Journal of Medical Internet Research

Journal Impact Factor (JIF) (2023): 5.8
Volume 18 (2016), Issue 11 ISSN 1438-8871 Editor in Chief: Gunther Eysenbach, MD, MPH

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Original Paper

Impact of a Collective Intelligence Tailored Messaging System on Smoking Cessation: The Perspect Randomized Experiment

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Abstract

Background: Outside health care, content tailoring is driven algorithmically using machine learning compared to the rule-based approach used in current implementations of computer-tailored health communication (CTHC) systems. A special class of machine learning systems (“recommender systems”) are used to select messages by combining the collective intelligence of their users (ie, the observed and inferred preferences of users as they interact with the system) and their user profiles. However, this approach has not been adequately tested for CTHC.

Objective: Our aim was to compare, in a randomized experiment, a standard, evidence-based, rule-based CTHC (standard CTHC) to a novel machine learning CTHC: Patient Experience Recommender System for Persuasive Communication Tailoring (PERSPeCT). We hypothesized that PERSPeCT will select messages of higher influence than our standard CTHC system. This standard CTHC was proven effective in motivating smoking cessation in a prior randomized trial of 900 smokers (OR 1.70, 95% CI 1.03-2.81).

Methods: PERSPeCT is an innovative hybrid machine learning recommender system that selects and sends motivational messages using algorithms that learn from message ratings from 846 previous participants (explicit feedback), and the prior explicit ratings of each individual participant. Current smokers (N=120) aged 18 years or older, English speaking, with Internet access were eligible to participate. These smokers were randomized to receive either PERSPeCT (intervention, n=74) or standard CTHC tailored messages (n=46). The study was conducted between October 2014 and January 2015. By randomization, we compared daily message ratings (mean of smoker ratings each day). At 30 days, we assessed the intervention’s perceived influence, 30-day cessation, and changes in readiness to quit from baseline.

Results: The proportion of days when smokers agreed/strongly agreed (daily rating ≥4) that the messages influenced them to quit was significantly higher for PERSPeCT (73%, 23/30) than standard CTHC (44%, 14/30, *P*=.02). Among less educated smokers (n=49), this difference was even more pronounced for days strongly agree (intervention: 77%, 23/30; comparison: 23%, 7/30, *P*<.001). There was no significant difference in the frequency which PERSPeCT randomized smokers agreed or strongly agreed that the intervention influenced them to quit smoking (*P*=.07) and use nicotine replacement therapy (*P*=.09). Among those who completed follow-up, 36% (20/55) of PERSPeCT smokers and 32% (11/34) of the standard CTHC group stopped smoking for one day or longer (*P*=.70).

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Conclusions: Compared to standard CTHC with proven effectiveness, PERSPeCT outperformed in terms of influence ratings and resulted in similar cessation rates.

ClinicalTrial: Clinicaltrials.gov NCT02200432; https://clinicaltrials.gov/ct2/show/NCT02200432 (Archived by WebCite at http://www.webcitation.org/6lEJY1KEd)

(J Med Internet Res 2016;18(11):e285) doi:10.2196/jmir.6465

KEYWORDS

recommender system; health communication; computer tailoring; smoking cessation

Introduction

In computer-tailored health communication (CTHC) systems, messages are tailored (what messages need to be selected for the patient) to patient characteristics [1]. Across health domains, CTHC systems are effective in motivating behavior change [2-8]. In the smoking cessation domain, meta-analyses have demonstrated the effectiveness of CTHC systems [9]. In a previous randomized controlled trial (RCT; N=900), we developed and demonstrated the effectiveness of a CTHC system. Compared with an active control group that received no messages, this CTHC system significantly impacted 6-month cessation outcomes (OR 1.70, 95% CI 1.03-2.81) [10]. Current implementations of CTHC systems (hereafter referred to as "standard CTHC") combine tailoring variables (what variables should be used to tailor) and if-then-else rules (how to select messages for the different tailoring variables) to select messages for a patient [1,11]. Experts (or study designers) specify these tailoring variables and develop the rules based on their knowledge of the targeted population, literature, and health behavior theories.

Outside health care, content tailoring is driven algorithmically using machine learning as opposed to the rule-based approach used in standard CTHC systems [12-14]. A special class of machine learning systems ("recommender systems") are used to select messages combining the collective intelligence of their users (ie, the observed and inferred preferences of users as they interact with the system) and their user profiles [12-14]. For example, Amazon recommends products that a customer may like based on the products they have purchased or viewed previously. The primary difference between standard CTHC and recommender systems is how the messages are selected. As noted, in standard CTHC systems, messages are selected using if-then-else rules. In recommender systems, machine learning algorithms select the messages. As published, recommender systems offer multiple potential advantages to CTHC including the ability to continually learn and adapt to user feedback; however, this approach has not been adequately tested for CTHC [11].

In an experiment funded by the Patient-Centered Outcomes Research Institute (PCORI), we developed and evaluated a recommender system, the Patient Experience Recommender System for Persuasive Communication Tailoring (PERSPeCT), and applied it to smoking cessation. We compare PERSPeCT with our existing, evidence-based, standard rule-based CTHC system that was demonstrated to be effective in our previous RCT [10]. Our primary hypothesis is that the PERSPeCT recommender system will outperform (ie, select messages of higher influence) the rule-based CTHC system. We also evaluate the perceived intervention influence and 30-day cessation at follow-up. Our study provides the first evidence for the use of machine learning recommender systems for motivating smokers, and has important implications for future behavioral interventions.

Methods

Study Overview

In a randomized experiment, we compared PERSPeCT (intervention) with a standard rule-based CTHC system (comparison). As noted previously, the purpose of this pilot experiment was to test whether selecting the messages by a recommender approach would provide marginal advances over a standard message selection approach. As noted, this comparison system tailored messages based on the smoker's readiness to quit and was demonstrated to be effective for smoking cessation in our previous RCT [10]. For the PERSPeCT intervention, we developed and implemented a recommender system [15,16]. Both the comparison and intervention system drew from the same motivational message content, but varied in how messages were selected for each participant. Messages were sent until the smoker entered ratings for 30 messages. Smokers in both arms were emailed daily motivational messages and were incentivized to rate messages. The study was conducted between October 2014 and January 2015. Our protocol is described in detail subsequently. This study was approved by the University of Massachusetts Medical School Institutional Review Board. See Multimedia Appendix 1.

The PERSPeCT Intervention and Comparison Standard System

Our study goal was to test the ability of the two systems to select influential messages for individual participants. Thus, for both the intervention and comparison systems we used the same message database. In this section, we first describe the messaging database used by both systems and then the PERSPeCT recommender and comparison rule-based standard CTHC system.

The Motivational Messaging Database

The messaging database included 261 messages that were developed in our previous RCT and included both expert-written messages and peer-written messages [17]. Messages written by experts (study designers, behaviorists, physicians, nurses) were developed through an iterative expert group review process. The creation of these messages was informed by current guidelines [18] and Social Cognitive Theory (SCT) [19]. The

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current guidelines provided evidence-based content on successful cessation strategies. The SCT, which incorporates vicarious learning and verbal persuasion, informed the content of the expert messages [17]. Messages reflected theoretical determinants of quitting, such as positive outcome expectations and self-efficacy enhancing small goals [19]. Peer-written messages were written by current and former smokers responding to an online survey that presented four scenarios tailored by gender, age, and readiness to quit, and solicited their responses. These messages were then reviewed for use in our system. More details of our methodology to generate peer-written messages have been previously published [17]. Peer-written messages included the more "social" and "real-life" aspects of smoking cessation and represented the day-to-day issues associated with smoking cessation and the social and interpersonal influences on quitting. Such messages align with the concepts of SCT in which the physical and social environment influences individual behavior change [17].

