Internet forums [17]. Suggested reasons for this included the supportive nature of health discussion groups, cognitive impairments or "brain fog" associated with ME/CFS, as well as a lack of experience or education around the Internet and the nature of social media.

Although the digital divide has been frequently discussed in relation to health literacy [42,43], this paper also points to its relevance to online privacy. This has been highlighted within the literature; Papacharissi and Gibson [35] describe privacy online as a luxury commodity, arguing that the level of computer literacy required in order to acquire it is inaccessible to many. Similarly, Osatuyi [44] highlights the link between confidence in Internet skills and privacy, where users who are less confident in their abilities to navigate social media are less likely to engage with these technologies due to concerns about information privacy. As a result, it is important to note that discussions around the use of online health discussion groups by individuals with long-term conditions may relate to those who have successfully navigated these complexities, rather than a wider population.

In addition, the findings illustrate the notion of privacy online as a nebulous concept. Rather than individuals drawing a clear-cut distinction between what they would and would not be comfortable sharing online, it was evident that these situations were contextually dependent and related to a number of unique and individual factors [18,19]. For example, forum users described how they shared certain information using private messaging or online chat facilities rather than posting on a public forum, indicating that their desire for privacy was shaped by the need to control the context in which the information was shared rather than a need to keep the information itself private [20,35]. This suggests that navigating the different spaces and performative "stages" of Internet forums [17,40] requires an awareness of both the social and technical aspects of these forms of social networks [20]. In addition, as Papacharissi and Gibson [35] highlight, there is an inherent difficulty in negotiating privacy in networked social environments that were designed for sharing rather than privacy. Although their argument relates to social media rather than Internet forums, it is evident that parallels can be drawn between the two spaces.

The results indicate that concerns around privacy are perceived as an additional barrier to those with insufficient levels of digital literacy accessing support online. Nutbeam [45] argues that in order for health literacy to occur, individuals are required to have both the confidence and the skills to gather information, understand it, and actively appraise it. Interviewees suggested that the utilization of forums was a complex process and achieving privacy was a difficult yet pivotal aspect of this utilization. Achieving privacy requires an understanding of networked privacy [20] and the role of contextual factors, such as forum norms and the function of the moderators, as well as the technical aspects of navigating around an Internet forum. As a result, maintaining an online persona, which for many of the participants in this study meant remaining anonymous and carefully considering where to share personal information, is at risk of becoming the preserve of a select few [35]. This means that research into the use of health-related forums must consider the impact of inequalities on forum usage and particularly highly contextual and nuanced factors such as privacy. In order to contribute to the body of knowledge in this area, this research highlights the need to examine how privacy is situated within online literacy. In addition, this has implications for those involved in the creation, curation, or moderation of online spaces because it emphasizes the need to cater for a broad range of users within health-related forums.

Finally, this research aimed to provide some guidance on the ethics of conducting research into online spaces. It was concluded that forums are predominately viewed as public spaces, and forum members adapt what they share online in light of this perception. This is similar to research on Facebook, which indicates that although there are privacy concerns about the medium, information posted on Facebook is tailored toward a broad social audience [46]. This has implications for the use of forum posts as data because it suggests that in the case of health discussion boards, participants generally expected that what they shared online would be accessed by a broader audience beyond those whom they were directly interacting with. However, the findings of this study are likely to be highly context specific and this should not be taken as a blanket suggestion that will apply to all health discussion boards.

Acknowledgments

This research was supported by a Doctoral Training Grant from the Medical Research Council.

Conflicts of Interest

None declared.

References

1. Frost JH, Massagli MP. Social uses of personal health information within PatientsLikeMe, an online patient community: what can happen when patients have access to one another's data. J Med Internet Res 2008;10(3):e15 [FREE Full text] [doi: 10.2196/jmir.1053] [Medline: 18504244]
2. Johnston AC, Worrell JL, Di Gangi PM, Wasko M. Online health communities: an assessment of the influence of participation on patient empowerment outcomes. Info Technology & People 2013 May 31;26(2):213-235. [doi: 10.1108/ITP-02-2013-0040]
3. King SA. Researching Internet communities: proposed ethical guidelines for the reporting of results. Inform Soc 1996 Jun;12(2):119-128. [doi: 10.1080/713856145]
4. Reid E. Informed consent in the study of on-line communities: a reflection on the effects of computer-mediated social research. Inform Soc 1996 Jun;12(2):169-174. [doi: 10.1080/713856138]
5. Eysenbach G, Till JE. Ethical issues in qualitative research on internet communities. BMJ 2001 Nov 10;323(7321):1103-1105 [FREE Full text] [Medline: 11701577]
6. Elwell L, Grogan S, Coulson N. Adolescents living with cancer: the role of computer-mediated support groups. J Health Psychol 2011 Mar;16(2):236-248. [doi: 10.1177/1359105310371398] [Medline: 20733012]
7. Coulson NS, Buchanan H, Aubeeluck A. Social support in cyberspace: a content analysis of communication within a Huntington's disease online support group. Patient Educ Couns 2007 Oct;68(2):173-178. [doi: 10.1016/j.pec.2007.06.002] [Medline: 17629440]
8. Rier DA. Internet social support groups as moral agents: the ethical dynamics of HIV+ status disclosure. Sociol Health Illn 2007 Nov;29(7):1043-1058 [FREE Full text] [doi: 10.1111/j.1467-9566.2007.01023.x] [Medline: 18092982]
9. Seale C, Ziebland S, Charteris-Black J. Gender, cancer experience and internet use: a comparative keyword analysis of interviews and online cancer support groups. Soc Sci Med 2006 May;62(10):2577-2590. [doi: 10.1016/j.socscimed.2005.11.016] [Medline: 16361029]
10. Bond CS, Ahmed OH, Hind M, Thomas B, Hewitt-Taylor J. The conceptual and practical ethical dilemmas of using health discussion board posts as research data. J Med Internet Res 2013;15(6):e112 [FREE Full text] [doi: 10.2196/jmir.2435] [Medline: 23748147]
11. Markham A, Buchanan E. Ethical Decision-Making and Internet Research: Recommendations from the AoIR Ethics Working Committee (Version 2.0). 2012. URL: http://aoir.org/reports/ethics2.pdf [WebCite Cache ID 6hhZbLexD]
12. Daker-White G, Sanders C, Greenfield J, Ealing J, Payne K. Getting a diagnosis v. learning to live with it? The case of the progressive ataxias. Chronic Illn 2011 Jun;7(2):120-133. [doi: 10.1177/1742395310390532] [Medline: 21273218]
13. boyd D, Marwick AE. Social privacy in networked publics: Teens' attitudes, practices, and strategies. 2011 Presented at: A Decade in Internet Time: Symposium on the Dynamics of the Internet and Society; Sep 21-24, 2011; University of Oxford URL: http://www.danah.org/papers/2011/SocialPrivacyPLSC-Draft.pdf
14. Sveningsson M. Ethics in Internet ethnography. In: Buchanan E, editor. Readings in Virtual Research Ethics: Issues and Controversies. Hershey, PA: Idea Group; 2003:45-61.
15. Suler J. The online disinhibition effect. Cyberpsychol Behav 2004 Jun;7(3):321-326. [doi: 10.1089/1094931041291295] [Medline: 15257832]
16. Bassett E, O'Riordan K. Internet Research Ethics. Ethics of Internet research: contesting the human subjects research model URL: http://www.nyu.edu/projects/nissenbaum/ethics_bas_full.html [accessed 2016-05-22] [WebCite Cache ID 6hhbKFIHH]
17. Hogan B. The presentation of self in the age of social media: distinguishing performances and exhibitions online. B Sci Technol Soc 2010 Nov 01;30(6):377-386. [doi: 10.1177/0270467610385893]
18. Nissenbaum H. Privacy as contextual integrity. Washingt. Law Rev. 2004. URL: https://crypto.stanford.edu/portia/papers/RevnissenbaumDTP31.pdf [accessed 2016-05-22] [WebCite Cache ID 6hhbkcR0P]
19. Nissenbaum H. A contextual approach to privacy online. Daedalus 2011 Oct;140(4):32-48. [doi: 10.1162/DAED_a_00113]
20. Marwick AE, boyd D. Networked privacy: how teenagers negotiate context in social media. New Media Soc 2014 Jul 21;16(7):1051-1067. [doi: 10.1177/1461444814543995]

21. Hudson JM, Bruckman A. “Go Away”: participant objections to being studied and the ethics of chatroom research. Inform Soc 2004 Apr;20(2):127-139. [doi: 10.1080/01972240490423030]
22. Bradley SK, Carter B. Reflections on the ethics of internet newsgroup research. Int J Nurs Stud 2012 May;49(5):625-630. [doi: 10.1016/j.ijnurstu.2011.10.018] [Medline: 22098925]
23. McKee R. Ethical issues in using social media for health and health care research. Health Policy 2013 May;110(2-3):298-301. [doi: 10.1016/j.healthpol.2013.02.006] [Medline: 23477806]
24. Palys T, Atchison C. Qualitative research in the digital era: obstacles and opportunities. Int J Qual Meth. 2012. URL: https://ejournals.library.ualberta.ca/index.php/IJQM/article/viewFile/11019/14343 [WebCite Cache ID 6hhcEJfT4]
25. Department of Health. Improving the Health and Well-Being of People with Long Term Conditions. London: Department of Health; 2010 Jan. URL: http://www.yearofcare.co.uk/sites/default/files/pdfs/dh_improving%20the%20h%26wb%20of%20people%20with%20LTCs.pdf [WebCite Cache ID 6hhcXNg8o]
26. Guise J, McVittie C, McKinlay A. A discourse analytic study of ME/CFS (Chronic Fatigue Syndrome) sufferers' experiences of interactions with doctors. J Health Psychol 2010 Apr;15(3):426-435. [doi: 10.1177/1359105309350515] [Medline: 20348363]
27. Dyer C. Research in Psychology: A Practical Guide to Methods and Statistics. Oxford: Wiley-Blackwell Publishers; 2006.
28. Jenkins N, Bloor M, Fischer J, Berney L, Neale J. Putting it in context: the use of vignettes in qualitative interviewing. Qual Res 2010 Apr 12;10(2):175-198. [doi: 10.1177/1468794109356737]
29. The National Archives. 2014 Mar 14. Highest levels of qualification across England and Wales infographic URL: http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/local-area-analysis-of-qualifications-across-england-and-wales/info-highest-qualifications.html [accessed 2016-05-22] [WebCite Cache ID 6hhcr8Y1e]
30. Mauthner N, Doucet A. Refections on a voice-centred relational method: analysing maternal and domestic voices. In: Ribbens J, Edwards R, editors. Feminist Dilemmas in Qualitative Research: Private Lives and Public Texts. London: Sage; 1998:119-146.
31. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
32. Basit T. Manual or electronic? The role of coding in qualitative data analysis. Educ Res 2003 Jun;45(2):143-154. [doi: 10.1080/0013188032000133548]
33. Sharf BF. Communicating breast cancer on-line: support and empowerment on the Internet. Women Health 1997;26(1):65-84. [doi: 10.1300/J013v26n01_05] [Medline: 9311100]
34. Sanders C, Rogers A, Gardner C, Kennedy A. Managing 'difficult emotions' and family life: exploring insights and social support within online self-management training. Chronic Illn 2011 Jun;7(2):134-146. [doi: 10.1177/1742395310390232] [Medline: 21357644]
35. Papacharissi Z, Gibson P. Fifteen minutes of privacy: privacy, sociality, publicty on social network sites. In: Trepte S, Reinecke L, editors. Privacy Online. Berlin: Springer; 2011:75-89.
36. Bullingham L, Vasconcelos AC. 'The presentation of self in the online world': Goffman and the study of online identities. J Inf Sci 2013 Jan 04;39(1):101-112. [doi: 10.1177/0165551512470051]
37. Greaves F, Ramirez-Cano D, Millett C, Darzi A, Donaldson L. Harnessing the cloud of patient experience: using social media to detect poor quality healthcare. BMJ Qual Saf 2013 Mar;22(3):251-255. [doi: 10.1136/bmjqs-2012-001527] [Medline: 23349387]
38. Shepherd A, Sanders C, Doyle M, Shaw J. Using social media for support and feedback by mental health service users: thematic analysis of a twitter conversation. BMC Psychiatry 2015;15:29 [FREE Full text] [doi: 10.1186/s12888-015-0408-y] [Medline: 25881089]
39. Parker AG. Reflection-through-performance: personal implications of documenting health behaviors for the collective. Pers Ubiquit Comput 2014 Aug 5;18(7):1737-1752. [doi: 10.1007/s00779-014-0780-5]
40. Goffman E. The Presentation of Self in Everyday Life. New York: Anchor Books; 1959.
41. Finn J. Computer-based self-help groups. Soc Work Groups 2008 Oct 18;18(1):109-117. [doi: 10.1300/J009v18n01_11]
42. Viswanath K. Cyberinfrastructure: an extraordinary opportunity to bridge health and communication inequalities? Am J Prev Med 2011 May;40(5 Suppl 2):S245-S248. [doi: 10.1016/j.amepre.2011.02.005] [Medline: 21521602]
43. Lee C. The role of Internet engagement in the health-knowledge gap. J Broadcast Electron Media 2009 Sep;53(3):365-382 [FREE Full text] [doi: 10.1080/08838150903102758] [Medline: 25530667]
44. Osatuyi B. Is lurking an anxiety-masking strategy on social media sites? The effects of lurking and computer anxiety on explaining information privacy concern on social media platforms. Comput Human Behav 2015 Aug;49:324-332. [doi: 10.1016/j.chb.2015.02.062]
45. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. Health Promot Int 2000;15(3):259-267. [doi: 10.1093/heapro/15.3.259]
46. Burkell J, Fortier A, Wong C, Simpson JL. Facebook: public space, or private space? Inform Commun Soc 2014 Jan 02;17(8):974-985. [doi: 10.1080/1369118X.2013.870591]

Abbreviations

AoIR: Association of Internet Researchers
DWP: Department of Work and Pensions
ME/CFS: myalgic encephalomyelitis/chronic fatigue syndrome

Edited by G Eysenbach; submitted 22.05.16; peer-reviewed by C Bond, F Vannieuwenborg; comments to author 16.06.16; revised version received 25.06.16; accepted 20.07.16; published 13.10.16.

Please cite as:
Brady E, Segar J, Sanders C
"I Always Vet Things": Navigating Privacy and the Presentation of Self on Health Discussion Boards Among Individuals with Long-Term Conditions
J Med Internet Res 2016;18(10):e274
URL: http://www.jmir.org/2016/10/e274/
doi:10.2196/jmir.6019
PMID:27737819

Original Paper

Health Literacy and Health Information Technology Adoption: The Potential for a New Digital Divide

Michael Mackert[1,2,3], PhD; Amanda Mabry-Flynn[4], PhD; Sara Champlin[5], PhD; Erin E Donovan[2,6], PhD; Kathrynn Pounders[1], PhD

[1]Stan Richards School of Advertising and Public Relations, Moody College of Communication, The University of Texas at Austin, Austin, TX, United States

[2]Center for Health Communication, Moody College of Communication, The University of Texas at Austin, Austin, TX, United States

[3]UTHealth School of Public Health, Houston, TX, United States

[4]Charles H Sandage Department of Advertising, College of Media, University of Illinois Urbana-Champaign, Champaign, IL, United States

[5]Mayborn School of Journalism, The University of North Texas, Denton, TX, United States

[6]Department of Communication Studies, Moody College of Communication, The University of Texas at Austin, Austin, TX, United States

Corresponding Author:
Michael Mackert, PhD
Stan Richards School of Advertising and Public Relations
Moody College of Communication
The University of Texas at Austin
300 West Dean Keeton A1200
BMC 4.338
Austin, TX, 78712
United States
Phone: 1 512 471 8558
Fax: 1 512 471 7018
Email: mackert@utexas.edu

Abstract

Background: Approximately one-half of American adults exhibit low health literacy and thus struggle to find and use health information. Low health literacy is associated with negative outcomes including overall poorer health. Health information technology (HIT) makes health information available directly to patients through electronic tools including patient portals, wearable technology, and mobile apps. The direct availability of this information to patients, however, may be complicated by misunderstanding of HIT privacy and information sharing.

Objective: The purpose of this study was to determine whether health literacy is associated with patients' use of four types of HIT tools: fitness and nutrition apps, activity trackers, and patient portals. Additionally, we sought to explore whether health literacy is associated with patients' perceived ease of use and usefulness of these HIT tools, as well as patients' perceptions of privacy offered by HIT tools and trust in government, media, technology companies, and health care. This study is the first wide-scale investigation of these interrelated concepts.

Methods: Participants were 4974 American adults (n=2102, 42.26% male, n=3146, 63.25% white, average age 43.5, SD 16.7 years). Participants completed the Newest Vital Sign measure of health literacy and indicated their actual use of HIT tools, as well as the perceived ease of use and usefulness of these applications. Participants also answered questions regarding information privacy and institutional trust, as well as demographic items.

Results: Cross-tabulation analysis indicated that adequate versus less than adequate health literacy was significantly associated with use of fitness apps (*P*=.02), nutrition apps (*P*<.001), activity trackers (*P*<.001), and patient portals (*P*<.001). Additionally, greater health literacy was significantly associated with greater perceived ease of use and perceived usefulness across all HIT tools after controlling for demographics. Regarding privacy perceptions of HIT and institutional trust, patients with greater health literacy often demonstrated decreased privacy perceptions for HIT tools including fitness apps (*P*<.001) and nutrition apps (*P*<.001). Health literacy was negatively associated with trust in government (*P*<.001), media (*P*<.001), and technology companies (*P*<.001). Interestingly, health literacy score was positively associated with trust in health care (*P*=.03).

Conclusions: Patients with low health literacy were less likely to use HIT tools or perceive them as easy or useful, but they perceived information on HIT as private. Given the fast-paced evolution of technology, there is a pressing need to further the understanding of how health literacy is related to HIT app adoption and usage. This will ensure that all users receive the full health benefits from these technological advances, in a manner that protects health information privacy, and that users engage with organizations and providers they trust.

(J Med Internet Res 2016;18(10):e264) doi:10.2196/jmir.6349

KEYWORDS

health literacy; personal health information; biomedical technology; medical informatics

Introduction

Health literacy—how people obtain, understand, use, and communicate about health information to make informed decisions [1]—is related to a host of poor health outcomes and increased health care system costs. With approximately one-half to one-third of US adults struggling with health information [2,3], from reading medication labels to following instructions from health care providers, the need for improved models of communicating clear and compelling health information is pressing.

eHealth (the practice of using the Internet and telecommunication technology to provide health communication and services) [4] presents a powerful tool for bringing health information to low health-literate audiences in ways that are easier to access. Indeed, populations in which low health literacy is more prevalent, such as households with low incomes and racial or ethnic minorities [2], are also found to be the most likely to own and rely on a smartphone to access the Internet [5]. Searching for health topics is a common activity among those with smartphones; a recent survey from the Pew Research Center suggested that 62% of individuals who own smartphones used their phone to acquire information about a health condition or topic [5]. In this study, we further examined the relationship between eHealth and health literacy by exploring an emerging concept, that of health information technology (HIT), which ranges from personalized fitness trackers to apps on smartphones, to patient portals for electronic health record (EHR) systems.

The rapid adoption of mobile phones and smartphones among populations who are more likely to have low health literacy presents a tremendous opportunity for improving access to health information and tools to improve health [6]. eHealth interventions developed specifically to meet the needs of lower health-literate users can be more broadly acceptable to health-literate users too [6,7]. Overall, creating effective eHealth interventions is an opportunity that could be easily missed, however, if designers of personal HIT apps do not keep in mind the needs and preferences of lower health-literate audiences. Hayrinen et al argue that, as HIT continues to evolve, the “needs and requirements of different users [should be] taken into account” [8]. Similarly, Bickmore and Paasche-Orlow argue that, if researchers work to reduce the barriers related to accessing and using this technology, HIT may “level the playing field” for patients of low health literacy [9]. By enabling this group to receive health information at the right time and place, patients’ understanding and use of this information will be facilitated [9]. Ensuring the broadest possible successful adoption of HIT will ensure a new “digital divide” does not emerge between more health-literate users who can benefit from personal HIT apps and less health-literate users who might struggle to use them to their full potential.