The Comparison: An Evidence-Based, Effective, Standard Computer-Tailored Health Communication System

As noted, our comparison standard CTHC was a rule-based system that tailored messages based on a smoker's readiness to quit. We had previously demonstrated this system to be effective in a large, nationwide RCT (N=900) compared to a robust website control without tailored messages. This website control included such functions as risk, decisional balance, cessation barrier calculators, games linking the chemicals in smoking with their other uses (eg, formaldehyde is used in both cigarettes and in embalming), and a library of informational resources about smoking [10]. In the RCT, two emails were sent in the first 2 weeks, followed by one email every week until 6 months postregistration. Using a 6-month, 7-day point prevalence cessation outcome, smokers who received the motivational messages were assessed to be more likely to quit than those smokers who received the control website (OR 1.69, 95% CI 1.03-2.80) [10]. For this study, we again used this standard CTHC and messages were sent daily to smokers.

We selected this system as our comparison for multiple reasons. Firstly, it allowed isolating the effect of the message selection because the motivational messages' content was the same for both systems. If we compared it to another system with different motivational messages content, estimating whether the differences between the two groups were due to message selection or the content of the two systems would have been challenging. Moreover, using an effective system provided a rigorous comparison for our system. At the time of the study design, there was no other online motivational messaging system with this level of effectiveness data.

The Intervention: The PERSPeCT Recommender System

The only difference between the comparison and intervention conditions was that the intervention smokers received motivational messages tailored by the PERSPeCT recommender system. Recommender systems can be implemented using either a content-based [20], collaborative filtering [21] or a hybrid approach [22]. PERSPeCT was implemented as a hybrid recommender system. Given a sample of rating data, content-based recommender systems can learn a function and match users to items based on the provided user profile information (ie, age, gender) and the metadata description of the item or message. Metadata is defined as data about data; it describes the structure or content of a particular resource, object, or entity [23]. Our coding of the messages by the readiness to quit categories in the comparison standard CTHC system is an example of the type of metadata that can be used by content-based recommender systems. Content-based recommender systems work similarly to standard CTHC systems, but the matching function can be optimized based on rating data instead of specified by experts.

In contrast to content-based recommender systems, collaborative filtering recommender systems match users to items based on past rating history. The simplest examples of this approach are nearest-neighbor methods [21]. These methods match a target user with other users that have given similar ratings to the items the users have rated in common. The set of users matched to the target user are referred to as the target user's nearest neighbors. The method then recommends items to the target user that their neighboring users have rated highly. The assumption behind these methods is that if two users are observed to have close agreement on the ratings of a sufficiently large number of items, they will likely agree closely on the ratings for the remainder of the items.

For PERSPeCT, we chose a hybrid approach because they merge the strengths of content-based and collaborative filtering recommender systems [22]. Thus, they can potentially benefit from expert-driven rules (content-based) and the recommender algorithms. We used the following data sources to develop the models for our algorithm: (1) metadata description of the messages, (2) implicit, and (3) explicit user feedback data (Figure 1). As explained previously, our coding of the messages by the readiness to quit categories is an example of metadata. In preparation for PERSPeCT, we expanded this metadata to include constructs from multiple behavioral theories, such as the SCT, the Transtheoretical Model, and the Theory of Reasoned Action [24]. We also coded the messages for content that may be pertinent to a specific user, including health and lifestyle status, health issues, and treatment options. In total, 40% (102/261) of messages had motivational content, such as reasons to quit, and 53% (139/261) of messages had information about behavioral treatments, such as substitution and distraction.

Implicit feedback data are derived from user actions (ie, website view patterns of each individual accessing the system). As our implicit feedback data, we used the website return data of 900 smokers that participated in our prior RCT [10]. When an email was sent to these smokers, we tracked their website usage in the days following the email. Thus, we had data on the frequency at which each message promoted engagement on the website and the characteristics of the smokers that received these messages.

Explicit feedback data consists of self-reported item ratings (ie, ratings provided by users for items like books or movies, often on a five-star scale). For companies such as Netflix, these are likely to be user ratings of movies. As previously published, two pilot studies were used to generate the explicit feedback

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data for PERSPeCT [16]. We first recruited 100 current or former smokers to determine appropriate questions for collecting explicit ratings. Each participant was asked to provide ratings using a five-point Likert scale of four different aspects of messages: influence, emotional response, relevance, and preference. Each participant provided ratings for five different randomly selected messages. Per-message analysis showed a positive correlation between the means and variances of the ratings for each question, suggesting that all questions provided similar information. Thus, we decided to use only one question for our data collection pilot, balancing the need to obtain multiple ratings per user and the resulting cognitive load. We chose the influence question stated in the data collection section because this single influence question had strong predictive validity in a previous RCT [25].

A second pilot test was performed to collect a larger rating dataset to bootstrap the learning and evaluation of collaborative filtering models for PERSPeCT [16]. We recruited 846 current or former smokers from online and local sources to provide perspectives on smoking, quitting, and sociocultural contextual information and ratings of the influential aspect of the 261 smoking cessation messages. Each smoker was asked to rate 20 messages, resulting in 16,920 ratings.

We tested a number of classical algorithms to identify one that provided maximal prediction accuracy (ie, we evaluated the ability of the algorithms to generalize ratings to nontraining users). These included the following algorithms: K-Nearest Neighbor (K-NN), probabilistic matrix factorization, Bayesian probabilistic matrix factorization (BPMF), collective matrix factorization, and Bayesian collective matrix factorization. We used a strong-generalization protocol that involved completely separating test users from train users, learning a model using all the train users' ratings, freezing all nonuser-specific parameters, and finally training the user-specific parameters on a subset of each test user's observed ratings. To implement this protocol, we first divided the users randomly into five folds and then generated three random train and validation sets for each test fold. We further divided each test user's ratings into five folds. To evaluate each method's performance given varying levels of information about a test user, we evaluated all methods with five, 10, and 16 of each test user's ratings available for inference and learning of user-specific parameters. Each test user has a constant set of four test ratings per test fold. The validation sets were used to set the hyperparameters of each method (eg, K in K-NN). Exhaustive grid search was used and the hyperparameter ranges were iteratively extended to ensure that no selected hyperparameter values occurred at the end-points of the search intervals.

In evaluating rating prediction methods, we used a range of standard performance metrics including root mean squared error (RMSE), Kendall tau-b, and normalized discounted cumulative gain. In all these tests, BPMF was identified as the best single model in our evaluation and was used in the development of PERSPeCT. For example, comparing the RMSE metric between the different algorithms, there was a small but statistically significant gap (P=.01) between the BPMF and other algorithms as determined by a paired t test with Bonferroni correction. The BPMF model estimates a probability distribution over a joint embedding of users and items into complementary latent spaces. The rating a given user supplies for a given item is approximated by the expected value of the product of the latent user and item factor vectors representing the user-item pair, with the expectation taken over the uncertainty in embeddings. Since the algorithm that only included explicit ratings of the 846 smokers performed as well as the model that included all the data sources, for simplicity we chose to develop the model with only this explicit rating. The algorithm was also programmed to choose only from among those messages that matched the participant's readiness to quit status. Further details regarding our algorithm selection methodology are described in previously published work [16].

Setting and Sample

Current smokers were recruited from our University hospital and affiliated output clinics using multiple methods. We posted flyers at these clinics with instructions on how to contact the study staff. We worked with a tobacco treatment specialist to identify eligible smokers and refer them to the study staff. We also used electronic medical records to identify current smokers and mailed each smoker a letter describing the study and the contact information for the study coordinator. The letter explained that study staff would call them in 2 weeks to determine their interest and to answer any questions they had about the study. Included was a self-addressed, prestamped opt-out card that individuals could send back if they did not want to be contacted.

Current smokers who were 18 years of age or older, English speaking, and had Internet access were considered eligible for the study. To confirm participation, all smokers had to complete the online registration with the study staff over the phone. Smokers received a total of US $100 in Amazon gift cards for participation (US $25 for completing registration, US $25 for rating 15 messages, US $50 for completing the final survey and rating 30 messages).

Randomization

As smokers registered online for our study, they were allocated to the two groups based on a prespecified, block-randomization allocation table (blocks of 10). Smokers were randomized to PERSPeCT or standard comparison in a 2:1 ratio (Figure 2). Unequal random allocation (favoring the intervention) increases experience with the experimental CTHC and can be desirable in early phase trials [26]. Because the standard system was proven effective and PERSPeCT was highly novel, 2:1 randomization allowed for additional subset analyses within the intervention group. Study staff was blinded to allocation during initial baseline assessment and follow-up.