As new HIT tools have become much more widely available, health-oriented apps designed for patients have exploded in recent years. There are now thousands of health-related apps offered through Apple and Android phone services available to patients for a wide variety of health concerns, from management of chronic illness management, to sleep behavior monitors, physical activity and educational and training videos, and calorie counters. For example, app searches performed by Eng and Lee [10] uncovered 240 applicable results for the Android platform when searching for “diabetes” and close to 600 apps designed for use on an iPhone. Additionally, recent industry reports indicate that the use of fitness and nutrition apps continues to grow in popularity as Americans are increasingly willing to use mobile phone apps to help manage their health [11]. Many of these apps are relatively affordable and are compatible with a variety of devices including mobile phones, tablets, computers, and wearable technology. The growth in this market over the past 5 years suggests that HIT tools are now available to a wider demographic, one that spans patients’ abilities to manage health information.

Another recent development in technology designed for patients is the creation of EHRs and patient portals, through which patients can directly access their health information when connected to the Internet. With the passing of the Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009, there has been notable growth in the number of nonfederal acute care hospitals becoming equipped with and using EHRs in the United States [12]. Between 2009 and 2014, the percentage of these hospitals adopting basic EHR grew from 12.2% to 75.5% [12]. In 2014, 34.4% of the EHRs adopted offered patients “comprehensive” information, including notes and orders from their provider and nurse, laboratory analyses and results, and support for taking medications appropriately (eg, guidelines, interaction information, and dosing) [12]. Patients, then, have a great deal of their personal health information at their fingertips and can monitor changes in their health through a patient portal. Additionally, EHRs enable patients to contact their provider with questions about information presented in the EHR and changes over time. There is limited research available regarding the factors that determine whether a patient will use a patient portal or EHR. However, in one study, the use of a personal health record was determined by patients' perceived ease of use of the technology, as well as their belief in the advantages offered by the technology and their ability to test-drive and witness the functions of the EHR [13]. Among hospitals that have not yet adopted EHRs, an increasing number have indeed been able to become equipped for EHR technology [12], and thus the availability of this technology is projected to continue to expand. Furthermore, health care providers are likely motivated to adopt EHRs by incentives provided by the federal government and to avoid penalties [14,15]. More research is needed to better understand patients' reception of this technology.

A review of the recent literature in this area suggests that evidence on patients' perceptions and use of HIT tools is rather limited. Most of the research in the area of HIT has focused on health care providers' perceptions of and experiences with these technologies and their benefits to patient care as a whole [16-18], yet even these studies were noted as limited [16]. However, it is the hope that HIT tools will "improve the quality of health care [and] prevent medical errors" for patients [19] as well. Governmental agencies note that, by providing patients with HIT tools, they put the patients in charge of their health care [20]. Additionally, this may facilitate the concept of a patient-centered medical home, which aims to bring together patients, their providers, and technology to develop a central place of communication and treatment [21]. This fundamentally changes the paradigm of patient care as it works to minimize previous barriers to patients having direct access to their personal health files and creates situations in which patients might feel empowered to track and manage their health.

However, providing patients with opportunities to engage with their health information directly over electronic sources also puts patients' private information at risk. This could come in two forms. First, patients who perceive themselves as having a high ability to manage health information may unknowingly share information they do not intend to and unknowingly share personal information they would prefer to be private. On the other hand, some patients may be reluctant to admit struggles and ask for assistance with health information, and thus may not make full use of HIT or could make mistakes that may compromise their personal information.

Privacy and the protection of personal health information varies across HIT apps, something perhaps not known by all patients. For example, EHRs must abide by the Health Insurance Portability and Accountability Act (HIPAA)'s Privacy Rule, which stipulates specific "safeguards" and rules about how a patient's health information is handled and disclosed through an electronic platform such as a patient portal. Because the Internet is available to everyone, these regulations help ensure that a patient's health information will not be "leaked" or be available to others who do not share an agreement with a health organization (such as an insurance company). These policies were set forth to "elicit greater consumer confidence, trust, and participation in electronic health information exchange" by patients of all backgrounds [22]. These regulations have extended privacy coverage so that some businesses such as Google are indeed held responsible for maintaining privacy of patient health information [13]. These policies, however, are limited to only EHRs and health information managed by health systems. As such, they do not yet apply to other HIT tools such as the aforementioned health apps and fitness trackers.

These types of privacy policies may lead to a greater sense of trust in the companies or institutions associated with various types of HIT. Trust is often an important factor contributing to the adoption of new technologies [23-25]; however, such policies could be misleading to patients who struggle with low health literacy, who might assume that all HIT have similar patient privacy rules and regulations. The degree to which a patient exhibits trust in institutions that may develop various HIT, such as health care organizations, the government, information technology companies, and media outlets, may influence their likelihood of adopting HIT and could be associated with health literacy level.

The purpose of this study was to investigate how health literacy might be related to use of a variety of HIT apps. Further, it was intended to investigate how health literacy is related to two crucial elements associated with HIT usage: (1) understanding privacy issues related to HIT adoption and (2) trust in various stakeholders associated in various ways with growth in HIT. As such, 4 research questions guided this research. (1) Is health literacy associated with a patient's use of various forms of HIT apps including fitness and nutrition apps, activity trackers, and patient portals? (2) Is health literacy associated with a patient's perceived ease of use and usefulness of these HIT apps? (3) Is a patient's health literacy associated with perceptions of privacy associated with HIT apps? (4) Is a patient's health literacy associated with perceptions of trust in various institutions (government, media, technology companies, and health care)?

The remainder of this paper provides an overview of research methods and a report of study results. This is followed by a discussion of the implications of this investigation for future research, practice, and policy. HIT has tremendous potential to improve the health of users, and this study is a crucial step toward better understanding how health literacy is associated with HIT adoption and ensuring that users of all levels of health literacy can realize those benefits.

Methods

Procedure

We recruited participants from an invitation-only research panel. All were enrolled members of the panel and received an email notification of their qualification for the study and a link to an online survey. The study took approximately 20 minutes to complete and participants were compensated for their time. The online survey included items to assess health literacy, participants' use and perceptions of four different types of HIT, and demographic information. The study protocol was approved by the relevant institutional review board.

Measures

Health Literacy

To measure health literacy, participants completed the task-based Newest Vital Sign (NVS) measure of health literacy. This measure asks patients to read and answer 6 questions about a nutrition label [26]. Sample questions include "If you eat the entire container, how many calories will you eat?" and "Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings. Is it safe for you to eat this ice cream?" These questions require participants to use basic quantitative (eg, 250 calories × 4 servings) and qualitative (eg, the list of ingredients includes peanut oil, and therefore someone allergic to peanuts should not eat the ice cream) problem-solving skills. Patients are awarded 1 point for each correct answer they provide. As such, health literacy scores using this measure range from a total of 0 to 6, where a score <4 indicates a potential for low health literacy [26]. The NVS is a valid and reliable measure of health literacy and commonly used in studies on this topic [26-32].

HIT Use

Participants were asked if they had ever used four different types of HIT: fitness apps (eg, C25K, MapMyRun, FitStar Personal Trainer), nutrition apps (eg, MyFitnessPal, Weight Watchers), activity trackers (eg, Fitbit, BodyBug, a pedometer), and patient portals (eg, BlueAccess, myUHC).

HIT Perceptions

For each HIT, participants were asked to indicate their degree of agreement on a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree) with a statement related to perceived ease of use (eg, "Learning to use a fitness app is easy for me.") and usefulness (eg, "Using a nutrition app is beneficial to me."). Perceived ease of use and perceived usefulness are core constructs of the technology acceptance model [33] and are helpful concepts for understanding participants' adoption and use of HIT.

HIT Privacy

Perceptions of privacy were assessed for each HIT: fitness apps (Cronbach alpha=.763), nutrition apps (Cronbach alpha=.779), activity trackers (Cronbach alpha=.795), and patient portals (Cronbach alpha=.821). Participants were asked to indicate their agreement with 6 statements using a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree). Sample items are "I am certain that all the information I reveal on nutrition apps remains under my control" and "I tell intimate, personal things about me to be stored in nutrition apps without hesitation" [34].

Trust

Perceptions of trust were examined for four different institutions: government (Cronbach alpha=.925), media (Cronbach alpha=.868), technology companies (Cronbach alpha=.885), and the health care system (Cronbach alpha=.824). Two items assessed trust in each institution. Participants were asked to indicate their agreement with statements using a 7-point Likert scale (1 = strongly disagree to 7 = strongly agree); sample items are "I feel assured the government does a good job making laws that protect people's health information" and "I feel the media does a good job monitoring issues related to health information privacy."

Demographics

We collected specific demographic information on sex, race/ethnicity, age, income, and whether the participant worked in health care.

Results

Participants

A total of 5151 American adults reflecting the demographic composition of the United States in terms of sex, age, race/ethnicity, and socioeconomic status participated in this study. After removing participants with missing data, we included a total of 4974 participants for analysis. Table 1 shows the demographic distribution of the sample. Overall, 15.96% (794/4974) of the sample exhibited low health literacy, by achieving a score of ≤3 on the NVS measure of health literacy. In the full sample, 27.64% (1375/4974) indicated having ever used a fitness app, 33.89% (1686/4974) had used a nutrition app, 33.39% (1661/4974) had used an activity tracker, and 41.95% (2087/4974) had used a patient portal.

Research Question 1

Research question 1 explored how the use of various HIT tools may differ between participants with adequate health literacy (NVS score ≥4) and those with less than adequate health literacy (NVS score ≤3) [26]. Cross-tabulation analysis indicated that adequate versus less than adequate health literacy was significantly associated with use of fitness apps, ($\chi^2_{1,\ N=4974}=5.663$, $P=.02$), nutrition apps ($\chi^2_{1,\ N=4974}=18.885$, $P<.001$), activity trackers ($\chi^2_{1,\ N=4974}=54.754$, $P<.001$), and patient portals ($\chi^2_{1,\ N=4974}=102.642$, $P<.001$). Across all HIT tools, fewer participants with less than adequate health literacy indicated technology use than those with adequate health literacy (Table 2).

Research Question 2

Research question 2 further examined participants' perceptions of various HIT; hierarchical linear regression analysis explored the association between perceived ease of use and usefulness for each technology and total NVS score. Specifically, we conducted eight regression models in which we regressed demographics (step 1) and total NVS score (step 2) onto perceived ease of use and perceived usefulness for four types of HIT (fitness apps, nutrition apps, activity trackers, and patient portals).

Overall, all eight models were significant (Table 3,Table 4,Table 5,Table 6), accounting for between 3.3% and 9.1% of total variance. Of most relevance to our study, NVS score was significantly associated with perceived ease of use and perceived usefulness across all HIT after controlling for demographics (see Table 3,Table 4,Table 5,Table 6 for demographic details).

Table 1. Participant demographics.

Characteristic	Mean (SD) or n (%)
Age in years, mean (SD)	16.7 (43.5)
Work in health care, n (%)	603 (12.1)
Male, n (%)	2102 (42.3)
Race, n (%)	
White	3146 (63.2)
Hispanic	671 (13.5)
African American	794 (16.0)
Asian	218 (4.4)
Other	121 (2.4)
2-Year college degree or higher, n (%)	2980 (59.9)
Household income in US $, n (%)	
<10,000	230 (4.6)
$10,000–49,999	1908 (38.3)
$50,000–99,000	1764 (35.5)
≥$100,000	1068 (21.5)

Table 2. Health literacy × health information technology (HIT) use cross-tabulation (N=4974).

HIT	Health literacy	Used HIT, n (%)		χ^2_1	*P* value
		Yes	No		
Fitness apps				5.663	.02
	Low	192 (24.2)	602 (75.8)		
	Adequate	1183 (28.3)	2997 (71.7)		
Nutrition apps				18.885	<.001
	Low	216 (27.2)	578 (72.8)		
	Adequate	1470 (35.2)	2710 (64.8)		
Activity trackers				54.754	<.001
	Low	175 (22.0)	619 (78.0)		
	Adequate	1486 (35.6)	2694 (64.4)		
Patient portals				102.642	<.001
	Low	204 (25.7)	590 (74.3)		
	Adequate	1883 (45.0)	2297 (55.0)		

Table 3. Standardized regression coefficients and model analyses for fitness apps.

Model	Predictors	Step 1[a]	*P* value	Step 2[b]	*P* value	*F* (*df*)	*P* value	R^2	Δ R^2	*P* value
Ease of use										
	Age	–.204	<.001	–.205	<.001					
	Sex	.032	.02	.027	.053					
	Work in health care	–.026	.07	–.033	.02					
	Income	.159	<.001	.141	<.001					
	Education	.072	<.001	.058	<.001					
	Asian	–.022	.11	–.013	.34					
	Hispanic	.024	.09	.035	.01					
	African American	.042	.003	.064	<.001					
	Race: other	–.002	.87	–.001	.97	45.937 (9,4894)	<.001	.078		
	NVS[c] score			.123	<.001	49.255 (10,4893)	<.001	.091	.014	<.001
Usefulness										
	Age	–.106	<.001	–.106	<.001					
	Sex	.094	<.001	.092	<.001					
	Work in health care	–.018	.13	–.022	.13					
	Income	.125	<.001	.117	<.001					
	Education	.017	.50	.011	.50					
	Asian	–.005	.95	–.001	.95					
	Hispanic	.029	.02	.035	.02					
	African American	.032	.004	.042	.004					
	Race: other	–.009	.58	–.008	.58	21.214 (9,4892)	<.001	.038		
	NVS score			.056	<.001	20.603 (10,4891)	<.001	.040	.003	<.001

[a] Regression of demographics onto perceived ease of use and perceived usefulness.

[b] Regression of Newest Vital Sign score onto perceived ease of use and perceived usefulness.

[c] NVS: Newest Vital Sign.

Table 4. Standardized regression coefficients and model analyses for nutrition apps.

Model	Predictors	Step 1[a]	*P* value	Step 2[b]	*P* value	*F* (*df*)	*P* value	R^2	Δ R^2	*P* value
Ease of use										
	Age	–.145	<.001	–.146	<.001					
	Sex	.085	<.001	.080	<.001					
	Work in health care	–.007	.63	–.015	.28					
	Income	.120	<.001	.100	<.001					
	Education	.094	<.001	.079	<.001					
	Asian	–.027	.06	–.017	.22					
	Hispanic	.021	.15	.033	.02					
	African American	.024	.10	.048	.001					
	Race: other	–.012	.37	–.011	.45	33.261 (9,4875)	<.001	.058		
	NVS[c] score			.134	<.001	39.002 (10,4874)	<.001	.074	.016	<.001
Usefulness										
	Age	–.054	<.001	–.055	<.001					
	Sex	.122	<.001	.119	<.001					
	Work in health care	–.005	.73	–.009	.53					
	Income	.102	<.001	.092	<.001					
	Education	.024	.13	.017	.29					
	Asian	–.022	.13	–.017	.23					
	Hispanic	.045	.002	.050	.001					
	African American	.018	.22	.029	.05					
	Race: other	–.017	.24	–.016	.26	17.479 (9,4874)	<.001	.031		
	NVS score			.063	<.001	17.580 (10,4873)	<.001	.035	.004	<.001

[a] Regression of demographics onto perceived ease of use and perceived usefulness.

[b] Regression of Newest Vital Sign score onto perceived ease of use and perceived usefulness.

[c] NVS: Newest Vital Sign.

Table 5. Standardized regression coefficients and model analyses for activity trackers.

Model	Predictor	Step 1[a]	*P* value	Step 2[b]	*P* value	*F* (*df*)	*P* value	R^2	ΔR^2	*P* value
Ease of use										
	Age	–.149	<.001	–.150	<.001					
	Sex	.034	.02	.029	.04					
	Work in health care	–.007	.64	–.015	.29					
	Income	.152	<.001	.132	<.001					
	Education	.094	<.001	.080	<.001					
	Asian	–.026	.07	–.016	.24					
	Hispanic	.020	.16	.032	.03					
	African American	.023	.12	.047	.001					
	Race: other	–.004	.76	–.002	.86	35.460 (9,4883)	<.001	.061		
	NVS[c] score			.130	<.001	40.54 (10,3882)	<.001	.077	.015	<.001
Usefulness										
	Age	–.082	<.001	–.082	<.001					
	Sex	.102	<.001	.100	<.001					
	Work in health care	–.008	.60	–.011	.43					
	Income	.129	<.001	.119	<.001					
	Education	.037	.02	.031	.06					
	Asian	–.003	.90	.002	.91					
	Hispanic	.027	.07	.032	.03					
	African American	.013	.36	.024	.10					
	Race: other	–.009	.51	–.009	.55	20.843 (9,4879)	<.001	.037		
	NVS score			.060	<.001	20.462 (10,4878)	<.001	.040	.003	<.001

[a] Regression of demographics onto perceived ease of use and perceived usefulness.

[b] Regression of Newest Vital Sign score onto perceived ease of use and perceived usefulness.

[c] NVS: Newest Vital Sign.

Table 6. Standardized regression coefficients and model analyses for patient portals.

Model	Predictor	Step 1[a]	*P* value	Step 2[b]	*P* value	*F* (*df*)	*P* value	R^2	Δ R^2	*P* value
Ease of use										
	Age	.018	.23	.017	.25					
	Sex	.060	<.001	.056	<.001					
	Work in health care	–.020	.17	–.027	.06					
	Income	.107	<.001	.089	<.001					
	Education	.074	<.001	.062	<.001					
	Asian	–.005	.72	.003	.83					
	Hispanic	.010	.51	.020	.16					
	African American	.028	.60	.049	.001					
	Race: other	–.005	.75	–.003	.83	15.509 (9,4887)	<.001	.028		
	NVS[c] score			.116	<.001	20.310 (10,4886)	<.001	.040	.012	<.001
Usefulness										
	Age	.051	<.001	.050	.001					
	Sex	.106	<.001	.102	<.001					
	Work in health care	–.016	.26	–.022	.13					
	Income	.083	<.001	.070	<.001					
	Education	.040	.01	.031	.052					
	Asian	–.008	.59	–.002	.91					
	Hispanic	.017	.25	.025	.09					
	African American	.038	.01	.053	<.001					
	Race: other	–.039	.01	–.038	.01	14.610 (9,4886)	<.001	.026		
	NVS score			.084	<.001	16.466 (10,4885)	<.001	.033	.006	<.001

[a] Regression of demographics onto perceived ease of use and perceived usefulness.

[b] Regression of Newest Vital Sign score onto perceived ease of use and perceived usefulness.

[c] NVS: Newest Vital Sign.

Table 7. Standardized regression coefficients and model analysis for privacy.

Model	Predictors	Step 1[a]	*P* value	Step 2[b]	*P* value	*F* (*df*)	*P* value	R^2	ΔR^2	*P* value
Fitness app privacy										
	Age	–.111	<.001	–.106	<.001					
	Sex	–.093	.001	–.079	.004					
	Work in health care	.005	.86	.006	.83					
	Income	–.044	.16	–.028	.36					
	Education	–.132	<.001	–.115	<.001					
	Asian	.048	.07	.038	.16					
	Hispanic	.024	.38	.011	.69					
	African American	–.007	.80	–.032	.25					
	Race: other	–.048	.08	–.047	.08	8.460 (9,1335)	<.001	.054		
	NVS[c] score			–.127	<.001	9.776 (10,1334)	<.001	.061	.014	<.001
Nutrition app privacy										
	Age	–.092	<.001	–.091	<.001					
	Sex	–.063	.01	–.053	.03					
	Work in health care	–.048	.053	–.040	.11					
	Income	–.076	.01	–.061	.03					
	Education	–.128	<.001	–.118	<.001					
	Asian	.032	.20	.023	.36					
	Hispanic	.013	.61	.007	.84					
	African American	–.003	.90	–.021	.41					
	Race: other	–.048	.05	–.047	.05	9.594 (9,1630)	<.001	.050		
	NVS score			–.097	<.001	10.170 (10,1629)	<.001	.059	.008	<.001
Activity tracker privacy										
	Age	–.152	<.001	–.150	<.001					
	Sex	–.060	.02	–.060	.02					
	Work in health care	–.016	.52	–.011	.65					
	Income	–.005	.85	.001	.98					
	Education	–.129	<.001	–.123	<.001					
	Asian	.000	.99	–.001	.98					
	Hispanic	–.002	.94	–.005	.83					
	African American	.003	.91	–.004	.87					
	Race: other	–.028	.26	–.028	.25	8.383 (9,1611)	<.001	.045		
	NVS score			–.049	.053	7.934 (10,1610)	<.001	.047	.002	.053
Patient portal privacy										
	Age	–.076	.001	–.075	.001					
	Sex	–.029	.21	–.029	.20					
	Work in health care	–.019	.40	–.021	.36					
	Income	–.008	.74	–.012	.64					

Model	Predictors	Step 1[a]	*P* value	Step 2[b]	*P* value	*F* (*df*)	*P* value	R^2	ΔR^2	*P* value
	Education	–.038	.13	–.040	.11					
	Asian	–.009	.68	–.009	.70					
	Hispanic	.007	.75	.010	.67					
	African American	–.045	.05	–.042	.07					
	Race: other	–.052	.02	–.052	.02	2.733 (9,2023)	.004	.012		
	NVS score			.023	.31	2.563 (10,2022)	.004	.013	.001	.31

[a] Regression of demographics onto perceived ease of use and perceived usefulness.

[b] Regression of Newest Vital Sign score onto perceived ease of use and perceived usefulness.

[c] NVS: Newest Vital Sign.

For fitness apps, NVS score was positively associated with both perceived ease of use (*b*=.126, t_{4892}=8.546, *P*<.001, beta=.123) and usefulness (*b*=.057, t_{4890}=3.818, *P*<.001, beta=.056) such that as NVS score increased, fitness apps were perceived as easier to use and more useful. Results were similar for NVS score associated with nutrition app ease of use (*b*=.135, t_{4873}=9.246, *P*<.001, beta=.134) and usefulness (*b*=.063, t_{4872}=4.236, *P*<.001, beta=.063), activity tracker ease of use (*b*=.133, t_{4881}=9.005, *P*<.001, beta=.130) and usefulness (*b*=.061, t_{4877}=4.054, *P*<.001, beta=.060), and patient portal ease of use (*b*=.115, t_{4885}=7.861, *P*<.001, beta=.116) and usefulness (*b*=.079, t_{4884}=5.686, *P*<.001, beta=.084).

Research Question 3

Research question 3 sought to understand how health literacy might influence perceptions of privacy associated with HIT. Hierarchical linear regression analysis suggested that NVS score was significantly associated with perceptions of privacy for fitness apps, nutrition apps, and activity trackers after controlling for demographics (Table 7).

Overall, all four regression models explained a significant proportion of variance in privacy perceptions, ranging from 1.3% to 6.1% (Table 7). NVS score was negatively associated with privacy perceptions of fitness apps (*b*=–.106, t_{1333}=–4.528, *P*<.001, beta=–.127) and nutrition apps (*b*=–.087, t_{1628}=–3.825, *P*<.001, beta=–.097). Thus, as NVS score decreased, perceptions of privacy were more likely to be positive. Although the overall models for activity trackers and patient portal privacy were indeed significant, the variance explained was not significantly associated with NVS score in either model (activity trackers: *b*=–.048, t_{1609}=–1.938, *P*=.053, beta=–.049; patient portal: *b*=.024, t_{2021}=1.1014, *P*=.03, beta=.023).

Research Question 4

Research question 4 looked at the association between health literacy and perceptions of trust in various institutions (government, media, technology companies, and health care). Four hierarchical regression models examined the association of NVS score and trust in each institution; the models explained a significant proportion of variance in trust perceptions, ranging from 0.06% to 4.6% (Table 8). After controlling for demographics, NVS score was negatively associated with trust in government (*b*=–.091 t_{4887}=–5.513, *P*<.001, beta=–.081), media (*b*=–.126, t_{4880}=–8.494, *P*<.001, beta=–.126), and technology companies (*b*=–.161, t_{4874}=–10.705, *P*<.001, beta=–.158). However, NVS score was positively associated with trust in health care (*b*=.031, t_{4868}=2.141, *P*=.03, beta=.032).

Table 8. Standardized regression coefficients and model analyses for trust.

Model	Predictors	Step 1[a]	*P* value	Step 2[b]	*P* value	*F* (*df*)	*P* value	R^2	Δ R^2	*P* value
Trust in government										
	Age	–.078	<.001	–.077	<.001					
	Sex	.020	.16	.024	.10					
	Work in health care	–.049	.001	–.044	.002					
	Income	–.034	.03	–.022	.18					
	Education	.009	.56	.018	.27					
	Asian	.050	.001	.044	.002					
	Hispanic	.060	<.001	.052	<.001					
	African American	.103	<.001	.089	<.001					
	Race: other	–.040	.005	–.041	.004	17.518 (9,4889)	<.001	.031		
	NVS[c] score			–.081	<.001	18.900 (10,4888)	<.001	.037	.006	<.001
Trust in media										
	Age	.011	.45	.012	.41					
	Sex	.004	.77	.009	.54					
	Work in health care	–.043	.003	–.035	.02					
	Income	–.006	.71	.013	.41					
	Education	–.035	.03	–.021	.19					
	Asian	.057	<.001	.048	.001					
	Hispanic	.048	.001	.037	.01					
	African American	.077	<.001	.054	<.001					
	Race: other	–.017	.22	–.019	.18	6.966 (9,4882)	<.001	.013		
	NVS score			–.126	<.001	13.576 (10,4881)	<.001	.027	.014	<.001
Trust in technology companies										
	Age	–.062	<.001	–.060	<.001					
	Sex	–.019	.20	–.013	.37					
	Work in health care	–.044	.002	–.034	.01					
	Income	–.023	.16	.001	.94					
	Education	–.059	<.001	–.042	.01					
	Asian	.073	<.001	.062	<.001					
	Hispanic	.053	<.001	.038	.02					
	African American	.062	<.001	.034	.02					
	Race: other	–.020	.16	–.022	.12	12.979 (9,4876)	<.001	.023		
	NVS score			–.158	<.001	23.413 (10,4875)	<.001	.046	.022	<.001
Trust in health care										
	Age	.028	.06	.028	.06					
	Sex	.034	.02	.033	.02					
	Work in health care	–.040	.02	–.042	.004					
	Income	–.026	.11	–.031	.06					

Model	Predictors	Step 1[a]	*P* value	Step 2[b]	*P* value	*F* (*df*)	*P* value	R^2	ΔR^2	*P* value
	Education	.018	.27	.014	.38					
	Asian	–.016	.27	–.014	.34					
	Hispanic	–.015	.31	–.012	.41					
	African American	.011	.47	.017	.27					
	Race: other	–.023	.12	–.022	.12	2.879 (9,4870)	.002	.005		
	NVS score			.032	.03	3.051 (10,4869)	.001	.006	.001	.03

[a] Regression of demographics onto perceived ease of use and perceived usefulness.

[b] Regression of Newest Vital Sign score onto perceived ease of use and perceived usefulness.

[c] NVS: Newest Vital Sign.

Discussion

The purpose of this study was to better understand how health literacy is associated with HIT adoption, and relevant issues such as information privacy and trust. In this study, patients with low health literacy were less likely to use HIT tools or perceive them as easy or useful, but they perceived information on HIT as private. To our knowledge, this is the first wide-scale investigation of these interrelated concepts.

As might have been expected, HIT adoption—linked to perceived ease of use and perceived usefulness—was associated with higher health literacy. This stands to reason, given that health literacy is defined as how people obtain, understand, use, and communicate about health-related information [1]. Our results suggest that the actual design of HIT apps, ranging from wearable technology to patient portals, has room for improvement so that lower health-literate audiences will perceive the apps as more useful and easy to use. Indeed, Bickmore and Paasche-Orlow [9] argue that researchers do not often consider the limitations of patients of varying abilities when designing HIT tools. Given that more health-literate users still appreciate the simplicity and approach of interventions designed for lower health-literate users [7,35], a focus on design and usability for lower health-literate users would benefit all users. This is particularly true given the importance of first impressions in evaluating technology such as patient portals [36], meaning that gaining attention from patients may be difficult if their initial experiences are not positive. The relationship between health literacy and perceived ease of use was stronger than that between health literacy and perceived usefulness; while users' perceived usefulness might be driven by some factors beyond the control of HIT developers (eg, potential users might already be successfully managing a chronic condition and see no need for a diet app), perceived ease of use matters for all potential users and a focus on usability could lower barriers to users trying an app and successfully integrating it into their lives.

The association between health literacy and privacy issues related to HIT apps was straightforward: lower health literacy was associated with greater perceptions of privacy when using HIT apps. This relationship points to fruitful directions for future research, including focused study of how users of various health literacy levels make decisions about information to share with apps and by what criteria they judge the privacy protections of various HIT apps. This finding also suggests a need for education on information privacy, perhaps as part of interventions designed to build health literacy and computer self-efficacy skills for underserved populations, to help them make the most informed decisions possible about their health information privacy.

The relationship between health literacy and trust in various stakeholders associated with HIT apps was more nuanced. Less health-literate participants were less trusting of the government, media, and technology companies; the relationship between low health literacy and trust in government as an information source is not new [37], but this research confirms that finding with a more representative sample. At the same time, those with lower health literacy were more likely to place trust in health care providers. Further research is needed to better understand the drivers of these feelings of trust, but they have major implications for how HIT apps might be successfully rolled out to the public. The greater feelings of trust in health care providers among lower health-literate users suggest that companies and government organizations interested in rolling out new HIT to lower health-literate populations should consider partnering with trusted health care providers to help ensure adoption.

This study has several limitations that must be acknowledged when considering the implications of these findings and directions for future research. First and foremost, this was an online survey. While the final sample was generally representative of the US public on key demographic measures, all users must have had some level of comfort with technology to be part of the participant pool—the participants in this study were almost certainly more comfortable with the Internet than were the US public. Additionally, the study sample was more health-literate than the general US population. More targeted data collection focused on less health-literate users is needed to confirm these findings, but the association of health literacy with HIT usage and associated issues in this sample suggests that these associations with less health-literate and technologically sophisticated users may be even more pronounced. Given the recent emergence of HIT, this study only asked participants whether they had ever used the technologies of interest (ie, fitness and nutrition apps, activity trackers, and patient portals); thus, some may have used the HIT only one time while others used it regularly. Future research would benefit from a more precise measure of HIT use. The variety of new HIT apps also means that the potential privacy issues involved in their use is constantly evolving, suggesting more focused attention on measurement of different privacy issues related to HIT usage are needed to strengthen research in this area going forward.

We used a valid and reliable measure of health literacy, the NVS, in this study [26]; however, disagreement exists in the field about the best method for measuring health literacy [38]. Indeed, there are numerous measures of health literacy that capture this concept in a variety of ways, including general and topic-specific health literacies [39]. Future work should explore the impact of general, objective health literacy (as measured in this study) versus self-reported or topic-specific literacy (such as fitness or nutrition health literacy) on HIT use. Finally, while the focus of this study was on the relationship between health literacy level and various factors related to HIT, the proportion of variance explained in each model indicates there may be other important factors that should be considered. Future research should explore patients' comfort with and previous history of using new technology to find and use health information.

HIT apps, from smartphone apps to wearables devices to patient portals, have seen widespread adoption in recent years. The pace of development and capabilities of such tools will only increase in the future. There is a pressing need to understand how health literacy is related to HIT app adoption and usage to ensure that all users receive the full health benefits from these technological advances, in a manner that protects health information privacy, and that users engage with organizations and providers they trust.

Acknowledgments

Support for this research was provided by the University of Texas at Austin Center for Identity.

Conflicts of Interest

None declared.

References

1. Berkman ND, Davis TC, McCormack L. Health literacy: what is it? J Health Commun 2010;15 Suppl 2:9-19. [doi: 10.1080/10810730.2010.499985] [Medline: 20845189]
2. Nielsen-Bohlman L, Panzer A, Kindig D. Health Literacy: A Prescription to End Confusion. Washington, DC: National Academy of Sciences; 2004.
3. Kutner M, Greenberg E, Jin Y, Paulsen C. The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy (NCES 2006-483). Washington DC: U.S. Department of Education, National Center for Education Statistics; 2006.
4. Eysenbach G. What is e-health? J Med Internet Res 2001 Jun;3(2):E20. [doi: 10.2196/jmir.3.2.e20] [Medline: 11720962]
5. Smith A. U.S. Smartphone Use in 2015. Washington, DC: Pew Research Center; 2015 Apr 01. URL: http://www.pewinternet.org/2015/04/01/us-smartphone-use-in-2015/ [accessed 2016-08-21] [WebCite Cache ID 6jwBGNs85]
6. Mackert M, Love B, Whitten P. Patient education on mobile devices: an e-health intervention for low health literate audiences. J Inf Sci 2008 Jul 03;35(1):82-93. [doi: 10.1177/0165551508092258]
7. Mackert M, Whitten P, Garcia A. Interventions for low health literate audiences. J Comput Mediated Commun 2008 Jan;13(2):504-515. [doi: 10.1111/j.1083-6101.2008.00407.x]
8. Häyrinen K, Saranto K, Nykänen P. Definition, structure, content, use and impacts of electronic health records: a review of the research literature. Int J Med Inform 2008 May;77(5):291-304. [doi: 10.1016/j.ijmedinf.2007.09.001] [Medline: 17951106]
9. Bickmore TW, Paasche-Orlow MK. The role of information technology in health literacy research. J Health Commun 2012;17 Suppl 3:23-29. [doi: 10.1080/10810730.2012.712626] [Medline: 23030559]
10. Eng D, Lee J. Mobile health applications for diabetes and endocrinology: promise and peril? Pediatr Diabetes 2013;14(4):1-12.
11. Borison R. Health and Fitness Apps are Exploding in Popularity: Here's Who is Using Them. New York, NY: Business Insider Inc; 2014. URL: http://www.businessinsider.com/health-and-fitness-apps-exploding-in-popularity-2014-6 [accessed 2016-08-21] [WebCite Cache ID 6jwBO3nIs]
12. Charles D, Gabriel M, Searcy T. Adoption of Electronic Health Record Systems Among U.S. Non-Federal Acute Care Hospitals 2008-2014. ONC Data Brief, no. 23. Washington, DC: Office of the National Coordinator for Health Information Technology; 2015.
13. Emani S, Yamin CK, Peters E, Karson AS, Lipsitz SR, Wald JS, et al. Patient perceptions of a personal health record: a test of the diffusion of innovation model. J Med Internet Res 2012;14(6):e150 [FREE Full text] [doi: 10.2196/jmir.2278] [Medline: 23128775]
14. HealthIT.gov. Are There Penalties for Providers Who Don't Switch to Electronic Health Records (EHR)?. 2013 Jan 15. URL: https://www.healthit.gov/providers-professionals/faqs/

are-there-penalties-providers-who-don%E2%80%99t-switch-electronic-health-record [accessed 2016-08-21] [WebCite Cache ID 6jwBX191k]

15. HealthIT.gov. EHR Incentives & Certification. 2013 Jan 15. URL: https://www.healthit.gov/providers-professionals/ehr-incentive-programs [accessed 2016-08-21] [WebCite Cache ID 6jw5UEf3x]
16. Chaudhry B, Wang J, Wu S, Maglione M, Mojica W, Roth E, et al. Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. Ann Intern Med 2006 May 16;144(10):742-752. [Medline: 16702590]
17. Boonstra A, Broekhuis M. Barriers to the acceptance of electronic medical records by physicians from systematic review to taxonomy and interventions. BMC Health Serv Res 2010;10:231 [FREE Full text] [doi: 10.1186/1472-6963-10-231] [Medline: 20691097]
18. Buntin MB, Burke MF, Hoaglin MC, Blumenthal D. The benefits of health information technology: a review of the recent literature shows predominantly positive results. Health Aff (Millwood) 2011 Mar;30(3):464-471 [FREE Full text] [doi: 10.1377/hlthaff.2011.0178] [Medline: 21383365]
19. U.S. Department of Health and Human Services. Health Information Technology. Washington, DC: Office for Civil Rights; 2015 Nov 06. URL: http://www.hhs.gov/hipaa/for-professionals/special-topics/health-information-technology/index.html [accessed 2016-08-21] [WebCite Cache ID 6jwCNXUvn]
20. HealthIT.gov. Basics of Health IT. 2013 Jan 15. URL: https://www.healthit.gov/patients-families/basics-health-it [accessed 2016-08-21] [WebCite Cache ID 6jwBf7XA1]
21. Patient-Centered Primary Care Collaborative. Defining the Medical Home: A Patient-Centered Philosophy That Drives Primary Care Excellence. 2015. URL: https://www.pcpcc.org/about/medical-home [accessed 2016-08-22] [WebCite Cache ID 6jwMODnpM]
22. U.S. Office of Civil Rights. The HIPPA Privacy Rule and Electronic Health Information Exchange in a Networked Environment URL: https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/healthit/introduction.pdf [accessed 2016-09-28] [WebCite Cache ID 6krXRNN44]
23. Gefen D, Karahanna E, Straub D. Trust and TAM in online shopping: an integrated model. MIS Quarterly 2003;27(1):51-90.
24. Bélanger F, Carter L. Trust and risk in e-government adoption. J Strategic Inf Syst 2008;17(2):165-176. [doi: 10.1016/j.jsis.2007.12.002]
25. Bahmanziari T, Pearson J, Crosby L. Is trust important in technology adoption? A policy capturing approach. J Comput Inform Syst 2003;43(4):46-54.
26. Weiss BD, Mays MZ, Martz W, Castro KM, DeWalt DA, Pignone MP, et al. Quick assessment of literacy in primary care: the newest vital sign. Ann Fam Med 2005;3(6):514-522 [FREE Full text] [doi: 10.1370/afm.405] [Medline: 16338915]
27. Escobedo W, Weismuller P. Assessing health literacy in renal failure and kidney transplant patients. Prog Transplant 2013 Mar;23(1):47-54. [doi: 10.7182/pit2013473] [Medline: 23448820]
28. Shah LC, West P, Bremmeyr K, Savoy-Moore RT. Health literacy instrument in family medicine: the “newest vital sign” ease of use and correlates. J Am Board Fam Med 2010;23(2):195-203 [FREE Full text] [doi: 10.3122/jabfm.2010.02.070278] [Medline: 20207930]
29. Osborn CY, Weiss BD, Davis TC, Skripkauskas S, Rodrigue C, Bass PF, et al. Measuring adult literacy in health care: performance of the newest vital sign. Am J Health Behav 2007;31 Suppl 1:S36-S46. [doi: 10.5555/ajhb.2007.31.supp.S36] [Medline: 17931135]
30. Powers BJ, Trinh JV, Bosworth HB. Can this patient read and understand written health information? JAMA 2010 Jul 7;304(1):76-84. [doi: 10.1001/jama.2010.896] [Medline: 20606152]
31. VanGeest JB, Welch VL, Weiner SJ. Patients' perceptions of screening for health literacy: reactions to the newest vital sign. J Health Commun 2010 Jun;15(4):402-412. [doi: 10.1080/10810731003753117] [Medline: 20574878]
32. Boxell EM, Smith SG, Morris M, Kummer S, Rowlands G, Waller J, et al. Increasing awareness of gynecological cancer symptoms and reducing barriers to medical help seeking: does health literacy play a role? J Health Commun 2012;17 Suppl 3:265-279. [doi: 10.1080/10810730.2012.712617] [Medline: 23030575]
33. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Quarterly 1989;13:319-340.
34. Child J, Pearson J, Petronio S. Blogging, communication, and privacy management: development of the Blogging Privacy Management Measure. J Assoc Inf Sci Technol 2009;60(10):2079-2094.
35. Meppelink CS, Smit EG, Buurman BM, van Weert JC. Should we be afraid of smple messages? The effects of text difficulty and illustrations in people with low or high health literacy. Health Commun 2015;30(12):1181-1189. [doi: 10.1080/10410236.2015.1037425] [Medline: 26372031]
36. Lazard AJ, Watkins I, Mackert MS, Xie B, Stephens KK, Shalev H. Design simplicity influences patient portal use: the role of aesthetic evaluations for technology acceptance. J Am Med Inform Assoc 2016 Apr;23(e1):e157-e161. [doi: 10.1093/jamia/ocv174] [Medline: 26635314]
37. Mackert M, Kahlor L, Tyler D, Gustafson J. Designing e-health interventions for low-health-literate culturally diverse parents: addressing the obesity epidemic. Telemed J E Health 2009 Sep;15(7):672-677 [FREE Full text] [doi: 10.1089/tmj.2009.0012] [Medline: 19694596]

38. Pleasant A, McKinney J, Rikard RV. Health literacy measurement: a proposed research agenda. J Health Commun 2011;16 Suppl 3:11-21. [doi: 10.1080/10810730.2011.604392] [Medline: 21951240]
39. Mackert M, Champlin S, Su Z, Guadagno M. The many health literacies: advancing the field or fragmentation? Health Commun 2015;30(12):1161-1165. [doi: 10.1080/10410236.2015.1037422] [Medline: 26372026]

Abbreviations

EHR: Electronic health record
HIT: Health information technology
HIPAA: Health Insurance Portability and Accountability Act
HITECH: Health Information Technology for Economic and Clinical Health
NVS: Newest Vital Sign

Edited by G Eysenbach; submitted 13.07.16; peer-reviewed by C Meppelink, B Holtz, JR Bautista, P Boisrond; comments to author 11.08.16; revised version received 24.08.16; accepted 18.09.16; published 04.10.16.