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Figure 1. The Patient Experience Recommender System for Persuasive Communication Tailoring (PERSPeCT) recommender computer-tailored health communication system.

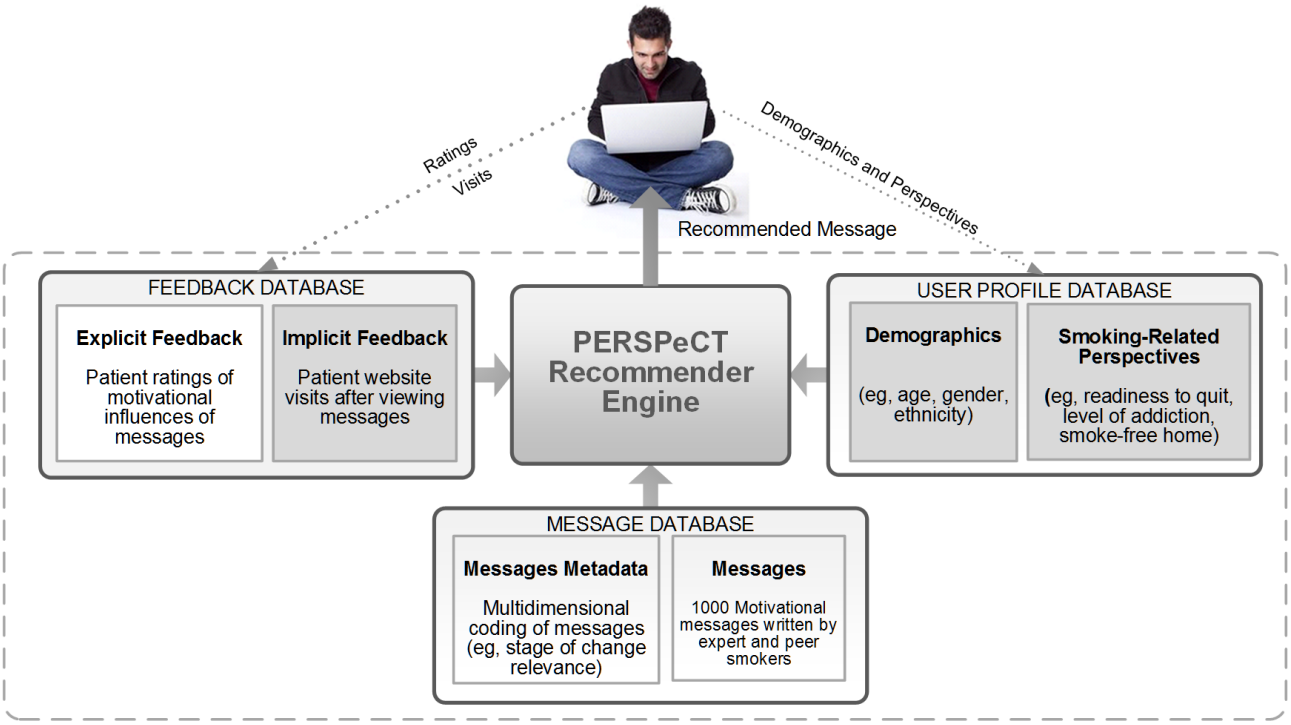
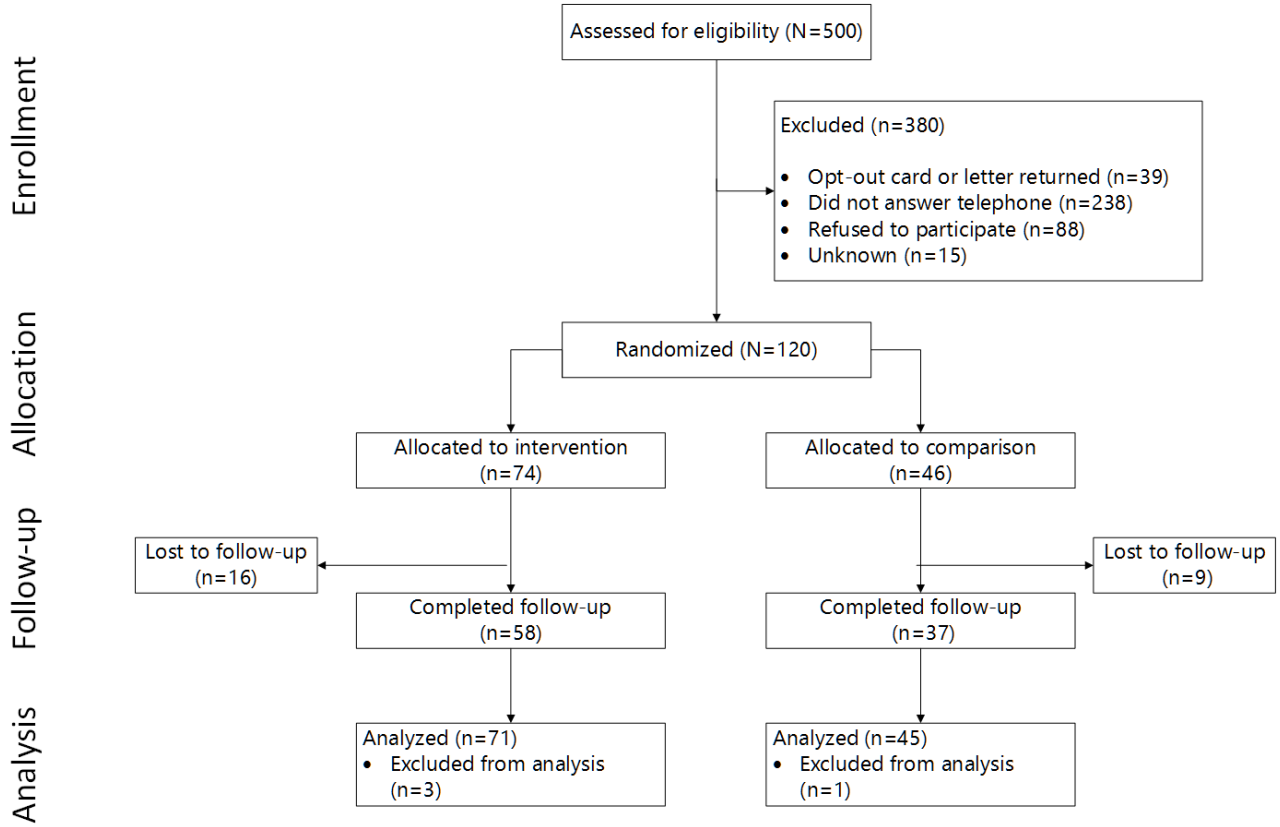


Figure 2. The Consolidated Standards of Reporting Trials (CONSORT) participant flow diagram.



Data Collection

During registration, smokers were asked questions about their demographics (age, sex, race, and ethnicity), smoking behaviors, prior quit attempts, and readiness to quit [27,28]. Internet use was assessed using the following question: "For which of the following activities do you routinely use the Internet?" Message ratings were collected daily. Smokers were asked to rate each motivational email on a five-point Likert scale by clicking on a link included with the email. These ratings were collected for

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the standard system and PERSPeCT. For PERSPeCT, the system used the ratings to further improve message recommendations; for the standard system, the ratings were used only for analyses and did not to change the intervention. We used the following question to collect the rating: "This message influences me to QUIT smoking."

At follow-up, the perceived influence of the intervention was assessed using seven questions adapted from prior measures of the influence of interventions on cessation [25]. We assessed 30-day cessation using the question: "Since starting the Quit Smoking Messaging System study have you stopped smoking for one day or longer because you were trying to quit?" Readiness to quit was assessed at baseline and the 30-day follow-up using the following options: I am not thinking of quitting, I am thinking of quitting, I have set a quit date, I quit today, and I have already quit.

Statistical Analysis

All analyses were conducted using Stata version 13 (StataCorp LP, College Station, TX, USA). As noted, our primary hypothesis was that the PERSPeCT system would select messages of higher influence than a rule-based CTHC system. We also evaluated the perceived intervention influence, and 30-day cessation. For each analysis, we included all data available. For each individual, the timing of attrition varied. Note that if patients were lost to follow-up for the final 30-day outcome measurement, they would still have had data for daily ratings.