Please cite as:
Mackert M, Mabry-Flynn A, Champlin S, Donovan EE, Pounders K
Health Literacy and Health Information Technology Adoption: The Potential for a New Digital Divide
J Med Internet Res 2016;18(10):e264
URL: http://www.jmir.org/2016/10/e264/
doi:10.2196/jmir.6349
PMID:27702738

Original Paper

Correlating Ratings of Health Insurance Plans to Their Providers' Attributes

Prajna Shetty[1], MS; Ryan Rivas[1], BS; Vagelis Hristidis[1], PhD

University of California, Riverside, Riverside, CA, United States

Corresponding Author:
Ryan Rivas, BS
University of California, Riverside
363 Winston Chung Hall
900 University Ave
Riverside, CA, 92521
United States
Phone: 1 951 827 2838
Fax: 1 951 827 4643
Email: rriva002@ucr.edu

Abstract

Background: There is a push towards quality measures in health care. As a consequence, the National Committee for Quality Assurance (NCQA) has been publishing insurance plan quality measures.

Objective: The objective of this study was to examine the relationship between insurance plan quality measures and the participating providers (doctors).

Methods: We collected and analyzed provider and insurance plan data from several online sources, including provider directories, provider referrals and awards, patient reviewing sites, and hospital rankings. The relationships between the provider attributes and the insurance plan quality measures were examined.

Results: Our analysis yielded several findings: (1) there is a moderate Pearson correlation (r=.376) between consumer satisfaction insurance plan scores and review ratings of the member providers, (2) referral frequency and provider awards are negligibly correlated to consumer satisfaction plan scores (correlations of r=.031 and r=.183, respectively), (3) there is weak positive correlation (r=.266) between the cost charged for the same procedures and consumer satisfaction plan scores, and (4) there is no significant correlation between member specialists' review ratings and specialty-specific insurance plan treatment scores for most specialties, except a surprising weak negative correlation for diabetes treatment (r=-.259).

Conclusions: Our findings may be used by consumers to make informed choices about their insurance plans or by insurances to understand the relationship between patients' satisfaction and their network of providers.

(J Med Internet Res 2016;18(10):e279) doi:10.2196/jmir.6475

KEYWORDS

health insurance; doctor reviews; doctor attributes; insurance plans quality

Introduction

There are several health insurance marketplaces and search portals (eg, ehealthinsurance.com) that help individuals and small employers shop for, select, and enroll in high-quality, affordable health plans. Insurance plans are generally ranked based on relative quality and price. These marketplaces and search portals need to establish criteria and selection processes for quality measures. Most of them measure the quality of health plans by surveying plan enrollees on their satisfaction with their coverage and then publishing quality and satisfaction data online [1]. However, the relationship between the quality of insurance plans and the properties of providers in their networks has not been adequately studied, which is the focus of this study.

We collected a rich set of data for each provider ranging from average patient review scores, referral patterns, affiliated hospital scores, relative costs, and provider awards. Specifically, we used data collected from Centers for Medicare & Medicaid Services (CMS) and provider profile websites on a set of 600,000 US health care providers. We also collected ranking data from other sources; specifically, U.S. News was used for specialty-specific hospital rankings. We converted each provider's information to a set of intuitive qualitative attributes. For instance, affiliated hospitals were mapped to specialty-specific rankings to assign a score to the affiliated hospitals of a provider relevant to their specialty. As a peer-nominated award, we selected the Castle Connolly award. Each year, Castle Connolly distinguishes top providers both nationally and regionally through a peer nomination process that involves over 50,000 providers, and hospitals and health care executives [2]. Similarly, we collected quality data from National Committee for Quality Assurance (NCQA) for each insurance plan ranging from state, plan category, ranking, overall review scores, customer satisfaction scores, as well as preventive care and treatment scores [3].

We then adopted a data-driven approach to determine if the provider attributes were correlated with the insurance quality indicators. Specifically, we measured the correlation between several provider attributes (reviews rating, awards, affiliated hospitals, etc) of member providers of an insurance plan to key quality scores of the insurance plans.

Key challenges to our data collection and analysis included mapping providers from CMS to providers in provider profile sites, mapping insurance names between accepted insurances obtained from provider profile sites and insurances obtained from NCQA, and mapping hospital names between each source. These challenges are due to the lack of a common identifier for providers, insurance plans, or hospitals across the data sources.

There have been several studies to determine the quality of health insurance plans. These studies can be split into two categories: (1) health insurance marketplaces and search sites, and (2) attributes associated with health plan quality.

Online Health Insurance Marketplaces and Search Sites

There are several health insurance marketplaces, authorized by the Affordable Care Act, that help individuals and small employers shop for, select, and enroll in high-quality, affordable private health plans. In fact, the Affordable Care Act requires the US Department of Health & Human Services to develop quality data collection and reporting tools such as a quality rating system, a quality improvement strategy, and an enrollee satisfaction survey system [1]. Information from the quality rating system, quality improvement strategy, and surveys will inform consumer selection of a quality health plan, decisions about quality health plan certification, and the Federal and State marketplaces' monitoring of quality health plan performance. All these measures use data collected through consumer experience surveys such as enrollee experience surveys and health insurance marketplace surveys. Other insurance search sites, such as einsurance.com and insure.com, collect user feedback regarding each interaction with their partner insurance providers. This feedback enables them to identify potential customer service issues and is also used as an essential component of the ranking system that they use to determine how these partners are presented to prospective future clients [4,5]. Hence, most of these studies focus on user-generated content and do not consider the rich set of provider data readily available. Research is lacking on the association between information from providers in the network with the respective health insurance plans. For example, if patients rate insurance plans based on cost, are these ratings useful for finding providers that provide quality health care?

Attributes Associated With Insurance Quality

Several surveys have examined the quality of health insurance plans based on consumer feedback and have tried to determine attributes associated with insurance quality. Feldman states that a cornerstone of high-quality integrated care for people with medical, behavioral, and long-term services and support needs is a dynamic person- or family-centered plan of care built on significant individual and caregiver involvement and comprehensive assessments and reassessments over time to capture changes in people's circumstances and preferences. Other key ingredients identified were (1) a multidisciplinary care team with one accountable care coordinator, and (2) a comprehensive provider network with a strong primary care base and a range of other providers and services that can accommodate diverse needs throughout a lifetime [6].

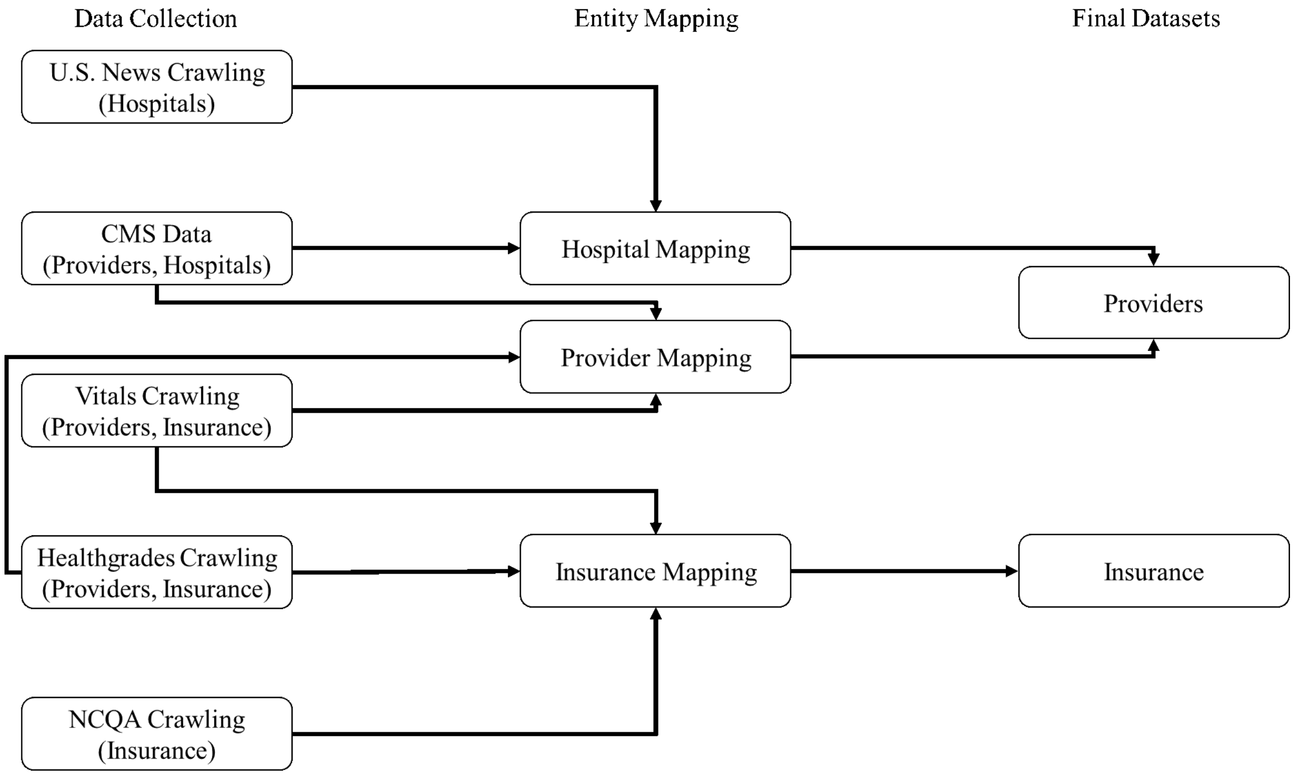
URAC (Utilization Review Accreditation Commission), which is an independent, nonprofit organization known for promoting health care quality through its accreditation, education, and measurement programs, addresses the following key areas aimed at helping plans deliver safe, high-quality, patient-centered, high-value care: Wellness and Health Promotion; Care Coordination; Medication Safety and Care Compliance; Rewarding Quality; Care Delivery through a Network; Mental Health Parity; Measures—patient centeredness, coordination of care, patient safety, health plan administration, efficiency, effectiveness of care and health information technology integration; and Patient Experience of Care (Consumer Assessment of Healthcare Providers and Systems Survey) [7]. In our study, we examine the correlation of provider attributes to quality indicators of health insurance plans.

Methods

Summary

For the purpose of our data-driven analysis, we have collected a large amount of information about US health providers, mainly physicians, from multiple online sources including the CMS data on providers and hospitals, U.S. News rankings of hospitals, and additional provider information and reviews from provider profile websites. We have also collected information about the rankings of private, Medicare, and Medicaid health insurance plans from NCQA. We then mapped entities across sources to create a database of providers and health plans. Figure 1 shows the process of mapping insurances accepted by the providers and the insurance plans obtained from NCQA. We then used this providers' information and insurance information database in each of our analyses.

Figure 1. Visual description of data preprocessing.



Data Collection

Insurance information and patient ratings of providers were collected from both Vitals and Healthgrades [8,9]. Hospital rankings were collected from U.S. News reports [10,11]. Additionally, insurance plan rankings for 2014-2015 were collected from NCQA. We also used the datasets released by CMS for health care providers (and hospitals) based in the United States. This information includes general information such as the provider’s specialties, medical training, and hospital affiliations [12,13]. Other provider information includes the Healthcare Common Procedure Coding System (HCPCS), physician referrals, and prescription data [14-16]. Note that all CMS datasets link providers using a National Provider Identifier (NPI). CMS hospital information includes names, location, and a unique identifier, which is used to link each NPI to their affiliated hospitals. CMS data were downloaded directly from CMS websites. Separate crawlers were built using jsoup [17], a Java library for obtaining and parsing webpages, for each of the other data sources: Vitals, Healthgrades, U.S. News, and NCQA.

Aggregating the datasets posed unique challenges for entity mapping, such as mapping providers from Healthgrades to providers in CMS, as described in the next section. In total, we collected information on 3.2 million distinct providers from CMS, 4600 distinct hospitals from CMS, 1.9 million distinct providers from Healthgrades, one million distinct providers from Vitals, and 1956 hospitals from U.S. News. We also collected information of 1264 health plans from NCQA. Of these, NCQA has ranked 1051 plans based on clinical performance, member satisfaction, and results from NCQA Accreditation surveys. The remaining insurances had partial data. After appropriate data transformations and entity mappings, we generated the set of provider attributes listed in Table 1 and health insurance plan attributes listed in Table 2.

Table 1. List of provider attributes used in our analysis based on the data collected.

Category	Attribute	Description	Source	Min.	Max.	Mean	Median
General information	NPI	National Provider Identifier.	CMS	N/A	N/A	N/A	N/A
	Gender	Male or Female, as specified in the CMS data.	CMS	N/A	N/A	N/A	N/A
	Specialties	A set of attributes, one for each specialty, eg, cardiologist.	CMS	N/A	N/A	N/A	N/A
From peers	NumReferrals	Normalized number of referrals.	CMS	0	4018	70.1	10
	Castle Connolly	Whether or not the provider is recognized by Castle Connolly as a distinguished provider.	Vitals	N/A	N/A	N/A	N/A
Average rating from patient reviews	UserRatings	Overall review score assigned by user (patient).	Reviews from Vitals and Healthgrades	0	100	82.06	87.5
	NumReviews	Number of patient reviews for the provider.	N/A	0	247	0.96	0
Insurance	NumInsurances	Number of insurers accepted by the provider.	Vitals and Healthgrades	1	8	1.7	1
	IndividualInsurers	A set of attributes, one for each insurer accepted by the provider, eg, Humana.	Vitals and Healthgrades	N/A	N/A	N/A	N/A
Hospital affiliations	HospitalRanking	The ranking of the provider’s affiliated hospitals.	CMS (hospitals) and U.S. News (ranks of hospitals)	N/A	N/A	N/A	N/A

Table 2. List of health insurance attributes used in our analysis based on the data allocated. All attributes in this table are from NCQA.

Category	Attribute	Description
General information	PlanName	Insurance plan name.
	State	The state to which the plan belongs.
	PlanCategory	The category of the plan, eg, private, Medicare, Medicaid.
	PlanType	The type of the plan, eg, preferred provider organization (PPO), health maintenance organization (HMO).
Quality indicators – Overall	Rank	The overall rank of the plan.
	OverallScore	The overall score of the plan.
Quality indicators – Customer service	OverallConsumerSatisfactionScore	The score for consumer satisfaction.
	GettingCareScore	Scores based on appointments, preventive care, test, and easy and quick access to treatments.
	SatisfactionWithPhysiciansScore	Scores based on providers, care revived and health promotion and education.
	SatisfactionWithHealthPlanServicesScore	Scores based on handling claims and other plans services.
Quality indicators – Prevention	OverallPreventionScore	The score for preventive care.
	ChildrenAndAdolescentsScore	Scores based on well-child visits, immunizations, nutrition counseling, physical activity counseling.
	Women’sReproductiveHealthScore	Scores based on prenatal checkup and postpartum care.
	CancerScreeningScore	Scores based on various cancer screenings.
	OtherPreventiveServicesScore	Scores based on flu vaccinations, chlamydia screening, and other preventive care.
Quality indicators – Treatment	OverallTreatmentScore	The score for different treatments.
	AsthmaTreatmentScore	Scores based on asthma medication and treatment.
	DiabetesTreatmentScore	Scores based on blood pressure control, glucose testing and control, low-density lipoprotein cholesterol screening and control, monitoring kidney diseases.
	HeartDiseaseTreatmentScore	Scores based on controlling blood pressure and cholesterol and beta-blockers after heart attack.
	MentalAndBehavioralHealthScore	Scores based on depression medication, alcohol and drug dependence treatment, etc.
	OtherTreatmentMeasuresScore	Scores based on monitoring key long-term medications, antibiotic use, testing for chronic obstructive pulmonary disease, etc.

Entity Mappings

The names of insurance obtained from Vitals and Healthgrades differ from the names of insurance in the NCQA data. For example, “United Healthcare Services, CA” and “United Healthcare, CA” refer to the same insurance plan, as do “Aetna Life Insurance, AR” and “Aetna HMO, AR”. In order to achieve this mapping, we used the Levenshtein distance metric [18] to map Healthgrades and Vitals insurance to NCQA insurance. This generated 242 mappings between Vitals and NCQA insurance and 1330 mappings between Healthgrades and NCQA insurance.

The hospital rankings listed by U.S. News categorize hospitals across several specialties for adults and children; for each hospital listed, the hospital’s score, name, and location were collected for each specialty for both adults and children. Further, the hospital specialties reported by U.S. News do not always correspond to the specialties listed by CMS. In particular, CMS uses a taxonomy of medical specialties that consider subspecialties, whereas U.S. News uses broad categories of specialties [19]. Note that this mapping is not necessarily one-to-one; for example, a provider specializing in internal medicine may map to several categories listed by U.S. News. Therefore, we manually mapped all specialties with more than 100 occurrences to the specialties used by U.S. News. This generated 5651 mappings. We then used these mappings to assign scores to each of the affiliated hospitals, using the average for a hospital’s score when the provider’s specialty mapped to more than one specialty listed by U.S. News. We then assigned HospitalScore to the hospital affiliation with the maximum score, where null values are used for providers whose hospital affiliations are missing from the mappings. Also, for each HCPCS code of a provider, we computed the amount charged for this provider, relative to others of same specialty in the area (1000 closest within a 30-mile radius, normalized to a range of 0 to 100, where 100 goes to the most expensive physician). We then took the weighted average (by the number of procedures of a provider) of these relative charges to get the relative cost with respect to area.

In order to identify Castle Connolly and patient reviews information for each provider, CMS providers needed to be mapped to Vitals and Healthgrades provider profiles. This mapping exercise allowed us to map 608,935 providers between CMS, Vitals, and Healthgrades, 25,514 of whom have received a Castle Connolly award. To map CMS providers to providers in the other sources (Heathgrades and Vitals), we followed a hybrid automatic-manual data integration approach. First, we identified a promising set of attributes to use for mapping, specifically, first name, middle name, last name, address, medical school, graduation year, affiliated hospitals, and specialties. For each attribute, we constructed a customized mapping algorithm. For example, the mapping between first names is computed using the Levenshtein distance between the two strings. Then, we assigned weights to each attribute matching score based on a large number of accuracy experiments, where the authors defined the ground truth mappings. We then computed a mapping threshold based on the mapping scores via more accuracy experiments. Note that each Vitals/Healthgrades provider is mapped to at most one CMS provider, so no duplicate provider data are present in the final dataset.

Only 4% of all mapped providers have received a Castle Connolly award, and 42% of all mapped providers have zero referrals. A majority of providers with zero referrals specialized in Internal Medicine, Family Medicine, or Emergency Medicine. Also, 213 of 1264 health plans collected had incomplete data. In order to correlate rank of affiliated hospitals and insurance scores, we needed the rank of the hospitals. However, only 50 out of the 1956 hospitals obtained from U.S. News were ranked. We considered the unranked hospitals to be at the bottom of the list. We then took the median of the unranked hospitals (ie, 1053) and considered this to be the rank of the unranked hospitals. Also, in order to account for local trends, we performed our analysis at both the national and state levels. Health care is regulated at both the state and federal levels. These regulations, along with demographics and population health, create localized trends in health care.

Results

Summary

The results of our analysis consist of a description of general statistics about the different types of insurance and a state-wise analysis of the consumer satisfaction insurance plans. Then we report on correlations between insurances' consumer satisfaction score and the average patient review scores of providers that accept those insurances. We report similar correlations between insurances' overall NCQA consumer satisfaction score and then average number of referrals per provider, ratio of Castle Connolly providers, average affiliated hospital scores of providers, and relative cost of providers with respect to area. Last, we break down the providers according to their specialties and describe correlations between the average patient review scores and treatment insurance scores for condition-specialty combinations.

General Statistics of Insurance Plans

We first analyzed general statistics about the various insurance plans at the national level. We calculated the average overall consumer satisfaction scores of the insurance plans (see corresponding row in Table 2), where we average across the types of insurance plans: private, Medicare, and Medicaid. We also calculated the average patient review scores of providers (referred as "UserRatings" in Table 1) accepting these different types of insurances. Our findings are shown in Table 3 along with the statistical analysis. The patient review scores are on average higher than the insurance satisfaction scores, and with high significance for private PPOs and Medicare plans.

Table 3. General statistics about different types of health insurance plans.

Insurance plan type	Average patient review score (*P* value)	Average consumer satisfaction insurance score (*P* value)
Private PPO	82.03 (<.001)	79.75 (.384)
Private HMO	82.54 (<.001)	81.63 (<.001)
Medicaid	82.78 (<.001)	77.52 (<.001)
Medicare PPO	82.39 (<.001)	76.71 (.263)
Medicare HMO	81.55 (<.001)	76.9 (.123)

Figure 2. Heat map showing average consumer satisfaction insurance scores of different plans.

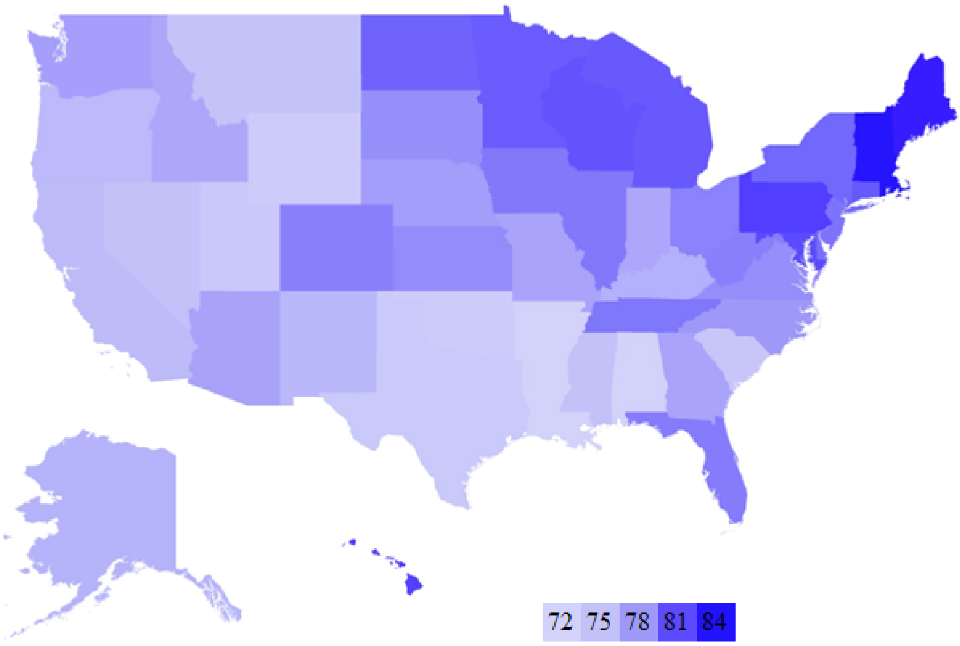


Figure 3. Heat map showing number of health care providers per 1000 people in each state.

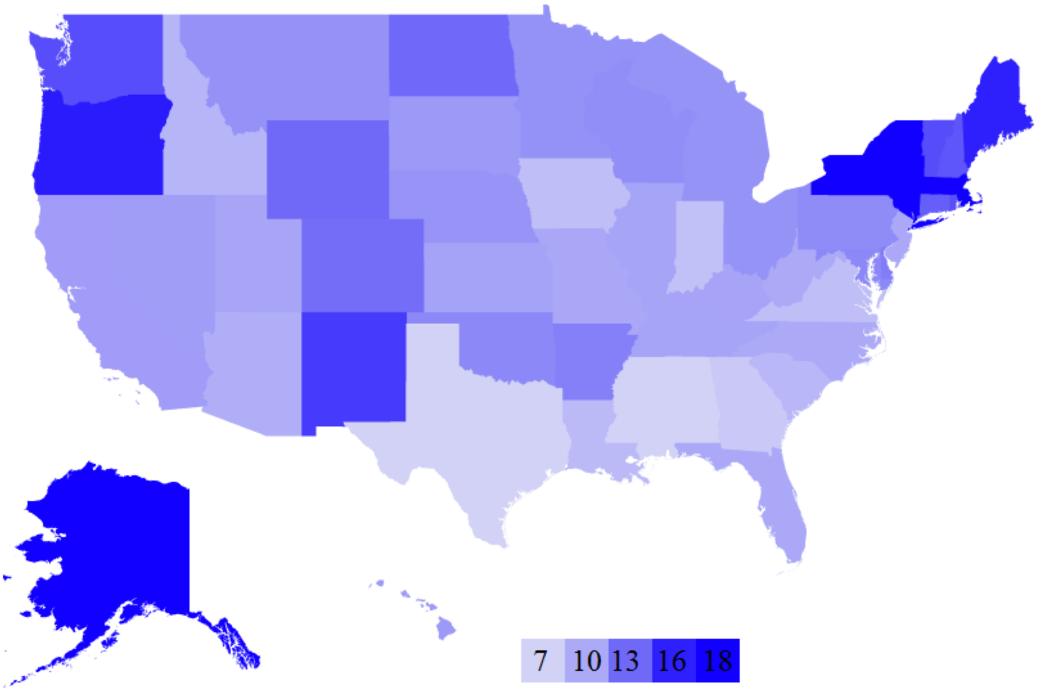
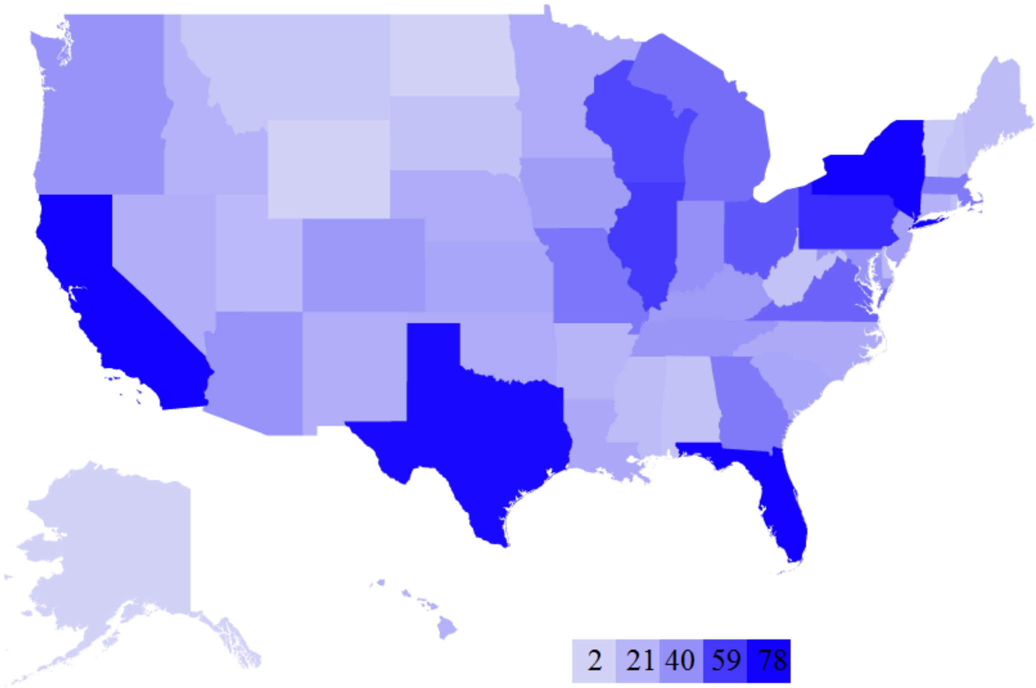


Figure 4. Heat map showing the number of health insurance plans evaluated by NCQA per state.



To estimate significance between values in the same row of Table 3, the Wilcoxon signed-rank test significance values are as follows, between average patient and insurance scores: private PPO .001, private HMO=.13, Medicaid=.008, Medicare PPO .001, and Medicare HMO .001. To compute significance of a value with respect to the union of the other four plan types in the same column (*P* value), we used the Mann-Whitney U test.

We also computed the average consumer satisfaction insurance scores for each state. The heat map in Figure 2 shows our findings. The darker colored states are those that have a higher overall consumer satisfaction insurance score while the lighter ones have lower consumer satisfaction insurance scores. From the map, we can conclude that northeastern states have higher consumer satisfaction insurance scores.

Similarly, we computed the number of health care providers per 1000 people for each state. As shown in Figure 3, the darker colored states have more providers per capita while the lighter states have fewer per capita. From this map, we can see that the northeastern states also tend to have more health care providers per capita.

Finally, we counted the number of insurance plans evaluated by NCQA per state. The heat map in Figure 4 shows our results. The darker colored states have more insurance plans while the lighter ones have fewer. The map shows that the most populous states have the most insurance plan options while the less populous states tend to have fewer.

Attribute Correlations

We computed the Pearson correlation of average patient review scores of providers that accept a particular insurance plan and that insurance plan’s NCQA scores. We found that there is a moderate positive correlation between these attributes (specifically .376). Figure 5 illustrates this correlation. We then did the same analysis state-wise and found that the Pearson coefficient increases in value, showing greater correlation when we localize the analysis. Table 4 shows the correlation coefficient between these same attributes for some of the different states. A couple of interesting observations can be made based on these correlations. First, there seems to be a moderate correlation between average patient review scores and consumer satisfaction insurance scores. Hence, insurance that includes providers with good reviews is more likely to have a better overall score. Also, the correlation between these two attributes seems to get stronger when we break down the data state-wise.

Table 4. Correlation between average patient review scores and consumer satisfaction insurance scores.

State	Correlation
Overall	.376
State-wise	
New York	.869
Texas	.794
Illinois	.738
Pennsylvania	.696
California	.647
Ohio	.549
Florida	.457

Next, we report correlations between average referrals per provider for insurances and those insurances' NCQA scores. Our analysis showed that there is a positive but very low correlation (specifically .031) between these two attributes. Hence, referral frequency of providers is negligibly correlated to consumer satisfaction insurance scores. Figure 6 further illustrates this correlation. Figure 7 illustrates the correlation between ratios of providers having the Castle Connolly award to the overall insurances' NCQA scores. We found a positive but negligible relationship between these attributes, specifically .183. Hence, whether a provider has received a Castle Connolly award or not does not affect the insurances' overall score. With respect to correlation between average ranks of affiliated hospitals and consumer satisfaction insurance scores, there exists a negative but negligible correlation between these two attributes (specifically -.108). Since we are considering ranks of hospitals, the negative correlation is expected. Hence, consumer satisfaction insurance scores are unlikely to be affected by the ranks of affiliated hospitals of the providers under that insurance plan. Figure 8 illustrates this correlation. We also determined the correlation relationship between relative cost of providers with respect to area and the consumer satisfaction insurance scores. Our findings showed a weak positive correlation of .266 between these two attributes. Figure 9 shows this correlation.

We then examined correlations between average patient review scores for specialist providers and the NCQA treatment insurance scores for these specialties. For this we used the individual treatment scores obtained from NCQA for the various conditions described in Table 2. We then compared these scores to the average patient review scores of only those providers that provide that kind of care, as shown by the mapping of condition to specialties in Table 5. For example, the average patient review scores of pediatricians were compared to the NCQA scores for treatment of children and adolescents. Table 5 lists our findings. We observed that for women's health, mental and behavioral health, and cancer screening there exists a positive but negligible correlation between the average NCQA scores and the average patient review scores. However, for heart diseases, child and adolescent health, and diabetes, there exists a negative and negligible to weak correlation between the attributes.

Table 5. Conditions and associated specialties ranked by correlation between NCQA scores and average patient review scores.

Condition from NCQA	Corresponding member specialties	Correlation of treatment insurance score with average patient review score
Women's health	Obstetrics and Gynecology, Gynecology Oncology	.135
Mental and behavioral health	Counselor, Psychoanalyst, Clinical Neuropsychologist, Psychologist, Psychoanalysis, Marriage and Family Therapist	.112
Cancer screening	Pediatric Oncology, Oncology, Hematology & Oncology, Radiation Oncology	.112
Heart disease	Cardiologist, Cardiac Rehabilitation, Cardiology Technician, Cardiovascular Diseases	-.002
Children and adolescent health	Pediatrics, Neonatal Pediatrics, Pediatrics Critical Care	-.083
Diabetes	Diabetes Educator, Endocrinology, Diabetes and Metabolism	-.259

Figure 5. Correlation between average patient review scores and consumer satisfaction insurance scores (overall) (correlation coefficient=.376, *P* .001).

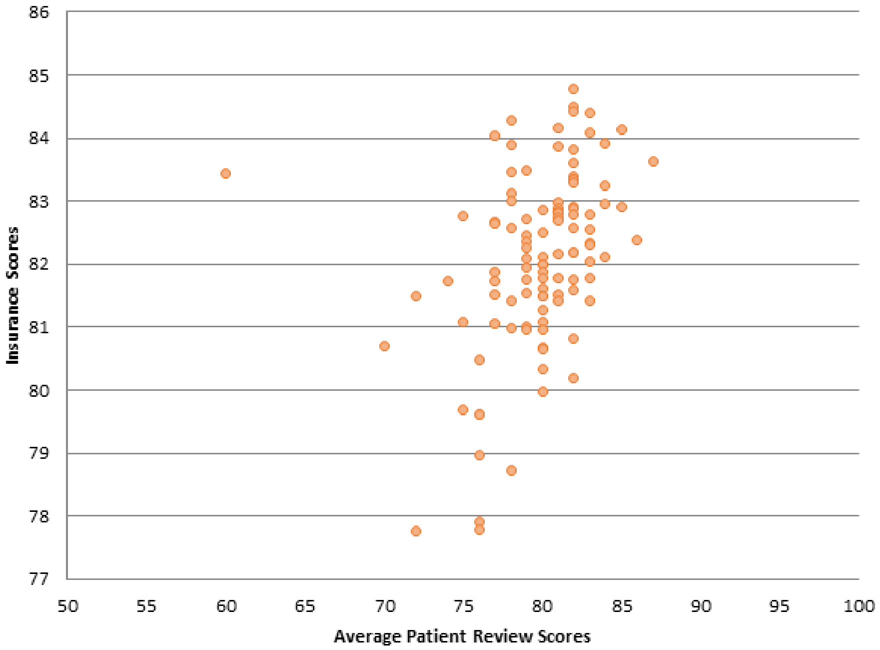


Figure 6. Correlation between average referrals per provider and consumer satisfaction insurance scores (correlation coefficient=.031, *P*=.715).

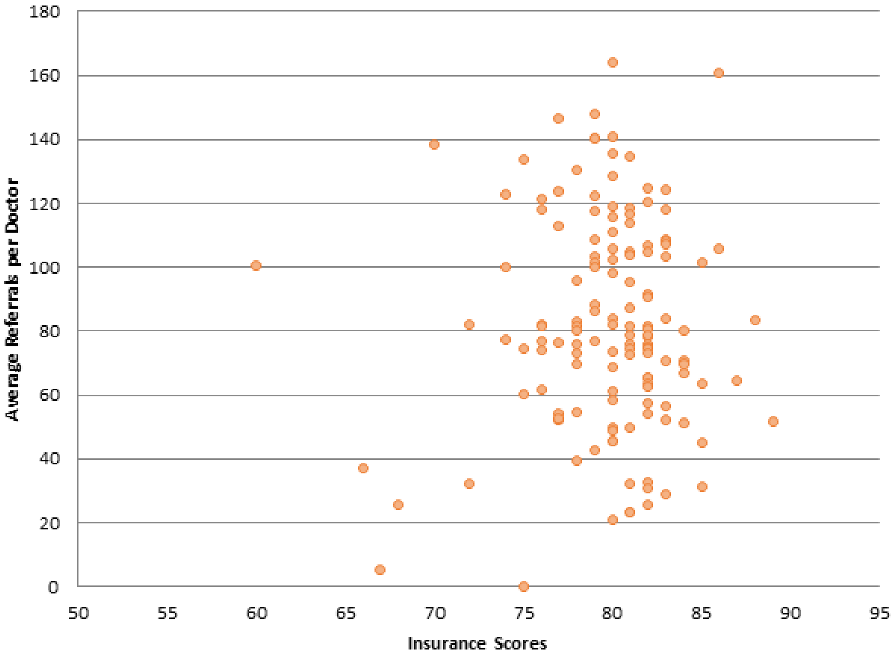


Figure 7. Correlation between ratio of Castle Connolly providers and consumer satisfaction insurance scores (correlation coefficient=.183, *P*=.001).

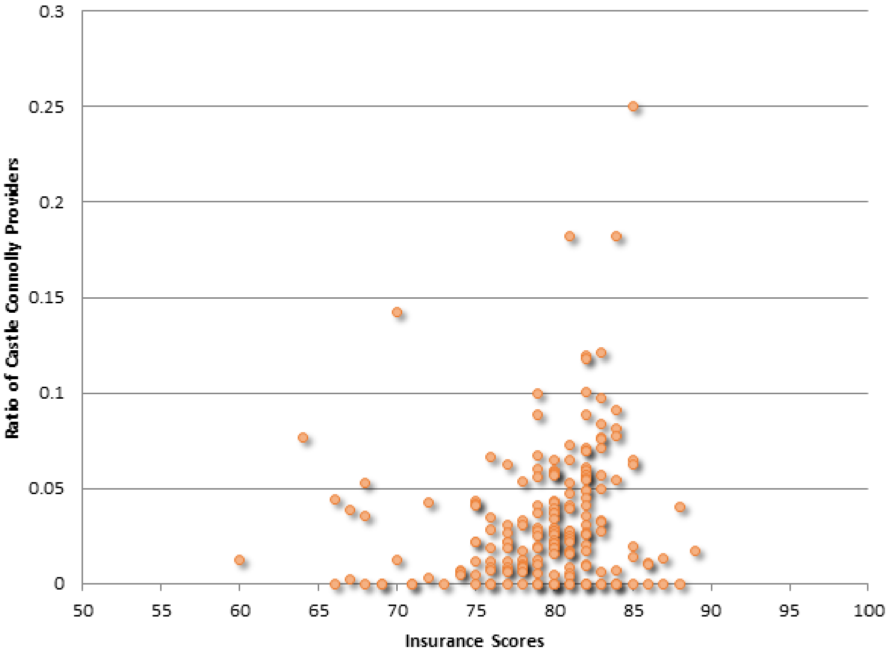


Figure 8. Correlation between ranks of affiliated hospitals and consumer satisfaction insurance scores (correlation coefficient=.108, *P*=.199).

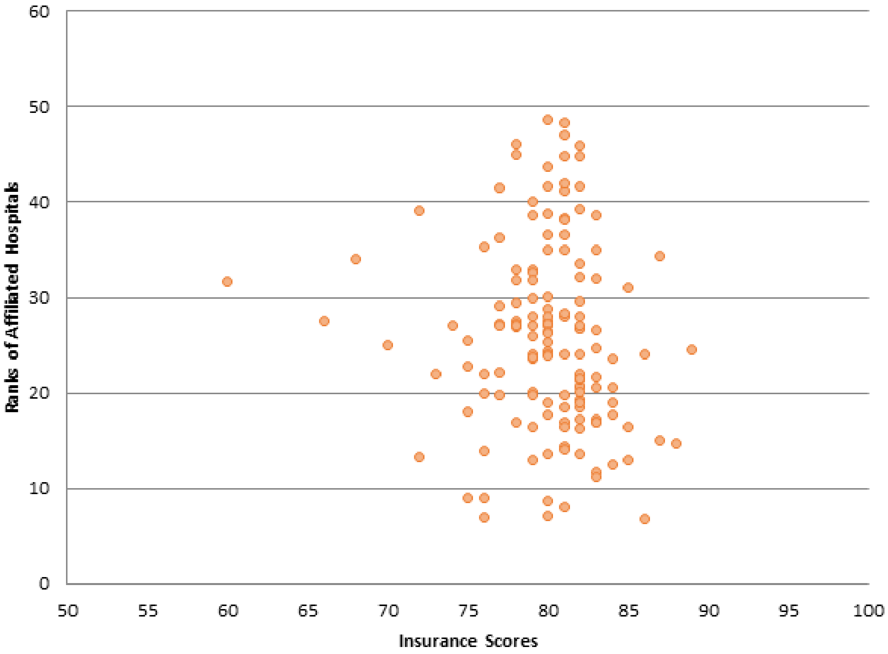
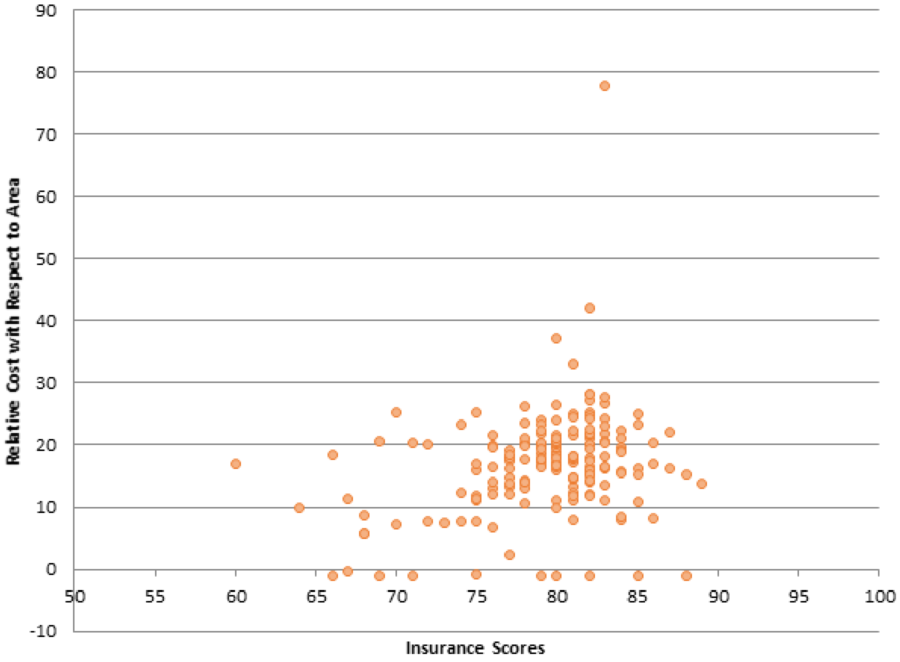


Figure 9. Correlation between relative cost of providers with respect to area and consumer satisfaction insurance scores (correlation coefficient=.266, *P*<.001).