Comparison of Message Ratings: Intervention Versus Control

For each day, we created a daily rating defined as the mean of the ratings provided by all smokers in the group that day. We then compared the daily ratings using a *t* test. To further explore the differences, we plotted a figure with the message day on the x-axis and the daily ratings on y-axis. We also compared the daily ratings stratified by the demographic characteristics.

Perceived Influence of the Intervention at 30 Days

We dichotomized the responses to each question that assessed the perceived influence of the intervention and used the chi-square statistic to test for differences. We conducted an additional sensitivity analysis of the perceived influence of the system stratified by the demographic characteristics (eg, age, gender, education, and readiness).

Cessation Influence

At 30 days, we evaluated change in smoking status compared to baseline. By randomization, we assessed change in smoking status (baseline to follow-up) using the chi-square statistic. Additionally, we assessed differences between the intervention and comparison groups of 30-day cessation using the chi-square statistic.

Results

Patient Characteristics

Smokers (N=120) were randomized to intervention (n=74) or comparison (n=46) (Figure 2). In total, 64.2% (77/120) of our sample were female, 38.3% (46/120) were aged 45 years or older, and 58.8% (70/120) were college graduate. There were no significant differences between the characteristics of intervention and comparison smokers (Table 1).

Comparison of Message Ratings

We used all users with ratings for this analysis. Most users (77.5%, 93/120) rated all 30 messages. In answer to our primary hypothesis, the proportion of days when smokers agreed/strongly agreed (daily rating ≥4) that the messages influenced them to quit was significantly higher in the intervention (73%, 23/30) than comparison (44%, 14/30, P=.02).

Fluctuation of daily ratings of intervention smokers was less than that of the comparison group (Figure 3). Group differences of daily ratings were greatest within the first 12 days of the study (intervention: mean 4.10, SD 0.03; comparison: mean 3.86, SD 0.04; P<.001). Difference in the daily ratings between intervention and comparison declined over time (intervention: mean 4.05, SD 0.03; comparison: mean 3.98, SD 0.04; P=.12).

In our stratified analysis, we found that among less educated smokers (n=49), the difference in the proportion of days when smokers agreed/strongly agreed (daily rating ≥4) that the messages influenced them to quit was even more pronounced (intervention: 77%, 23/30; comparison: 23%, 7/30; P<.001).

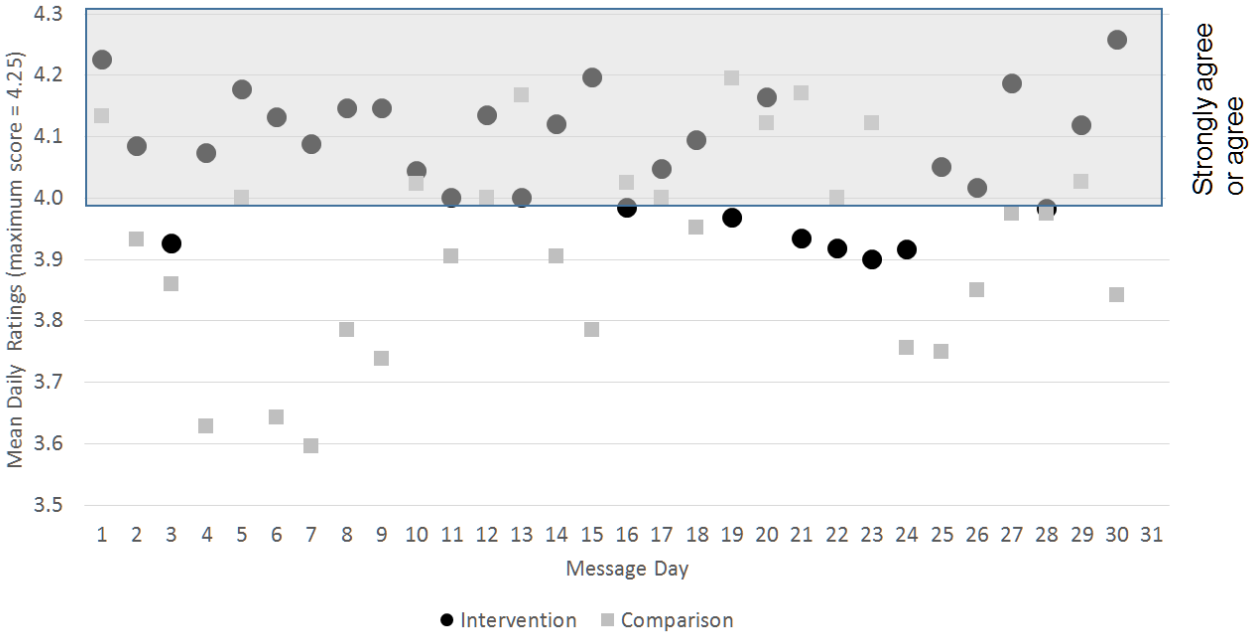
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Table 1. Demographic characteristics of participants.

Participant characteristics	Comparison, n (%) (n=46)	Intervention, n (%) (n=74)	Total, n (%) (N=120)	*P* value
Sex				.56
Male	15 (33)	28 (38)	43 (35.8)	
Female	31 (67)	46 (62)	77 (64.2)	
Age (years)				.45
19-34	11 (24)	25 (34)	36 (30.0)	
35-44	17 (37)	21 (28)	38 (31.7)	
≥45	18 (39)	28 (38)	46 (38.3)	
Education				.83
Less than high school	6 (13)	7 (10)	13 (10.9)	
High school graduate	14 (30)	22 (30)	36 (30.3)	
College graduate	26 (57)	44 (60)	70 (58.8)	
Race				.57
White	43 (94)	67 (91)	110 (91.7)	
Other	3 (7)	7 (9)	10 (8.3)	
Hispanic or Latino				.67
No	36 (78)	62 (84)	98 (81.7)	
Yes	4 (9)	6 (8)	10 (8.3)	
Don’t know/not sure	6 (13)	6 (8)	12 (10.0)	
Internet use (number of activities)				.55
No Internet use	2 (4)	2 (3)	4 (3.3)	
0-2	12 (26)	12 (16)	24 (20.0)	
2-4	6 (13)	12 (16)	18 (15.0)	
>4	26 (57)	48 (65)	74 (61.7)	
Allows smoking in home				.62
No	24 (52)	42 (57)	66 (55.0)	
Yes	22 (48)	32 (43)	54 (45.0)	
Visited a smoking cessation website				.45
No	36 (78)	62 (84)	98 (81.7)	
Yes	10 (22)	12 (16)	22 (18.3)	
Wants to stop smoking cigarettes				.52
No	9 (20)	13 (18)	22 (18.3)	
Yes	37 (80)	59 (80)	96 (80.0)	
I do not smoke now	0 (0)	2 (2)	2 (1.7)	
Stopped smoking for one day or longer to try to quit smoking				.68
No	25 (54)	43 (58)	68 (56.7)	
Yes	21 (46)	31 (42)	52 (13.3)	

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Figure 3. Mean daily ratings: intervention versus comparison.



Perceived Influence of the Intervention at 30 Days

In total, 79.2% (95/120) of the smokers completed follow-up. Those lost to follow-up were equally distributed across both groups (intervention: 22%, 16/74; comparison: 20%, 9/46). There were no significant demographic differences between those that completed follow-up and those who did not. Among the users that completed follow-up, the perceived influence of the PERSPeCT system was higher than the comparison system in several categories, but not statistically significant. These include the perceived influence on the use of nicotine replacement therapy, such as the patch or gum (*P*=.09) and quit smoking (*P*=.07) (Table 2). In the sensitivity analyses, we did not find any significant or meaningful effect modification by demographic characteristics (recognizing that power was limited for this secondary exploratory analysis).