Discussion

Principal Findings

Our analysis shows that there are several provider attributes that are correlated to insurance quality attributes. We showed that patient review scores for providers are correlated to consumer satisfaction insurance scores. This is expected given that patients who are happy with the care they receive from their providers are more likely to also be happy with their overall insurance plan. For example, if a patient has complaints about the billing at a provider's office, this patient will likely be unhappy with the insurance company who did not help cover or settle the bill.

On the other hand, our results showed negligible correlation between average referrals per provider and consumer satisfaction insurance scores. This is not surprising, as there is no convincing evidence that a higher number of referrals is connected to better skills for a provider or to better relationship with patients. Similarly, we demonstrated that there is a negligible correlation between the ratio of Castle Connolly providers and the consumer satisfaction insurance scores.

The case between rank of affiliated hospitals and consumer satisfaction insurance scores was similar. However, we found a weak positive correlation between the relative cost of providers with respect to their geographic area and consumer satisfaction insurance scores. This may be explained by the fact that providers with satisfied patients may increase their prices. Of course, the charged prices are not so important, as Medicare and Medicaid generally have fixed compensations per procedure.

Our results on the lack of correlation of patient reviews score and treatment quality metrics for various conditions may indicate that patients who are satisfied with their provider may not necessarily have better health outcomes, as studies have shown that patients often rate their providers based on non outcome-related attributes such as wait and visit times. For instance, research has shown that the average satisfaction score for wait times of 0-15 minutes was 94.3 on a 100-point scale [20].

Our findings can be used to help consumers make informed choices about their insurance plans. Health insurance marketplaces may find patient review scores for providers of each insurance plan to be a useful addition to other insurance plan metrics. Alternatively, consumers can use this information in their own research to identify potential insurance plans based on the review scores of providers on review sites such as Vitals and Healthgrades.

Further, insurers may use our results to better understand the relationship between their patients' satisfaction and their network of providers. For example, although it is not clear if there is a cause-effect relationship, our results indicate that hiring a provider with high patient review scores may contribute more to the overall consumer satisfaction insurance plan rating than hiring a provider who has been receiving many referrals from their colleagues. Further, our results indicate that more expensive providers are correlated with higher plan satisfaction, which seems to be at odds with the providers' "tier-ing" approach of insurers, who try to encourage patients to visit the cheaper providers.

Health care providers may also use our results to decide which insurance plans to accept. As noted above, a patient whose bill was not covered by an insurance company may complain about the billing at the provider's office on a provider review site, leading to a lower overall patient review score. A provider wishing to maintain a favorable score may thus choose to avoid accepting insurance plans with low consumer satisfaction scores.

Limitations

One of our biggest limitations is that not all of the data we obtained are complete. For example, a majority of the providers have zero reviews; this is likely due to the fact that only 4% of Internet users post online reviews for providers, and previous work has shown that most providers have zero reviews [21]. Similarly, a majority of the hospitals had no ranking information. A second limitation is that we sourced our data from multiple sites such as Vitals, CMS, Healthgrades, and NCQA. We then tried to map the various attributes across these sources. However, the accuracy of these data sources cannot be guaranteed. Another limitation is that referral frequency is greatly influenced by the specialty of the provider, and hence it needs to be normalized in terms of specialty in order to be used as an effective quality measure. Also, while the Castle Connolly award is prestigious and rigorously vetted, the award is biased towards providers who have more experience.

Conclusions

Our data-driven analysis led to several interesting findings. Higher consumer satisfaction insurance scores are correlated with their providers having better patient review scores. There also seems to be a correlation between cost of medical care and insurance ratings. However, there was negligible correlation between other quantitative attributes such as number of referrals per provider, ratio of Castle Connolly award recipients, affiliated hospitals scores, and health insurance ratings. These findings may provide new insights into what attributes should be adopted by insurance marketplaces and search portals to empower patients in a patient-centered setting.

Acknowledgments

The datasets on which this research relies are publicly available from [3,8-16].

This project was partially supported by National Science Foundation grants IIS-1216007, IIS-1447826, and IIP-1448848. Any opinions, findings, conclusions, or recommendations expressed in this material are those of the authors and do not necessarily reflect the views of the National Science Foundation.

Authors' Contributions

PS built crawlers to collect data about health insurance plans from ncqa.org and created the insurance mappings, carried out the analysis, and wrote the manuscript. RR built crawlers for collecting the provider data from multiple sources and handled the integration between these sources. VH conceived the study, researched the sources, and provided coordination and guidance in the experiments and writing of the manuscript.

Conflicts of Interest

None declared.

References

1. Weiss A. Health Affairs Blog. 2012 Jul 26. Health Insurance Exchanges: Improving Health Care Access And Quality URL: http://healthaffairs.org/blog/2012/07/26/health-insurance-exchanges-improving-health-care-access-and-quality/ [accessed 2016-08-08] [WebCite Cache ID 6jcUaUFAl]
2. Castle Connolly Top Doctors. URL: https://www.castleconnolly.com/ [accessed 2016-10-17] [WebCite Cache ID 6lKf0Xloq]
3. NCQA. URL: https://www.ncqa.org [accessed 2016-08-08] [WebCite Cache ID 6jcUpoUrD]
4. EINSURANCE. Privacy, Trust, and User Data URL: http://www.einsurance.com/info/privacy/ [accessed 2016-08-08] [WebCite Cache ID 6jcVGPPdU]
5. Insure.com. Methodology & Disclaimer URL: http://www.insure.com/best-insurance-companies/methodology [accessed 2016-08-07] [WebCite Cache ID 6jcVL9ENo]
6. Feldman PH. Center for Health Care Strategies. 2014 Aug. Key Attributes of High-Performing Integrated Health Plans for Medicare-Medicaid Enrollees URL: http://www.chcs.org/media/PRIDE-Key-Attributes-of-High-Performing-Health-Plans_090514.pdf [accessed 2016-08-08] [WebCite Cache ID 6jcVWPLIh]
7. URAC. Health Plan Quality Measures URL: https://www.urac.org/accreditation-and-measurement/accreditation-programs/all-programs/health-plan-quality-measures/ [accessed 2016-08-08] [WebCite Cache ID 6jcVcJcpG]
8. Vitals. URL: http://www.vitals.com/ [accessed 2016-08-08] [WebCite Cache ID 6jcVjHu5p]
9. Healthgrades. URL: https://www.healthgrades.com/ [accessed 2016-08-08] [WebCite Cache ID 6jcVko37e]
10. U.S. News & World Report. Best Hospitals: National Rankings URL: http://health.usnews.com/best-hospitals/rankings [accessed 2016-08-09] [WebCite Cache ID 6jcVoa6rm]
11. U.S. News & World Report. Best Medical Schools: Primary Care URL: http://grad-schools.usnews.rankingsandreviews.com/best-graduate-schools/top-medical-schools/primary-care-rankings [accessed 2016-08-09] [WebCite Cache ID 6jcVr8r65]
12. HealthData.gov. National Provider Identifier Standard - Data Dissemination URL: http://www.healthdata.gov/dataset/national-provider-identifier-standard-data-dissemination [accessed 2016-08-09] [WebCite Cache ID 6jcWGTjwR]

13. Medicare.gov. Physician Compare Datasets URL: https://data.medicare.gov/data/physician-compare [accessed 2016-08-09] [WebCite Cache ID 6jcWPLuyS]
14. Centers for Medicare & Medicaid Services. Medicare Provider Utilization and Payment Data: Physician and Other Supplier URL: http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Provider-Charge-Data/Physician-and-Other-Supplier.html [accessed 2016-10-17] [WebCite Cache ID 6lKfO6pVI]
15. Centers for Medicare & Medicaid Services. What physician shared patient data sets are available? URL: https://questions.cms.gov/faq.php?faqId=7977 [accessed 2016-08-09] [WebCite Cache ID 6jcWqeLmd]
16. Centers for Medicare & Medicaid Services. Part D Claims Data URL: http://www.cms.gov/Medicare/Prescription-Drug-Coverage/PrescriptionDrugCovGenIn/PartDData.html [accessed 2016-10-17] [WebCite Cache ID 6lKhi5AV3]
17. Hedley J. jsoup: Java HTML Parser. URL: https://jsoup.org/ [accessed 2016-08-09] [WebCite Cache ID 6jcX2bk18]
18. Levenshtein V. Binary codes capable of correcting deletions, insertions, and reversals. Soviet Physics Doklady 1966;10(8):707-710.
19. Washington Publishing Company. WPC References URL: http://www.wpc-edi.com/reference/ [accessed 2016-08-09] [WebCite Cache ID 6jcX5JLcC]
20. Dolan PL. American Medical News. Physician rating website reveals formula for good reviews URL: http://www.amednews.com/article/20120227/business/302279969/2/ [WebCite Cache ID 6jcXCXNh7]
21. Gao GG, McCullough JS, Agarwal R, Jha AK. A changing landscape of physician quality reporting: analysis of patients' online ratings of their physicians over a 5-year period. J Med Internet Res 2012 Feb 24;14(1):e38 [FREE Full text] [doi: 10.2196/jmir.2003] [Medline: 22366336]

Abbreviations

CMS: Centers for Medicare & Medicaid Services
HCPCS: Healthcare Common Procedure Coding System
HMO: Health Maintenance Organization
NCQA: National Committee for Quality Assurance
NPI: National Provider Identifier
PPO: Preferred Provider Organization

Edited by G Eysenbach; submitted 10.08.16; peer-reviewed by G Luo, H Singh; comments to author 15.09.16; revised version received 22.09.16; accepted 24.09.16; published 24.10.16.

Please cite as:
Shetty P, Rivas R, Hristidis V
Correlating Ratings of Health Insurance Plans to Their Providers' Attributes
J Med Internet Res 2016;18(10):e279
URL: http://www.jmir.org/2016/10/e279/
doi:10.2196/jmir.6475
PMID:27777217

Original Paper

The Impact of the Internet on Health Consultation Market Concentration: An Econometric Analysis of Secondary Data

Jia Li[1*], PhD; Ya Zhang[1*], BA; Ling Ma[1*], PhD; Xuan Liu[1*], PhD

E-commerce Institute, School of Business, East China University of Science and Technology, Shanghai, China
[*]all authors contributed equally

Corresponding Author:
Ling Ma, PhD
E-commerce Institute
School of Business
East China University of Science and Technology
130 Meilong Rd.
Shanghai, 200237
China
Phone: 86 2164253177
Fax: 86 2164253177
Email: maling@ecust.edu.cn

Abstract

Background: Many markets have traditionally been dominated by a few best-selling products, and this is also the case for the health care industry. However, we do not know whether the market will be more or less concentrated when health care services are delivered online (known as E-consultation), nor do we know how to reduce the concentration of the E-consultation market.

Objective: The aim of this study was to investigate the concentration of the E-consultation market and how to reduce its concentration through information disclosure mechanisms (online reputation and self-representation).

Methods: We employed a secondary data econometric analysis using transaction data obtained from an E-consultation Website (haodf.com) for three diseases (infantile pneumonia, diabetes, and pancreatic cancer) from 2008 to 2015. We included 2439 doctors in the analysis.

Results: The E-consultation market largely follows the 20/80 principle, namely that approximately 80% of orders are fulfilled by nearly 20% of doctors. This is much higher than the offline health care market. Meanwhile, the market served by doctors with strong online reputations (beta=0.207, $P<.001$) or strong online self-representation (beta=0.386, $P<.001$) is less concentrated.

Conclusions: When health care services are delivered online, the market will be more concentrated (known as the "Superstar" effect), indicating poor service efficiency for society as a whole. To reduce market concentration, E-consultation websites should provide important design elements such as ratings of doctors (user feedback), articles contributed by doctors, and free consultation services (online representation). A possible and important way to reduce the market concentration of the E-consultation market is to accumulate enough highly rated or highly self-represented doctors.

(J Med Internet Res 2016;18(10):e276) doi:10.2196/jmir.6423

KEYWORDS

long tail effect; superstar effect; E-consultation; market concentration; information asymmetry; signaling theory; online reputation; self-representation

Introduction

Background

The Pareto principle (also known as the 80/20 rule) states that, in many cases, approximately 80% of the effects result from 20% of the causes. The Pareto principle is very popular in the economic market, as it indicates that a small proportion (eg, 20%) of products in a market often generate a large proportion (eg, 80%) of sales [1]. For example, a relatively small number of titles by established best-selling authors account for a high percentage of book sales, Billboard's "top 40" hits account for the majority of radio playlists and music sales, and movie rentals are dominated by a few popular "new releases."

Not surprisingly, the Pareto principle also applies to the health care service market. In the health care service market, a few of the best hospitals or doctors have a much higher market share than do ordinary hospitals or doctors [2]. Market concentration or the Pareto principle may be an advantage in a business context (eg, in a supermarket or bookstore), but it is not good for the health care industry. A major concern for the health care industry is the limited service capability of each hospital or doctor; this is, of course, not a problem in the product sales context. When the market is highly concentrated on a few very good doctors, the efficiency of health service delivery to society as a whole will be negatively affected. That is, a few very good doctors will be extremely busy, while some other unknown doctors will be idle [3]. Therefore, a low concentrated market with balanced supply and demand is the ideal condition for the health care industry. Many efforts have been made to decrease the concentration of the health care market by balancing supply and demand. One example of such efforts is the role of family physicians in western countries, who make up a sizable portion of the primary care workforce [4]. A patient must see a family physician before seeing doctors at higher-level hospitals. Another example is the hierarchical diagnosis and treatment system in China, an important part of China's medical reform [5]. To encourage patients to see doctors initially at local, lower-level hospitals, China implemented new policies such as charging less at lower-level hospitals and increasing the rates that medical insurers pay to these hospitals.

A recent trend in eHealth is delivering health care services online [6,7]. Among online health services, E-consultation seems to be particularly attractive and is increasing in popularity [8-10]. This new type of online health care consultation can reduce both waiting time and travel expenses. It is also likely to be a valuable option in terms of providing patients with more efficient diagnoses. Most important, patients who have limited or even no medical resources have equal access to medical experts online, leading to better and more efficient use of nationwide medical resources. Online health care consultation will be of great significance in reducing medical costs and in improving the operational efficiency, effectiveness, and equity of medical resources, as well as in enhancing customer satisfaction. Therefore, the use of E-consultation is becoming popular and has been increasing rapidly in recent years [11]. It still has some downsides such as overreliance on it, which can lead to delays in care delivery, patients' privacy and confidentiality, and technical difficulties involving such technology. Examples of third party E-consultation websites include askthedoctor.com [12], askdoctorfree.com [13], and haodf.com [14]. E-consultation has also been used by some offline medical institutions, such as the Mayo Clinic, to deliver health care services online [15-17]. E-consultation appears to have improved access to specialists, who can be integrated into care processes when timely expert opinions are needed.

The new technologies embedded in E-consultation are not limited to digital communications, computing, and storage but also involve a qualitative transformation in search tools, recommendation tools, and social network technologies [18]. Therefore, E-consultation not only provides convenience and better decision results for the user but also changes the costs of seeking information and patterns of searching for information. Because the choice of a doctor is made based on the information received, the concentration of the online market will be different from the offline market. Two possible consequences of Internet technology on these concentrations have been observed in the E-commerce market, namely the "Long-Tail" effect and the "Superstar" effect. On one hand, the user can find more niche (unpopular) doctors at much lower searching costs than ever before, creating a "Long Tail" in the concentration of demand for doctors. On the other hand, users can more easily find the most high-profile doctors online, creating "Superstar" or "winner-take-all" markets where some very good doctors dominate the market [19]. However, we have no idea whether the E-consultation market will be more of a superstar market or a long-tail market compared with a traditional offline context. What can website designers do to turn the superstar market into a long-tail market?

In this study, we aim to investigate the following research questions:

RQ1: Will E-consultation be more of a long-tail or a superstar market? Or, will the E-consultation market be less concentrated or more concentrated than the offline market?

RQ2: Can information disclosure mechanisms (the doctor's online reputation and self-representation) help reduce market concentration?

Research Hypotheses

Star Effect Versus Long-Tail Effect

Choosing a doctor on a website is totally different from choosing a doctor at an offline hospital. A significant difference is the information available to the user when making a decision. With the help of information technology such as search engines, recommendation tools, and social networking technologies, the user can easily reach more doctors (especially unknown doctors) at a much lower cost than before. In the traditional offline context, the user's choice set of doctors is quite small. The user usually chooses a doctor near their home or workplace. However, in the online context, the user can choose any doctor nationwide with just a few clicks of the mouse. This means that the choice set in the context of E-consultation is much larger, and users have more of an opportunity to choose unknown doctors than ever before. Thus, the online market will be less concentrated on a small number of high-profile doctors, creating a long-tail effect.

Another possible consequence of E-consultation is the superstar effect, also known as the Matthew Effect or "the rich get richer." This is because popular doctors enjoy greater visibility on E-consultation platforms (eg, they are ranked highly by search engines or recommended preferentially by websites). As a consequence, the very good and popular doctors have a greater chance than before of being identified at the national level, which further increases their chance of being chosen by users. Thus, the online market will be more concentrated on a small number of famous doctors, creating a superstar effect.

In summary, both the long-tail and superstar effects may exist in the E-consultation context. We cannot know which effect will be dominant without an empirical study. Therefore, we propose the following two competitive hypotheses:

H1a: The online market is less concentrated than the offline market.

H1b: The online market is more concentrated than the offline market.

Information Asymmetry Theory and Information Disclosure

Health care is a market with high information asymmetry. Information asymmetry models assume that at least one party to a transaction has relevant information while the others do not. In the case of E-consultation, doctors have more information about their own service quality than do the patients. Although doctors know their own service quality, patients have little information on this very important question. This situation of information asymmetry creates an imbalance of power in transactions, which can sometimes cause the transactions to go awry—a type of market failure in a worst-case scenario.

According to signaling theory [20], information asymmetry can be reduced by one party (termed the agent) credibly conveying information about itself to another party (the principal). The recipient of the information can interpret the received signal and adjust their purchases accordingly. For example, in Spence's job-market signaling model [20], (potential) employees send signals about their abilities to employers by acquiring education credentials. The informational value of the credential comes from the fact that the employer believes the credential is positively correlated with having greater ability and is difficult for less-able employees to obtain. Thus, the credential enables the employer to reliably distinguish low-ability workers from high-ability workers.

In the E-consultation context, doctors send information about their service quality to patients. After receiving this information, patients may change their judgment about doctors' service quality and further change their choice of doctors. In this study, we focus on two signals that a doctor can send about their service quality on an E-consultation website, specifically, online reputation and online self-representation.

Doctors' Online Reputations

An online reputation (also known as online word-of-mouth) is built based on feedback from patients. E-consultation websites usually provide a feature known as "rate a doctor." A patient who has visited the doctor previously can write a review of the doctor in terms of technical competence, interpersonal manner, systems issues, etc. The online reputation system is very popular on E-commerce platforms and has been demonstrated as a reliable mechanism to reduce market information asymmetry. For example, eBay uses a system of customer feedback to publicly rate each member. Amazon [21] has a similar reputation mechanism in place, and merchants develop their reputations across different dimensions [22]. According to a recent study, a doctor's online reputation, as rated by patients is a good indicator of that doctor's service quality in the real world [7].