Smoking Cessation at 30 Days

Among those who completed follow-up, 36% (20/55) of intervention smokers and 32% (11/34) of control smokers stopped smoking for one day or longer because they were trying to quit (*P*=.70). A higher proportion of intervention smokers reported that they had already quit or set a quit date (40%, 23/58 vs 30%, 11/37), but this did not meet statistical significance (Figure 4). In all, 35% (26/74) of participants in the intervention group and 30% (14/46) in the comparison group moved up the readiness-to-quit ladder (*P*=.60). The increase in the proportion of smokers who reported that they already quit in the intervention group was 15% and 11% in the comparison group.

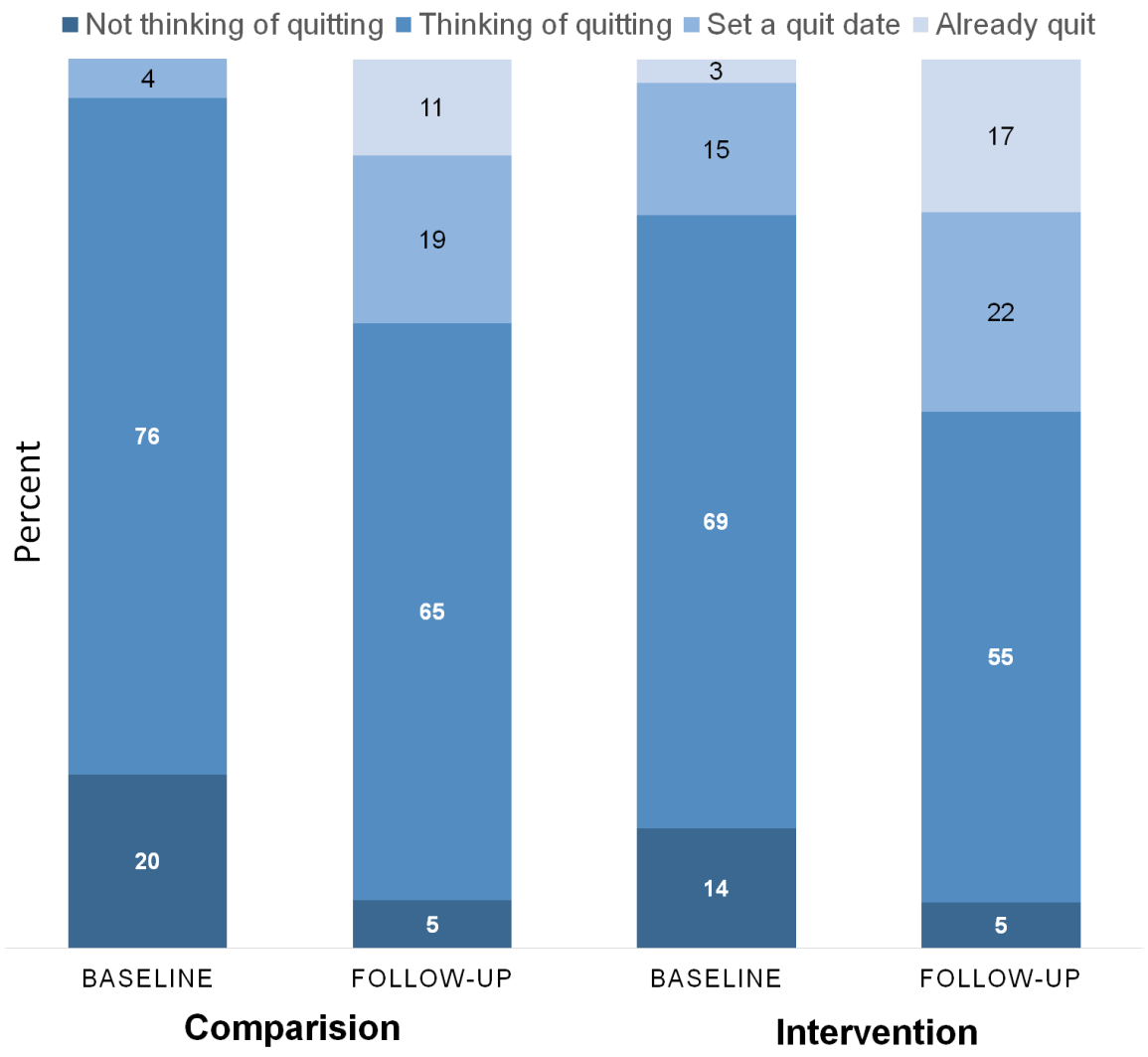
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Table 2. Influence of messages to participate in smoking cessation activities.

Perceived influence of the intervention	Comparison, n (%) (n=46)	Intervention, n (%) (n=74)	*P* value
Use nicotine replacement therapy (eg, the patch or gum)			.09
Strongly disagree/disagree/neutral	20 (54)	21 (36)	
Agree/strongly agree	17 (46)	37 (64)	
Talk to a doctor about quitting smoking			.39
Strongly disagree/disagree/neutral	16 (43)	20 (34)	
Agree/strongly agree	21 (57)	38 (65)	
Quit smoking			.07
Strongly disagree/ disagree/neutral	14 (38)	12 (21)	
Agree/strongly agree	23 (62)	46 (79)	
Make a list of reasons to quit smoking			.35
Strongly disagree/disagree/neutral	10 (27)	11 (19)	
Agree/strongly agree	27 (73)	47 (81)	
Use behavioral strategies such as distraction or substitution			.96
Strongly disagree/disagree/neutral	7 (19)	11 (19)	
Agree/strongly agree	30 (81)	47 (81)	
Get support from those around you to help quit smoking			.22
Strongly disagree/disagree/neutral	9 (24)	21 (36)	
Agree/strongly agree	28 (76)	37 (64)	
Set a quit date			.42
Strongly disagree/disagree/neutral	23 (62)	28 (48)	
Agree/strongly agree	14 (38)	30 (52)	

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Figure 4. Baseline and follow-up readiness to quit status in percentages: PERSPeCT intervention (n=74) versus standard computer-tailored health communication comparison (n=46).



Discussion

We developed a novel machine learning recommender system (PERSPeCT) directly driven by user feedback. In a small randomized experiment using the same database of motivational messages, the message selections produced by the new recommender system outperformed a robust rule-based standard CTHC system (previously demonstrated to be effective) in terms of both daily mean rating and self-reported intervention influence. At 30-day follow-up, a higher proportion of intervention smokers also reported a change in status to already quit or set a quit date, and 30-day cessation.

The ultimate goal of our CTHC intervention was to increase motivation and influence cessation. We tested this in a number of ways: (1) daily ratings of messages (hypothesis), (2) perceived influence of the intervention, and (3) cessation behavior. Comparing the daily ratings of the two systems, messages selected by the PERSPeCT system had more statistically significant days with mean ratings higher than 4 (agree or strongly agree) than the comparison system. In particular, during the initial messaging days, the daily ratings of the PERSPeCT messages were consistently higher than the ratings of the comparison system. As prior studies have demonstrated, most technology interventions suffer from high attrition rates, with the use highest in the initial days [29-34]. The ability to engage and motivate participants in the initial days is crucial to the success of an intervention. The potential ability of PERSPeCT to select messages of higher influence during the initial messaging period might be an important advantage over a standard CTHC system and this needs to be further tested.

Even in the short time span of our study (30 days) and compared with an effective rule-based CTHC, the PERSPeCT system demonstrated a greater influence on cessation behavior. Although not significant, more users in the intervention reported that they had a positive change in readiness to quit. More smokers in the intervention also reported that they had stopped smoking for one day or longer because they were trying to quit. A larger RCT is needed to test these promising results further.

Our study has some limitations. The goal of the study was to demonstrate feasibility and potential of PERSPeCT (comparing the system to a known effective system). Our comparison system

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has demonstrated effectiveness on long-term smoking outcomes, but we did not assess 6-month point prevalence cessation in this study, assessed only short-term quit outcomes. Thus, we are limited to surrogate outcomes (ratings of influence) that have been demonstrated in prior work to be associated with longer-term cessation. Our smaller sample size was driven by our primary hypothesis (differences in ratings). In this study, we only compared to one other system. Although this enhanced the internal comparison and isolated the tailoring algorithm effect, our results may not be generalizable to other systems. Before conducting a definitive trial of outcomes for a novel technology with lack of prior research, it is appropriate to conduct a smaller experiment to demonstrate effect on more proximal outcomes, justifying the larger trial. Further, our patients may not be representative of all smokers. Note that we delivered our messages only in English. In addition, many smokers who do not have Internet access would not be able to receive the motivational emails. These smokers would benefit from translation of the system into another commonly available communication format, such as texting.