If the E-consultation website does not provide an online reputation feature, the user judges the doctor's service quality based only on the doctor's professional standing (eg, director, associate director). Therefore, the user's consideration set is small because only those doctors with high offline positions will be considered. When the E-consultation website does provide an online reputation feature, users have more clues to evaluate the doctor's service quality. If the market has many doctors with strong reputations, users will consider those who are highly rated but perhaps have lower offline positions. This means that the consideration set is enlarged. However, if the market is full of doctors with poor reputations, users will not include those poorly rated doctors in the consideration set. This means the consideration set remains at the same size or is even smaller (if doctors with high positions are poorly rated). Thus, having a market with highly rated doctors is very important. If the market has many highly rated doctors, market efficiency will be improved because users have more credible doctors from which to choose (ie, the supply of high-quality doctors is increased). In the same vein, market efficiency will not be improved if the market has few highly rated doctors. Therefore, we propose the following hypothesis:

H2: A market served by many doctors with strong online reputations is less concentrated than a market served by many doctors with poor online reputations.

Doctors' Online Self-Representation

Self-representation is the activity a doctor commits online for the purpose of sending quality information. There are several ways for doctors to represent themselves on an E-consultation website. For example, a doctor can post articles or provide free consultation services. Such efforts are another type of signal the doctor sends to users. The user can evaluate the doctor's service quality in terms of the efforts reflected online. For example, doctors who post popular medical science articles demonstrate not only their medical knowledge and skills but also their positive attitudes toward E-consultation as well as their Internet savvy. Meanwhile, the quality and number of free consultation services provided are good indicators of the doctor's expertise and social responsibility.

Therefore, when an E-consultation website provides self-representation features, the users have more information with which to judge the doctor's service quality. If the market has many doctors representing and promoting themselves, users will consider these highly represented doctors, who may not be well known offline. This means the consideration set, as well as the supply of high quality doctors, is enlarged. However, if the market is full of doctors with low self-representation, users will not consider these low-effort doctors, and thus the consideration set remains the same. For the same reason, if the market has many highly represented doctors, market efficiency will be improved because users will have more credible doctors from which to choose. Therefore, we propose the following hypothesis:

H3: A market served by many doctors who are highly represented online is less concentrated than a market served by many doctors who are not well represented online.

In summary, we aim to investigate the concentration of the E-consultation market and how to reduce its concentration through information disclosure mechanisms. We hypothesize that the online market is less or more concentrated than the offline market, and the online reputation or self-representation can be used to reduce market concentration.

Methods

Data Collection

We employ a secondary data analysis as the research method. Secondary data refers to data that were collected by someone other than the researcher. Primary data, by contrast, are collected by the investigator conducting the research. In this study, the data were originally collected by the E-consultation website, haodf.com [14]. We developed a network spider to crawl data from the website indirectly. Therefore, the data used in this study are secondary data.

We collected data from Good Doctor (haodf.com [14]) to test the hypotheses proposed in the previous section. Haodf.com is a leading E-consultation website in China. As of May 2016, the platform had 397,587 registered doctors from 5332 regular hospitals. Good Doctor provides two types of consultation services: free consultation using written asynchronous communication and consultation via phone for which there is a charge. Haodf.com provides a home page for each doctor, which contains their demographic information, clinic information, service fees, user feedback, contributed articles, and service records (both free and paid services). Each user can choose any doctor from the website, as long as the doctor is providing service at that moment. The search engine, the recommendation systems, and the social networks are all accessed on haodf.com. Therefore, the doctor's online word of mouth, contributed articles, and free and paid services are all accessible to the users. A network spider was used to collect data from the site about three diseases (infantile pneumonia, diabetes, and pancreatic cancer) from 2008-2015. The three diseases were chosen because we intend to cover both acute and chronic diseases, as well as both high mortality rate and low mortality rate diseases.

Empirical Model

Following Brynjolfsson et al's work [1], we fit the sales, sales rank, reputation, and self-representation data to the following log-linear relationship. More details about the empirical econometric model are provided in Multimedia Appendix 1.

Measures

Online reputation is measured by the number of votes, letters of thanks, and gifts received by the doctor (the three variables are standardized and then averaged to create a composite variable). The review score is not used to measure online reputation in this study because we observe a ceiling effect (most doctors have a top score, making it very difficult to distinguish doctors). Self-representation is measured by the number of scientific papers the doctor has contributed and the number of free services they have provided (the two variables are standardized and then averaged to create a composite variable).

Control variables include the doctor's position, hospital level, service price, and duration of providing online service. Position is measured on a scale of 1-5, with 1 being the lowest and 5 the highest. Hospital level is measured on a scale of 1-3, with 1 being the lowest and 3 the highest. Service price is measured by the service fee (in Chinese Yuan) per phone call. Duration is measured by the number of months since the doctor's homepage was established.

Results

Summary Statistics

The descriptive statistics of variables used in this study are shown in Table 1. The correlations between major variables are listed in Table 2.

Table 1. Descriptive statistics.

Variable	Observations	Mean	SD	Min.	Max.
Order number	2439	341.360	826.100	1	12518
Order rank	2439	461.880	322.077	1	1231
Vote	2439	21.320	34.134	1	429
Gift	2439	17.791	61.205	0	1003
Thank-you letter	2439	5.988	13.203	0	157
Reputation	2439	0.000	0.922	-0.447	13.162
Articles	2439	13.242	145.257	0	6871
Free service	2439	319.798	783.135	0	10876
Self-represent	2439	0.000	0.733	-0.250	23.536
Position	2439	4.221	1.067	1	5
Hospital level	2439	2.824	0.529	1	3
Service price	2439	147.984	44.283	0	1200
Online duration	2439	53.024	27.465	1	94

Table 2. Variable correlations (Pearson correlation coefficient).

	Order number	Reputation	Self-endeavor	Position	Hospital level	Service price	Online duration
Order number	1						
Reputation	.581	1					
Self-represent	.715	.428	1				
Position	.001	.090	.018	1			
Hospital level	.018	.004	.019	.062	1		
Service price	.040	.161	.012	.118	.009	1	
Online duration	.200	.290	.183	.106	-.049	.079	1

Table 3. Regression results.

Variable	Model 1 (standard error)	Model 2 (standard error)	Model 3 (standard error)	Model 4 (standard error)
Position	-0.082[a] (0.043)	-0.007 (0.021)	-0.001 (0.019)	0.005 (0.018)
	P=.06	P=.73	P=.96	P=.76
Level	0.119 (0.086)	0.007 (0.041)	0.010 (0.038)	0.014 (0.035)
	P=.17	P=.87	P=.80	P=.68
Price	0.001 (0.001)	0.0003 (0.0005)	0.0004 (0.0005)	-0.0003 (0.0004)
	P=.20	P=.49	P=.41	P=.45
Duration	-0.022 (0.002)	-0.001 (0.010)	-0.0002 (0.001)	0.001 (0.001)
	P<.001	P=.43	P=.82	P=.27
Lrank		-1.950 (0.022)	-2.086 (0.024)	-2.301 (0.024)
		P<.001	P<.001	P<.001
Reputation			-1.011 (0.052)	
			P<.001	
Reputation*Lrank			0.207 (0.012)	
			P<.001	
Self-represent				-2.024 (0.066)
				P<.001
Self-represent*Lrank				0.386 (0.014)
				P<.001
Constant	2.439 (0.330)	15.056 (0.211)	15.840 (0.204)	17.266 (0.200)
	P<.001	P<.001	P<.001	P<.001
R^2	0.068	0.786	0.815	0.845

[a] P<.1.

Evaluation Outcomes

The regression results are shown in Table 3. Model 1 contains only control variables, which builds a benchmark for the following models.

Model 2 includes the order rank. The results from Model 2 show that the order rank is negatively related to the number of orders (beta$_1$ =-1.950, P<.001). The Lorenz curve (the relationship between the cumulative percentage of doctors and the cumulative percentage of orders) for the E-consultation market is shown in Figure 1. The Lorenz curve is a graphical representation of the distribution of orders. It shows for the bottom x% of doctors, what percentage (y%) of the total order they have. The percentage of doctors is plotted on the x-axis, and the percentage of order on the y-axis. We can estimate from Figure 1 that the market concentration largely follows the 80/20 principle, such that approximately 80% of the orders are dominated by nearly 20% of doctors. The concentration of 80/20 at the doctor level is much higher than any of the offline markets [23,24]. Thus, the online market is more of a superstar market than a long-tail market. Therefore, H1a is rejected and H1b is supported.

Model 3 focuses on the interaction between reputation and order rank. The results of Model 3 reveal a significant negative interaction between online reputation and rank ($beta_4$ =0.207, *P*<.001). A positive and significant $beta_4$ (given $beta_1$ is negative and significant) indicates online reputation weakens market concentration. The interaction plot between online reputation and rank is shown in Figure 2. We can see that the line for the high reputation doctors is smoother than the low reputation doctors, indicating less rank effect. This means that the market served by doctors with strong online reputations is less concentrated than the market served by doctors with low online reputations. Therefore, H2 is supported.

Model 4 focuses on the interaction between self-representation and order rank. The results of Model 4 reveal a significant negative interaction between online self-representation and rank ($beta_5$ =0.386, *P*<.001). A positive and significant $beta_5$ (given $beta_1$ is negative and significant) indicates that self-representation weakens market concentration. The interaction plot between online reputation and rank is shown in Figure 3. The line for the high self-representation doctors appears smoother than the low self-representation doctors, indicating less rank effect. This means that the market served by doctors with strong online self-representation is less concentrated than the market served by doctors with low online self-representation. Therefore, H3 is supported.

Robustness Check

We ran a robustness check by using alternative measures for reputation and self-endeavor and got similar results (see Multimedia Appendix 2).

Figure 1. Lorenz curve.

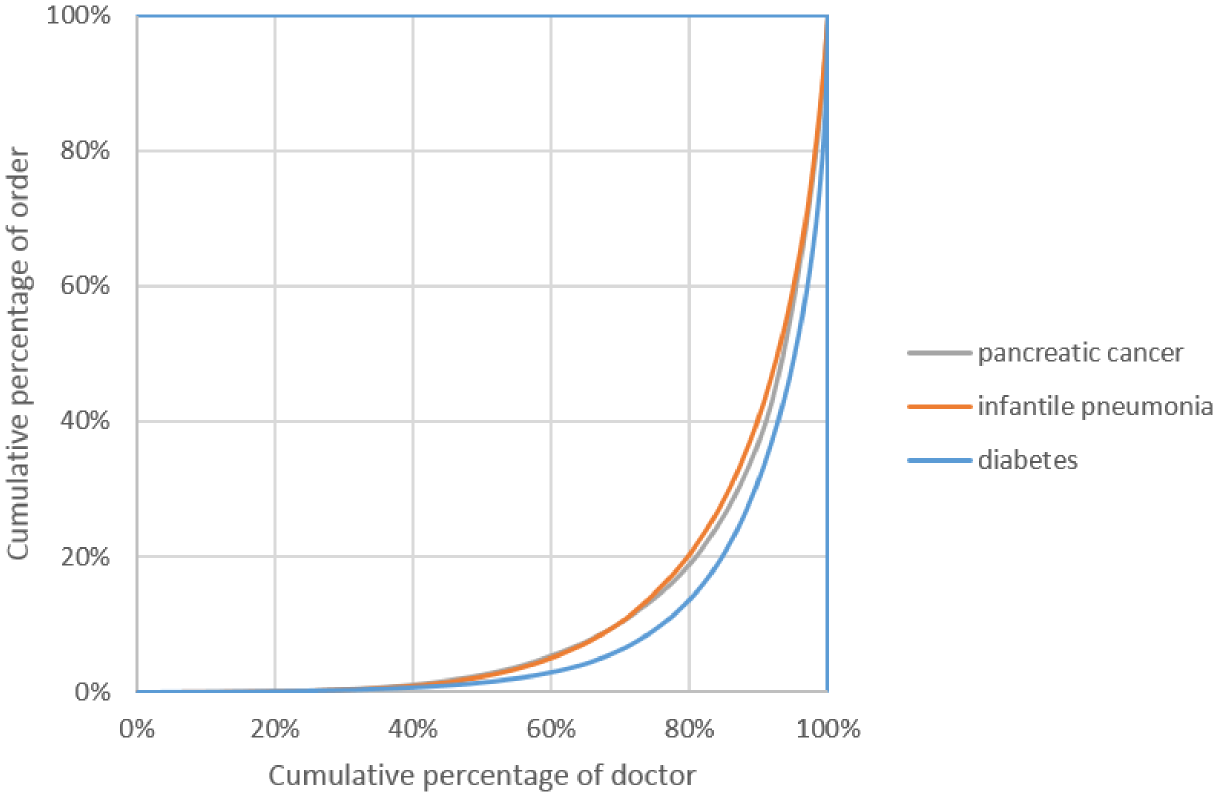


Figure 2. The interaction between online reputation and order rank.

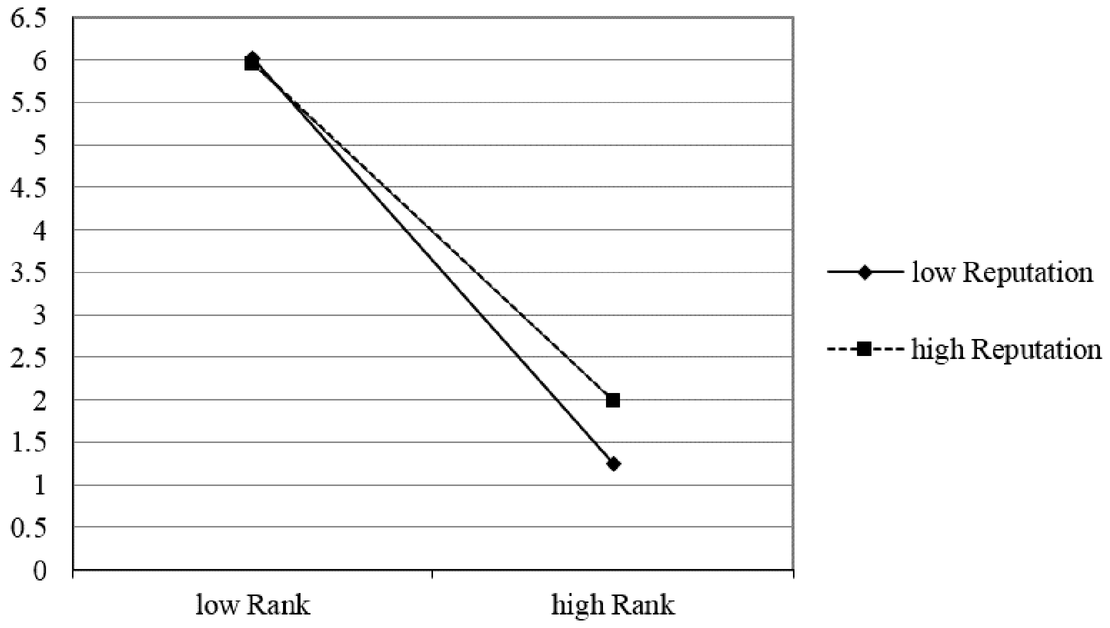
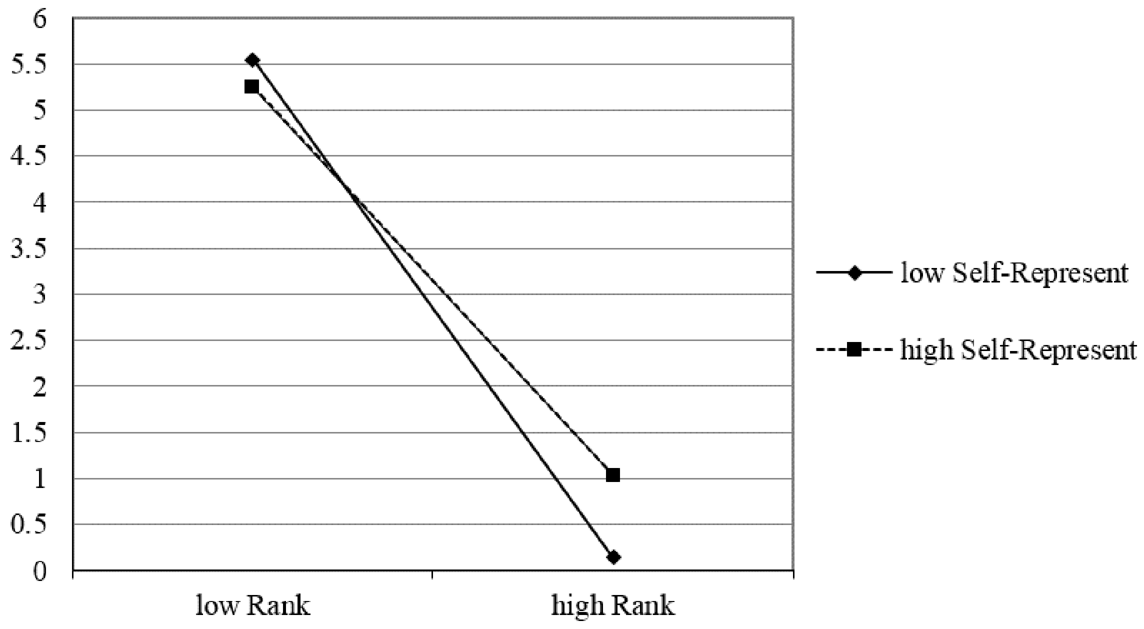


Figure 3. The interaction between online self-representation and order rank.



Discussion

Principal Results

In this study, we found the E-consultation market to be more concentrated than the offline health care market, and both online reputation and self-representation help reduce market concentration. Specifically, we found the following. First, the E-consultation market is more concentrated than the offline health care market. In other words, the E-consultation market is more of a superstar market than a long-tail one.

Second, the market served by many doctors with strong online reputations is less concentrated than the market served by many doctors with poor online reputations.

Third, the market served by many doctors with high levels of online self-representation is less concentrated than the market served by many doctors with low levels of online self-representation.

Comparison With Prior Work

The Impact of the Internet on Market Concentration

Many prior studies have investigated the effect of the Internet on sales concentration. One of the most frequently cited phenomena is the long-tail effect (ie, the online market is less concentrated than the offline one). The main drivers of the long-tail effect come from both the supply side and the demand side [25].On the supply side, as e-tailers expand, centralized warehousing allows for more offerings, thus making it possible for them to cater to more varied tastes. On the demand side, tools such as search engines, recommender software and sampling tools allow customers to find products outside of their geographic areas. The long-tail effect has been confirmed by many previous studies [1,26]. Subsequent research further distinguished the two drivers and confirmed that a significant amount of niche product consumption online is due to the direct influence of the channel on consumer behavior, not just due to selection effects from the types of consumers who decide to use an Internet channel or the types of products that consumers decide to purchase online [27]. Specifically, consumers' use of Internet search and discovery tools, such as recommendation engines, is associated with an increase in the share of niche products [1,28,29].

Another frequently cited phenomenon is the superstar effect (ie, the online market is more concentrated than the offline one). The superstar phenomenon emerges when a comparatively small number of participants excel, surpass others in their field, and reap much greater rewards [30]. This phenomenon has been observed in virtually all categories of human activity, for example, in sports [31], music [32], entertainment [33], word frequency [34], and science [35]. Many studies observe the superstar effect when consumers move from brick-and-mortar to Internet markets [36-38]. For example, Hendricks and Sorensen [37] found that in the online music market, the distribution of sales is substantially more skewed than it would be if consumers were more fully informed. Zhong and Michahelles [38] verified that Google Play is more of a superstar market—strongly dominated by popular hit products—than a long-tail market.

Previous studies of the impact of the Internet on market concentration mainly focus on the business context. We do not know of any studies investigating the impact of the Internet on health care market concentration. The results of this study show that the E-consultation market will be more of a superstar market than a long-tail market, revealing a "rich-getting-richer" picture. Some actions (eg, providing user feedback, allowing doctors self-representation, the adoption of human or automated medical guidance) must be taken to reduce this undesirable outcome.