In conclusion, recommender systems have not been applied to CTHC and our paper demonstrates that recommender systems can improve performance of CTHC. There are several reasons for this improved performance [11]. A primary reason is that recommender systems can learn and adapt to a participant's behavior, whereas standard CTHC adapt only to predicted changes in behavior (ie, based on identified tailoring variables and rules). In our experiment, PERSPeCT adapted to the daily ratings (ie, explicit feedback) of the smoker. Future versions can be also be developed to adapt to the implicit behavior of a smoker receiving the messages. Leaders in the field of CTHC have demonstrated that high tailoring (tailoring on many variables) is better than low tailoring (using fewer variables) [8]. Rule-based standard CTHC systems have limitation in the number of variables that can be incorporated [11], whereas sophisticated machine learning algorithms may be able to tailor use of all available user variables and tailor based on these variables. Recommender systems also augment theory-based approaches because they would identify important variables from user data and behavior. Our small experiment successfully demonstrates the potential of the PERSPeCT system and highlights the need for larger trials to assess its true impact.

Acknowledgments

Funding for these studies was received from the Patient-Centered Outcomes Research Institute (PI12-001), the National Cancer Institute grants R01 CA129091, and the National Center for Advancing Translational Sciences of the National Institutes of Health under award number UL1TR000161. Dr Sadasivam is funded by a National Cancer Institute Career Development Award (K07CA172677). Dr Marlin is also funded by a National Science Foundation CAREER award (1350522). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute on Aging or the National Institutes of Health, or the Department of Veterans Affairs or the United States government.

Authors' Contributions

RSS lead the writing of this manuscript; all authors contributed to the study design, data collection, data analysis and interpretation, and writing of this manuscript; BM and RA led the development (programming) of the system; TKH is the PI of the study.

Conflicts of Interest

Dr Sadasivam and Houston have a patent (14/055098) pending for the technology-assisted tobacco intervention. The other authors reported no conflict.

Multimedia Appendix 1

CONSORT 2010 checklist of information.

[PDF File (Adobe PDF File), 147KB - jmir_v18i11e285_app1.pdf]

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Abbreviations

BPMF: Bayesian probabilistic matrix factorization
CTHC: computer-tailored health communication
K-NN: K-Nearest Neighbor
PCORI: Patient-Centered Outcomes Research Institute
PERSPeCT: Patient Experience Recommender System for Persuasive Communication Tailoring
RCT: randomized controlled trial
RMSE: root mean squared error
SCT: Social Cognitive Theory

Edited by G Eysenbach; submitted 09.08.16; peer-reviewed by S Doan, T English; comments to author 08.09.16; revised version received 15.09.16; accepted 07.10.16; published 08.11.16.

Please cite as:
Sadasivam RS, Borglund EM, Adams R, Marlin BM, Houston TK
Impact of a Collective Intelligence Tailored Messaging System on Smoking Cessation: The Perspect Randomized Experiment
J Med Internet Res 2016;18(11):e285
URL: http://www.jmir.org/2016/11/e285/
doi:10.2196/jmir.6465
PMID:27826134

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Original Paper

mHealth or eHealth? Efficacy, Use, and Appreciation of a Web-Based Computer-Tailored Physical Activity Intervention for Dutch Adults: A Randomized Controlled Trial

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Abstract

Background: Until a few years ago, Web-based computer-tailored interventions were almost exclusively delivered via computer (eHealth). However, nowadays, interventions delivered via mobile phones (mHealth) are an interesting alternative for health promotion, as they may more easily reach people 24/7.

Objective: The first aim of this study was to compare the efficacy of an mHealth and an eHealth version of a Web-based computer-tailored physical activity intervention with a control group. The second aim was to assess potential differences in use and appreciation between the 2 versions.

Methods: We collected data among 373 Dutch adults at 5 points in time (baseline, after 1 week, after 2 weeks, after 3 weeks, and after 6 months). We recruited participants from a Dutch online research panel and randomly assigned them to 1 of 3 conditions: eHealth (n=138), mHealth (n=108), or control condition (n=127). All participants were asked to complete questionnaires at the 5 points in time. Participants in the eHealth and mHealth group received fully automated tailored feedback messages about their current level of physical activity. Furthermore, they received personal feedback aimed at increasing their amount of physical activity when needed. We used analysis of variance and linear regression analyses to examine differences between the 2 study groups and the control group with regard to efficacy, use, and appreciation.

Results: Participants receiving feedback messages (eHealth and mHealth together) were significantly more physically active after 6 months than participants in the control group (B=8.48, *df*=2, *P*=.03, Cohen d=0.27). We found a small effect size favoring the eHealth condition over the control group (B=6.13, *df*=2, *P*=.09, Cohen d=0.21). The eHealth condition had lower dropout rates (117/138, 84.8%) than the mHealth condition (81/108, 75.0%) and the control group (91/127, 71.7%). Furthermore, in terms of usability and appreciation, the eHealth condition outperformed the mHealth condition with regard to participants receiving (t_{182}=3.07, *P*=.002) and reading the feedback messages (t_{181}=2.34, *P*=.02), as well as the clarity of the messages (t_{181}=1.99, *P*=.049).

Conclusions: We tested 2 Web-based computer-tailored physical activity intervention versions (mHealth and eHealth) against a control condition with regard to efficacy, use, usability, and appreciation. The overall effect was mainly caused by the more effective eHealth intervention. The mHealth app was rated inferior to the eHealth version with regard to usability and appreciation. More research is needed to assess how both methods can complement each other.

Trial Registration: Netherlands Trial Register: NTR4503; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=4503 (Archived by WebCite at http://www.webcitation.org/6lEi1x40s)

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(J Med Internet Res 2016;18(11):e278) doi:10.2196/jmir.6171

KEYWORDS

mHealth; eHealth; Web-based intervention; computer-tailored intervention; physical activity

Introduction

Insufficient physical activity is considered to be a major public health issue worldwide [1,2]. The Dutch public health guidelines recommend adults to engage in moderate- to vigorous-intensity physical activity for at least 30 minutes on at least 5 days per week [3,4]. Studies suggest that sufficient physical activity can effectively prevent numerous chronic diseases and mental health issues [2,4-6]. Lee et al [7] argued that 6% to 10% of worldwide deaths caused by noncommunicable diseases, such as cancer, cardiovascular diseases, and diabetes, can be attributed to physical inactivity. Therefore, there is a need for interventions that increase the level of physical activity and can reach a broad population cost effectively [1].

Empirical research suggests that Web-based computer-tailored interventions are a promising solution [8]. These interventions provide tailored information and feedback via the Internet and therefore have some important advantages. First, Web-based computer-tailored interventions can adapt intervention materials according to the specific situation, characteristics, and needs of an individual and accordingly make information more personally relevant for the individual [9-11]. Second, research has shown that tailored messages are more likely to be read, understood, discussed with others, and remembered by the receiver [12-14]. Third, due to the fact that more and more people are using the Internet to search for health-related information and health advice [15-17], Web-based computer-tailored health interventions offer an effective method to reach a broad population cost effectively [18-22]. Fourth, even though a broad population is targeted simultaneously, each individual can make use of the intervention privately at any given point in time or place [18,23].

Until a few years ago, Web-based computer-tailored interventions were almost exclusively delivered via computer. This medium of delivery has formed the term eHealth (electronic Health). The concept of eHealth has been described as the use of the Internet and related technologies to deliver health-related information and interventions [23]. Even though eHealth has been shown to be an efficient strategy to lower costs and deliver health messages more interactively, it also has several disadvantages. One of the major problems with eHealth interventions is the high percentage of dropout [24,25].

To make interventions even more accessible, and thereby decrease chances of dropout, health promotion professionals are increasingly interested in the use of mHealth (mobile Health). mHealth refers to the delivery of health messages and interventions via mobile phones or tablets by making use of telecommunication and multimedia technologies [26-31]. In the Netherlands, almost 70% of Dutch households use the Internet via mobile phones and approximately 45% use tablets [32]. Based on the increasing usage of mobile phones as a lifestyle device, it has been argued that mHealth might increase the use of interventions and thereby also their efficacy [28,29]. Whereas computers and laptops are relatively stationary, mobile phones and tablets can be carried and used everywhere [33]. People are able to use mHealth independent of time or space, which could improve the usage and evaluation of interventions compared with eHealth [28,31,33].

Most people already use their phones for a variety of personal and work-related matters, such as social networking, calendaring, financial tracking, or emailing [33]. This leads to the assumption that the inclusion of health-related information would be advisable. However, previous research shows some pitfalls of mHealth. First, mobile phone technology is a rapidly changing field that introduces new apps, communication possibilities, and additional gadgets nearly by the day. This makes it difficult for intervention developers to keep up with the newest technologies and interests of their users [34,35]. Second, although using text messaging can be a very effective way of communicating, some intervention messages might be too long or difficult to be presented in such a short manner. This restricted communication can lead to more misunderstandings between the participant and health professional, which in turn can influence the effectiveness of the intervention [36]. And third, both participants and health professionals claim to feel unsure about the safety of private and sensitive information. Although this concern can also arise in the eHealth sector, the inferior but rapidly growing mHealth sector evokes skepticism on both sides [37].

To examine whether mHealth can improve the use and efficacy and reduce dropout rates of Web-based computer-tailored interventions, this study examined the effects of an mHealth and eHealth intervention on physical activity compared with a control group. Both interventions were identical with regard to content but differed in the medium of delivery. The main aim of the study was to examine the efficacy of the 2 versions on physical activity and to compare them with a control group. A secondary aim was to study potential differences in dropout and appreciation of the mHealth and eHealth intervention.

Methods

Study Design

The study was a 3-armed randomized controlled trial consisting of a no-treatment control group and 2 experimental conditions (eHealth and mHealth). We recruited participants from a Dutch online research panel and randomly assigned them to 1 of 3 conditions (eHealth, mHealth, or control). Participants were excluded from the study in case of (1) physical conditions hindering engagement in physical activity, (2) pregnancy at the time of recruitment, (3) having a holiday scheduled for more than 5 working days during the study period, and (4) participation in another intervention during the study period.

The baseline measurement took place in April 2014 and the follow-up measurement took place 6 months after baseline (in

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October 2014). All participants (control, eHealth, and mHealth) were informed about the study by email and asked to complete online questionnaires at 5 points in time: at baseline (T0), 7 days after baseline (T1), 7 days after T1 (T2), 7 days after T2 (T3), and 6 months after baseline (T4: follow-up questionnaire). When a questionnaire had not been completed within 7 days after the invitation email, a reminder was sent. The reminder was sent to prevent dropout and stimulate participants to continue with the intervention. It was not possible for participants to skip sessions, and the next session could only be accessed when the previous one was completed. So when participants received a reminder and accessed the intervention, they continued with the session that followed their last completed session; for example, after session 3, participants could not continue with session 5 until they had completed session 4. Participants received 2 bonus points amounting to €2.50 as an incentive for completing the intervention (the first bonus point after T3, the second one after T4). The 2 intervention groups (eHealth and mHealth) received, additionally to the questionnaires, feedback messages and advice based on their answers to the questionnaires at T0, T1, and T2. Participants allocated to the control condition were also asked to complete all questionnaires but did not receive any feedback or information.

Power Calculation

To determine the sample size, we conducted a power analysis using G*Power (version 3.1; Heinrich-Heine University Dusseldorf, Germany) [38,39] taking into account an effect size of 0.20, a power of 0.80, and an alpha of 5%. Based on this calculation, a minimum total sample size of 423 (141 participants per condition) was required.

Intervention

Both the eHealth and the mHealth versions of the intervention were developed using the TailorBuilder software (OverNite Software Europe, Geleen, the Netherlands). Both interventions had exactly the same content. The mHealth intervention was specifically developed for use with a mobile phone, while the eHealth version was developed for use with a computer. Therefore, the intervention within the eHealth condition was delivered via email, whereas in the mHealth condition advice was delivered via short text messages (short message service; SMS). Questionnaires for both groups were sent via email; however, participants allocated to the mHealth group were requested to complete this questionnaire via their mobile phone. Participants in the control condition received an email to inform and remind them that they could assess a questionnaire.

Before starting, participants were clearly instructed that they should use the intervention only via the medium that belonged to their study condition. Participants in the eHealth condition were asked to use the intervention only via the computer and participants in the mHealth version were asked to use the intervention only via their mobile phone or tablet.

We assessed this adherence (use of the intervention) by means of a question in the follow-up questionnaire that asked participants which medium they had used for the intervention. It should be noted that this adherence is correspondingly based on self-reports. It unfortunately was not possible to use the logs of the intervention to assess the medium of use. Hence, we cannot 100% guarantee that the self-reported answers are actually in line with the medium of use. The visual format of the feedback messages was the same in the eHealth and mHealth interventions. In both interventions the feedback messages were merely provided by means of text, without any additional visual content.

The intervention (named *SmartMobiel*) was specifically focused on physical activity as a healthy lifestyle behavior. It was built on an existing eHealth intervention [10] and framed by the I-Change model [40,41] and the health action process approach [42,43]. The main goal of *SmartMobiel* was to stimulate participants' awareness, ability factors (ie, action plans and goal action), and self-efficacy (see Table 1) to engage in more physical activity. The intervention consisted of 5 successive rounds.

Table 1. Theoretical methods, practical strategies, and intervention components of the physical activity intervention *SmartMobiel*.

Determinant	Theoretical method	Practical application	Intervention components
Awareness	Consciousness raising and feedback on performance	Compare baseline physical activity level with physical activity recommendation and current physical activity level	Feedback on participants' physical activity pattern and sedentary behavior compared with physical activity guideline and additional information on their progress on a weekly basis
Ability factors	Action planning (active learning)	Encourage to formulate action plans	Example of action plan to help formulate appropriate action plans (what, when, where, with whom)
	Preparatory planning (active learning)	Invite to formulate preparatory plans	Suggestion to organize social support (eg, to find a buddy, inform people in the social environment, ask for support, choose a start date)
	Coping planning (active learning)	Encourage to formulate coping plans	Example of coping plan to help formulate appropriate coping plans (if-then)
Self-efficacy	Reinforcement	Compare baseline level in planning, enactment of plans, satisfaction with physical activity, and increased physical activity with current level	Feedback included compliments if planning, etc, were improved; if not successfully improved, feedback included questions stimulating self-reflection

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Round 1 Feedback: Messages 1-3

The intervention started with a baseline questionnaire (T0) consisting of 38 items concerning demographics, physical activity, sedentary behavior, and psychosocial factors (action planning, intention, satisfaction, and self-efficacy). All measurements were used as input for the tailored feedback messages, which were sent 2 days apart. The main aim of this first round was to inform participants how to successfully plan behavior change regarding physical activity. Based on the baseline questionnaire, participants received 3 feedback messages. The first message provided feedback about participants' physical activity level. Depending on their reported physical activity level at baseline, the message indicated how their behavior compared with the standards and how they could improve their physical activity level. The second feedback message addressed participants' intention to engage in physical activity. Finally, the last feedback message of step 1 was focused on planning precisely when, where, and in what type of physical activity participants planned to engage in the following week.

Round 2 Feedback: Messages 4-6

Respondents received the second questionnaire (T1) 1 week after baseline, which consisted of questions on physical activity and sedentary behavior (ie, the same questions as in the baseline measurement), intention, and self-efficacy. The main aim of this round was to give participants an overview of their physical activity level and ideas about how to overcome difficulties regarding their behavior change. In this round, 3 tailored feedback messages were sent (message 4, 5, and 6). The fourth feedback message compared participants' physical activity level with their baseline physical activity level. After 2 days, respondents received the fifth feedback message, which focused on their sedentary behavior and indicated how many hours they sat per week and how they could decrease the time spent sitting. Respondents received a sixth feedback message focusing on self-efficacy with regard to overcoming situations in which it was difficult to be physically active, 5 days after the first follow-up questionnaire had been filled in.