The Market Concentration in Health Care

There are previous studies on the concentration of the health care market. The most frequently investigated topic is the impact of market concentration on service prices. Previous studies reveal that higher market concentration usually leads to higher service prices [23,39,40]. For example, Dunn and Shapiro [39] found that physicians in more concentrated markets charge higher service prices; a physician in the 90th percentile of market concentration will charge 14-30% higher fees than a physician in the 10th percentile. Their estimates imply that physician consolidation has caused an approximately 8% increase in fees, on average, over the last 20 years and substantially higher increases in concentrated markets. Austin and Baker [40] found that counties with the highest average physician concentrations had prices 8-26% higher than prices in the lowest counties and concluded that physician competition is frequently associated with higher prices. However, market concentration also provides some benefits. Dunn and Shapiro [41] reveal that physician concentration has a small but statistically significant effect on service utilization. An increase in 1 standard deviation in cardiologist concentration causes a 5% increase in cardiologist service provision. Higher concentration also leads to fewer readmissions, implying potential health benefits.

Existing studies on health care market concentration are mainly conducted at the hospital level. The major reason is that most data are available at the hospital level.

E-consultation websites and historical transaction data provide a good opportunity to study market concentration at the level of individual doctors. Therefore, an important contribution of this study compared to previous studies is the unit of analysis. In addition, most previous studies are interested in the consequences of market concentration. However, we are interested in how to build a more or less concentrated health care market.

Theoretical Contributions

Our research offers several important theoretical contributions. First, this study investigates, for the first time, the important question of market concentration in the E-consultation context and compares it with the traditional offline health care market. The results indicate a superstar market rather than a long-tail market.

Second, previous studies on health care market concentration have mainly been conducted at the hospital level. Due to data limitations, very few studies have investigated the health care market concentration at the level of individual doctors. However, secondary data from an E-consultation website provided a unique opportunity to explore this important question at the individual doctor's level.

Third, this study explores possible ways to decrease E-consultation market concentration from the information asymmetry perspective. Our findings reveal that two types of information disclosure mechanisms (ie, user feedback-based reputation and online self-representation) help to balance the supply and demand of health care service, which results in improved market efficiency.

Limitations

This study has several limitations. First, only cross-sectional data were used in this study. Therefore, the role of intertemporal factors cannot be explored, and influences from many specific individual attributes cannot be completely eliminated. In the future, the panel data analysis method could be incorporated. Panel analysis uses panel data to examine changes in variables over time and differences in variables between subjects. The panel data contain rich information and would allow us to control for specific indicators. If the theory we proposed is correct and the data are sufficient, the results from panel analysis should be consistent with the cross-sectional analysis.

Second, data on only three disease types and from only one website (haodf.com) were used in this study. Therefore, the results of this study may not be fully representative of all diseases and the whole E-consultation market. In the future, we will continue this research by collecting data from multiple E-consultation websites and for more disease types.

Conclusions

Our findings suggest that the E-consultation market is more concentrated than the offline market, exhibiting a superstar effect. Meanwhile, concentration can be reduced if the doctor's signals of quality are sent properly. A market served by many doctors with strong reputations or high levels of self-representation will be less concentrated.

These findings provide significant insights for E-consultation website designers as well as for policy makers. This research reveals that user feedback and online representation are two important mechanisms that E-consultation websites should provide and encourage. A possible and important way to reduce the market concentration of E-consultation services is to accumulate enough highly rated and highly self-represented doctors.

We intend to explore how the level of market concentration varies based on different conditions in the future. For example, how does level of concentration vary based on specific type of online services (eg, diagnosis, monitoring, or intervention services)? How does level of concentration vary based on different condition types (eg, acute vs chronic, high mortality vs low mortality, rare vs common, urgency vs non-urgency)? How does level of concentration vary based on the distribution of offline medical resources? Answering these research questions may help us better understand the impact of internet on health consultation market concentration.

Acknowledgments

This research was supported by the National Natural Science Foundation of China with grants 71371005, 71471064, and 71503108.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Empirical model.

[PDF File (Adobe PDF File), 30KB - jmir_v18i10e276_app1.pdf]

Multimedia Appendix 2

Robustness check.

[PDF File (Adobe PDF File), 34KB - jmir_v18i10e276_app2.pdf]

References

1. Brynjolfsson E, Hu Y, Simester D. Goodbye pareto principle, hello long tail: the effect of search costs on the concentration of product sales. Manage Sci 2011 Aug;57(8):1373-1386. [doi: 10.1287/mnsc.1110.1371]
2. Feng T, Sun X, Wu H, Jiang C. The essential of hierarchy of e-continuing medical education in china. In: Frontier and future development of information technology in medicine and education. Netherlands: Springer; 2014:2267-2272.
3. Wun Y, Lam T, Lam K, Goldberg D, Li D, Yip K. How do patients choose their doctors for primary care in a free market? J Eval Clin Pract 2010;16(6):1215-1220. [doi: 10.1111/j.1365-2753.2009.01297.x]
4. Bodenheimer T, Pham H. Primary care: Current problems and proposed solutions. Health Affairs 2010;29(5):799-805. [Medline: 20439864]
5. Jia W, Tong N. Diabetes prevention and continuing health-care reform in China. Lancet Diabetes Endocrinol 2015 Nov;3(11):840-842. [doi: 10.1016/S2213-8587(15)00382-4] [Medline: 26496828]
6. Miscione G. Telemedicine in the Upper Amazon: Interplay with local health care practices. MIS Quarterly 2007;31(2):403-425.
7. Gao GG, Greenwood BN, Agarwal R, Jeffrey S. Vocal minority and silent majority: how do online ratings reflect population perceptions of quality? MIS Quarterly 2015;39(3):565-589.
8. Shuyler KS, Knight KM. What are patients seeking when they turn to the Internet? Qualitative content analysis of questions asked by visitors to an orthopaedics Web site. J Med Internet Res 2003 Oct 10;5(4):e24 [FREE Full text] [doi: 10.2196/jmir.5.4.e24] [Medline: 14713652]

9. Umefjord G, Hamberg K, Malker H, Petersson G. The use of an Internet-based Ask the Doctor Service involving family physicians: Evaluation by a web survey. Fam Pract 2006 Apr;23(2):159-166 [FREE Full text] [doi: 10.1093/fampra/cmi117] [Medline: 16464871]
10. Katz SJ, Moyer CA. The emerging role of online communication between patients and their providers. J Gen Intern Med 2004 Sep;19(9):978-983 [FREE Full text] [doi: 10.1111/j.1525-1497.2004.30432.x] [Medline: 15333064]
11. Roettl J, Bidmon S, Terlutter R. What predicts patients' willingness to undergo online treatment and pay for online treatment? Results from a web-based survey to investigate the changing patient-physician relationship. J Med Internet Res 2016;18(2):e32 [FREE Full text] [doi: 10.2196/jmir.5244] [Medline: 26846162]
12. Ask the Doctor. 2016. URL: https://www.askthedoctor.com/ [accessed 2016-08-29] [WebCite Cache ID 6k7vddDFv]
13. Ask a Doctor Free. 2016. URL: http://www.askdoctorfree.com/ [accessed 2016-08-29] [WebCite Cache ID 6k7vkvztY]
14. The Good Doctor. 2016. URL: http://www.haodf.com/ [accessed 2016-08-29] [WebCite Cache ID 6k7uJhj6w]
15. North F, Uthke LD, Tulledge-Scheitel SM. Integration of e-consultations into the outpatient care process at a tertiary medical centre. J Telemed Telecare 2014 May 6;20(4):221-229. [doi: 10.1177/1357633X14533886] [Medline: 24803274]
16. Tieu L, Sarkar U, Schillinger D, Ralston J, Ratanawongsa N, Pasick R, et al. Barriers and facilitators to online portal use among patients and caregivers in a safety net health care system: a qualitative study. J Med Internet Res 2015;17(12):e275 [FREE Full text] [doi: 10.2196/jmir.4847] [Medline: 26681155]
17. Das A, Faxvaag A, Svanæs D. The impact of an ehealth portal on health care professionals' interaction with patients: qualitative study. J Med Internet Res 2015;17(11):e267 [FREE Full text] [doi: 10.2196/jmir.4950] [Medline: 26601678]
18. Caiata-Zufferey M, Abraham A, Sommerhalder K, Schulz PJ. Online health information seeking in the context of the medical consultation in Switzerland. Qual Health Res 2010 Aug;20(8):1050-1061. [doi: 10.1177/1049732310368404] [Medline: 20442347]
19. Serenko A, Cox R, Bontis N, Booker L. The superstar phenomenon in the knowledge management and intellectual capital academic discipline. J of Informetr 2011 Feb 26;5(3):333-345. [doi: 10.1016/j.joi.2011.01.005]
20. Spence M. Job market signaling. The Quarterly Journal of Economics 1973 Aug;87(3):355-374. [doi: 10.2307/1882010]
21. Amazon. 2016. URL: https://www.amazon.com/ [accessed 2016-08-29] [WebCite Cache ID 6k7wLo4UN]
22. Ghose A, Ipeirotis P, Sundararajan A. The dimensions of reputation in electronic markets. NYU Center for Digital Economy Research Working Paper 2009:CeDER-06-02.
23. Connor R, Feldman R, Dowd B. The effects of market concentration and horizontal mergers on hospital costs and prices. Int J Econ Bus 1998;5(2):159-180.
24. Melnick G, Keeler E, Zwanziger J. Market power and hospital pricing: are nonprofits different? Health Aff (Millwood) 1999;18(3):167-173 [FREE Full text] [Medline: 10388213]
25. Brynjolfsson E, Hu Y, Smith M. From niches to riches: Anatomy of the long tail. Sloan Manage Rev 2006;47(4):67-71 [FREE Full text]
26. Peltier S, Moreau F. Internet and the 'long tail' versus superstar effect' debate: evidence from the French book market. Appl Econ Lett 2012;19(8):711-715. [doi: 10.1080/13504851.2011.597714]
27. Zentner A, Smith M, Kaya C. How video rental patterns change as consumers move online. Manage Sci 2013 Nov;59(11):2622-2634. [doi: 10.1287/mnsc.2013.1731]
28. Fleder D, Hosanagar K. Blockbuster culture's next rise or fall: the impact of recommender systems on sales diversity. Manage Sci 2009;55(5):697-712.
29. Matt C, Hess T, Weiß C. The differences between recommender technologies in their impact on sales diversity. Presented at: International Conference on Information Systems; December 15-18, 2013; Milano, Italy.
30. MacDonald G. The economics of rising stars. The American Economic Review 1988;78(1):155-166.
31. Lucifora C, Simmons R. Superstar effects in sport evidence from Italian soccer. J Sport Econ 2003;4(1):35-55. [doi: 10.1177/1527002502239657]
32. Krueger A. The economics of real superstars: the market for rock concerts in the material world. J Labor Econ 2005 Jan;23(1):1-30. [doi: 10.1086/425431]
33. Frank R, Cook P. The winner-take-all society: why the few at the top get so much more than the rest of us. New York: Penguin Books; 1996.
34. Booth A. A "law" of occurrences for words of low frequency. Inform Control 1967 Apr;10(4):386-393. [doi: 10.1016/S0019-9958(67)90201-X]
35. Rossiter M. The Matthew Matilda effect in science. Soc Stud Sci 1993 May 01;23(2):325-341. [doi: 10.1177/030631293023002004]
36. Latcovich S, Smith H. Pricing, sunk costs, and market structure onlinevidence from book retailing. Oxford Rev Econ Pol 2001;17(2):271-234.
37. Hendricks K, Sorensen A. Information and the skewness of music sales. J Polit Econ 2009 Apr;117(2):324-369. [doi: 10.1086/599283]
38. Zhong N, Michahelles F. Google Play is not a long tail market: an empirical analysis of app adoption on the Google play app market. Presented at: 28th Annual ACM Symposium on Applied Computing; March 18-22, 2013; Coimbra, Portugal p. 499-504.

39. Dunn A, Shapiro A. Do physicians possess market power? J Law Econ 2014 Feb;57(1):159-193. [doi: 10.1086/674407]
40. Austin DR, Baker LC. Less physician practice competition is associated with higher prices paid for common procedures. Health Aff (Millwood) 2015 Oct;34(10):1753-1760. [doi: 10.1377/hlthaff.2015.0412] [Medline: 26438753]
41. Dunn A, Shapiro A. Physician competition and the provision of carevidence from heart attacks. Federal Reserve Bank of San Francisco Working Paper 2015:e.

Edited by G Eysenbach; submitted 29.07.16; peer-reviewed by F Nazneen, E Charbek; comments to author 17.08.16; revised version received 30.08.16; accepted 03.09.16; published 28.10.16.

Please cite as:
Li J, Zhang Y, Ma L, Liu X
The Impact of the Internet on Health Consultation Market Concentration: An Econometric Analysis of Secondary Data
J Med Internet Res 2016;18(10):e276
URL: http://www.jmir.org/2016/10/e276/
doi:10.2196/jmir.6423
PMID:27793793

Corrigenda and Addenda

Correction of: Exploring Concordance of Patient-Reported Information on PatientsLikeMe and Medical Claims Data at the Patient Level

Gabriel S Eichler[1], PhD; Elisenda Cochin[1], BA; Jian Han[2], PhD; Sylvia Hu[2], PhD; Timothy E Vaughan[1], PhD; Paul Wicks[1], PhD; Charles Barr[2], MPH, MD; Jenny Devenport[2], PhD

[1]PatientsLikeMe, Cambridge, MA, United States

[2]Genentech, Medical Affairs, South San Francisco, CA, United States

Corresponding Author:
Paul Wicks, PhD
PatientsLikeMe
160 Second Street
Cambridge, MA,
United States
Phone: 1 6173144352
Fax: 1 8668506240
Email: pwicks@patientslikeme.com

Related Article:

Correction of: https://www.jmir.org/2016/5/e110/

(J Med Internet Res 2016;18(10):e271) doi:10.2196/jmir.6757

The authors of, “Exploring Concordance of Patient-Reported Information on PatientsLikeMe and Medical Claims Data at the Patient Level” (J Med Internet Res 2016;18(5):e110) would like to make changes in the fourth paragraph under the heading of Principal Findings in the Discussion section of the paper.

The text should read, “A larger percentage of diagnosis-unmatched patients reported having Primary Progressive MS, than those who did have a matching diagnosis (15% vs 4%, respectively).” instead of “A larger percentage of diagnosis-unmatched patients reported having primary progressive MS than those who did have a matching diagnosis (15% vs 3%, respectively).”

The second correction is in Table 1. There were missing cells that lead to the absence of a key MS subgroup, relapsing-remitting MS, with knock-on consequences for other cells in that table.

1. The value of “Age in years (SD)” was changed in the column “Consenting patients with claims match” from 47.4 (10.63) to 57.4 (10.63).

2. The value of “PLM patients with MS as primary or secondary condition (%)” was changed in the column “Consenting patients with claims match” from 391 (69.2) to 392 (69.4).

3. The row “Relapsing-remitting” was added under “MS subtype.” The values, 2,429 (61.1), 2,165 (60.8), 250 (63.8), and 14 (66.7) were added for columns “Patients invited (N=5,362),” “Patients who did not consent (N=4,759),” “Consenting patients with claims match (N=565),” and “Consenting patients with no claims match (N=36),” respectively.

4. The values for the row “Primary progressive” under “MS subtype” were changed from 2682 (67.5), 2392 (65.5), 275 (70.3), and 15 (71.4) to 253 (6.4), 227 (6.4), 25 (6.4), and 1 (4.76) in each column, respectively.

5. The values for the row “Unreported” under the “MS subtype” were changed from 676 (18.5) and 28 (7.2) to 586 (16.5) and 29 (7.4) under columns “Patients who did not consent (N=4,759)” and “Consenting patients with claims match (N=565),” respectively.

6. The percentages have also been adjusted in the “Reported MS DMT use in PML” category from 3118 (58.2), 2751 (57.8), 351 (62.1), and 16 (44.4) to 3,118 (78.4), 2,751 (77.2), 351 (90.0), and 16 (76.2) in each column, respectively.

The corrected Table 1 is as below:

Table 1. Demographic characteristics.

Patient Characteristics[a]	Patients invited[b] (N=5,362)	Patients who did not consent (N=4,759)	Consenting patients with claims[b] match (N=565)	Consenting patients with no claims match (N=36)
Age in yrs (SD)	54.7 (11.53)	54.3 (11.60)	57.4 (10.63)	56.5 (11.02)
Number of Females (%)	3,546 (66.1)	3,136 (65.9)	385 (68.1)	25 (69.4)
Primary condition in PLM				
MS (%)	3,869 (72.2)	3,470 (72.9)	379 (67.1)	20 (55.6)
PD (%)	1,333 (24.9)	1,151 (24.2)	168 (29.7)	14 (38.9)
Other (%)	160 (2.9)	138 (2.9)	18 (3.2)	2 (5.6)
Patient Reports MS or PD Diagnosed by Physician (%)	4,512 (84.2)	3,934 (73.4)	544 (96.3)	34 (94.4)
PLM patients with MS as primary or secondary condition (%)	3,976 (74.2)	3,564 (74.9)	392 (69.4)	21 (58.3)
MS subtype (% MS)				
Relapsing-Remitting	2,429 (61.1)	2,165 (60.8)	250 (63.8)	14 (66.7)
Primary progressive	253 (6.4)	227 (6.4)	25 (6.4)	1 (4.76)
Secondary progressive	551 (13.9)	470 (13.2)	78 (19.9)	3 (14.3)
Progressive relapsing	127 (3.2)	116 (3.3)	10 (2.6)	1 (4.8)
Unreported	616 (15.5)	586 (16.5)	29 (7.4)	2 (9.5)
Years since MS Diagnosis[a] (%)				
0 - ≤5 Years	581 (14.6)	524 (14.7)	53 (13.5)	4 (19.05)
>5 - ≤10 Years	1,102 (27.7)	980 (27.5)	116 (29.6)	6 (28.6)
>10 - ≤15 Years	711 (17.9)	619 (17.4)	87 (22.2)	5 (23.8)
>15 - ≤20 Years	408 (10.3)	358 (10.0)	48 (12.2)	2 (9.5)
>20 Years	566 (14.3)	492 (10.8)	71 (18.1)	3 (14.3)
[Not Reported]	609 (15.3)	591 (16.6)	17 (4.3)	1 (4.8)
Reported MS DMT use in PLM (%)	3,118 (78.4)	2,751 (77.2)	351 (90.0)	16 (76.2)
Reported Insurance Type (%)				
Indian Health Service	1 (0.02)	1 (0.02)	0 (0.0)	0 (0.0)
Medicaid/ other low-income plan	195 (3.64)	165 (3.47)	29 (5.13)	1 (2.78)
Medicare	1023 (19.08)	799 (16.79)	209 (36.99)	15 (41.67)
National health service	7 (0.13)	7 (0.15)		
Other type of insurance	49 (0.91)	42 (0.88)	6 (1.06)	1 (2.78)
Private (individual plan)	210 (3.92)	183 (3.85)	27 (4.78)	
Private (via employer /union)	1351 (25.20)	1141 (23.98)	203 (35.93)	7 (19.44)
TRICARE (or oth military ins)	55 (1.03)	47 (0.99)	7 (1.24)	1 (2.78)
Veteran's Administration	69 (1.29)	54 (1.13)	13 (2.30)	2 (5.56)
No Insurance	87 (1.62)	79 (1.66)	6 (1.06)	2 (5.56)
Prefer not to answer	77 (1.44)	74 (1.55)	2 (0.35)	1 (2.78)
[Not Reported]	2238 (41.74)	2167 (45.53)	63 (11.15)	6 (16.67)

[a] Source for all characteristics is PLM; all statistics reported are n (%) unless otherwise noted.

[b] Two patients who were invited, consented and had at least 1 claim in the claims dataset asked to have their profiles removed from PLM and are, therefore, not represented in this analysis.

Both these alterations have been made in the online version of the paper on the JMIR website on October 27, 2016 together with publishing this correction notice. Because these were made after submission to PubMed and other full-text repositories, the correction notice has been submitted to PubMed, and the original paper has been resubmitted to PubMed Central. The corrected metadata have also been resubmitted to CrossRef.

Edited by G Eysenbach; submitted 06.10.16; this is a non–peer-reviewed article;accepted 06.10.16; published 27.10.16.

Please cite as:
Eichler GS, Cochin E, Han J, Hu S, Vaughan TE, Wicks P, Barr C, Devenport J
Correction of: Exploring Concordance of Patient-Reported Information on PatientsLikeMe and Medical Claims Data at the Patient Level
J Med Internet Res 2016;18(10):e271
URL: http://www.jmir.org/2016/10/e271/
doi:10.2196/jmir.6757
PMID:27788121

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org