Round 3 Feedback: Messages 7-9

During the third round, participants filled in the second follow-up questionnaire (T2). It assessed items regarding physical activity, sedentary behavior, satisfaction, plan enactment, intention, and self-efficacy. The main aim of this round was to encourage participants to act on their plans. Participants received a motivating feedback SMS or email 1 day after the second follow-up questionnaire. After 2 days, respondents received the eighth feedback message, which focused on participants' habits and goal enactment. Respondents received a last feedback message about their physical activity progress during the intervention, 5 days after the second follow-up questionnaire had been filled in.

Round 4 Follow-Up Measurement and Progress Evaluation

The posttest served as a short-term follow-up measurement (T3). This measurement contained 41 items measuring physical activity, sedentary behavior, plan enactment, planning, intention, and self-efficacy. Additionally, we invited both experimental groups to fill in an evaluation questionnaire, consisting of 10 items, which focused on their appreciation of the content of the intervention.

Round 5 Final Follow-Up Measurements

This final 6-month follow-up questionnaire contained 35 items and assessed the effects of the intervention on physical activity, sedentary behavior, plan enactment, planning, intention, and self-efficacy.

Measurements

Demographics

At baseline (T0), respondents were asked to indicate their age, sex (1=male; 2=female), marital status (0=no relationship: unmarried without relationship, divorced without new relationship, widowed without new relationship; 1=relationship: married, unmarried in relationship, divorced in new relationship, widowed in new relationship), educational level (1=primary or basic vocational school; 2=secondary vocational school or high school; 3=high vocational school or university), work status (1=student; 2=job: employed, self-employed; 3=no job: unemployed, nonworking, retired), and height (in meters) and weight (in kilograms) to calculate the body mass index (BMI).

Outcome Variable

We measured physical activity both at baseline (T0) and at follow-up (T4) with the International Physical Activity Questionnaire (IPAQ) [44-46]. The IPAQ consists of 6 items with a reference period of the past 7 days; participants were asked to indicate how many days per week they had engaged in, respectively, low, moderate, and vigorous physical activity. Additionally, they were asked for how many minutes they usually engaged in these activities on those days. In order to acquire an accurate measure of total physical activity per day, we multiplied the frequency and average duration of vigorous, moderate, and low physical activity and then divided the result by 7.

Sociocognitive Variables

We measured all sociocognitive variables (ie, intention, self-efficacy, and action planning) at baseline (T0) and follow-up (T4) using adapted measures from previous studies [47-49] and a 5-point Likert answering scale (1= low to 5= high). Assessment of these variables served as the basis for the feedback messages, as well as correction for potential confounders within the effect analyses. For each variable, we calculated a mean score.

Intention to engage in physical activity was assessed with 4 items (Cronbach alpha=.72). Participants were asked to indicate to what extent they intended to be physically active during the following week; for example, "I intend to be regularly physically active the upcoming week." The subsequent questions concerned their intention to perform vigorous activities or moderate activities, and finally their intention to walk regularly.

Self-efficacy was measured by means of 6 items (Cronbach alpha=.86). Participants were asked to indicate to what extent they thought they were able to engage in physical activity when

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encountering difficult situations; for example, "I am going to be physically active next week even though I am stressed."

Planning was measured by means of 4 items (Cronbach alpha=.89). Plans were related to the participants' actual planned physical activity; that is, which type of activity, where to be performed, on which days, and for how long. The item stem "I have made a detailed plan regarding..." was followed by the items (1) "which type of physical activity," (2) "where to exercise," (3) "on which days to exercise," and (4) "for how long to exercise."

Action planning was assessed by 8 items (Cronbach alpha=.85) measuring whether participants planned to execute each of the 8 predefined plans. Action planning included plans that are likely to facilitate physical activity, such as "During the next week, I will buy the necessary equipment to be physically active."

Plan enactment (T3) was assessed using 8 items (Cronbach alpha=.88) asking participants to indicate the extent to which they actually had executed the 8 actions plans on a 5-point scale. Plan enactment was directly related to the action planning items; for example, "During the last week, I have bought the necessary equipment to be physically active."

Intervention Completion

We measured intervention completion using log file data in order to assess whether participants had completed the separate questionnaires. These scores were summed in order to calculate a total score for intervention use ranging from 0 completed rounds per questionnaire to a maximum of 4 completed rounds per questionnaire.

Process Evaluation

At T3, we asked both experimental groups to complete a process evaluation questionnaire. This questionnaire consisted of 10 items that assessed their appreciation of the intervention. One item measured the overall grade of the *SmartMobiel* intervention by asking respondents to give an overall score from 1 (very bad) to 10 (very good). Additionally, we assessed the appreciation of the feedback messages by means of 5 items (1=disagree; 5=agree) to investigate whether the feedback messages were (1) "convincing," (2) "interesting," (3) "informative," (4) "clear," and (5) "helpful." Furthermore, we included 1 item using a 5-point scale (1=not appealing at all; 5=very appealing) to measure participants' appreciation of the intervention design.

Statistical Analyses

All statistical analyses were performed using IBM SPSS Statistics version 20 (IBM Corporation). We used multiple imputation with 25 iterations to replace missing values on sociocognitive and outcome variables at T0. Additionally, we replaced missing values on BMI and physical activity at T4.

Descriptive statistics and frequencies described the characteristics of the study population. We analyzed differences at baseline using analyses of variance (ANOVAs) with Tukey post hoc tests for continuous variables and chi-square tests with Bonferroni correction for categorical variables.

We analyzed attrition using logistic regression, with attrition at follow-up (T4) as the outcome variable (0=not completed; 1=completed whole intervention), and intervention condition and all baseline variables (ie, age, sex, educational level, BMI, baseline physical activity, and baseline sedentary behavior) as predictors. Process evaluation was analyzed using ANOVA with Tukey post hoc tests to assess the differences between the experimental conditions with regard to usability and appreciation.

Effect analyses were performed using linear regression analyses with the ENTER method. Analyses examined 3 independent effects: (1) intervention (eHealth and mHealth) versus control condition, (2) eHealth versus control condition, and (3) mHealth versus control condition. To analyze the last 2 effects, we recoded the study condition variable into 2 different dummies. We compared each intervention group only with the control group to examine their independent efficacy. All effect analyses were corrected for potential confounders (ie, baseline behavior, baseline differences, and predictors of attrition). We calculated Cohen *d* to assess the size of the possible effects.

Ethical Approval

The study was approved by the Ethical Committee Psychology of the Faculty of Psychology and Neuroscience at Maastricht University, the Netherlands (ECP-138 08_03_2014) and registered at the Netherlands Trial Register (NTR4503).

Results

Sample Characteristics

Table 2 shows the characteristics of the total sample and the baseline differences between the 3 study conditions in terms of demographics, total minutes of physical activity per day, and minutes of moderate to vigorous physical activity. Comparison of baseline variables between groups showed no statistically significant differences.

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Table 2. Characteristics of the study sample and differences between the study conditions at baseline.

Baseline characteristics	Overall sample (N=373)	eHealth (n=138)	mHealth (n=108)	Control (n=127)	*F* value	*df*	*P* value
Sex (female), n (%)	258 (69.2)	98 (71.0)	77 (71.3)	83 (65.4)	0.74	2	.48
Educational level, n (%)					0.36	2	.70
Low	23 (6.2)	8 (5.8)	4 (3.7)	11 (8.7)			
Medium	121 (32.4)	48 (34.8)	42 (38.9)	31 (24.4)			
High	224 (60.1)	81 (58.7)	58 (53.7)	85 (66.9)			
Age in years, mean (SE)	38.69 (11.99)	39.32 (12.10)	38.03 (12.23)	38.55 (11.74)	0.36		.70
Self-efficacy, mean (SD)	3.40 (0.77)	3.35 (0.76)	3.47 (0.78)	3.39 (0.77)	0.73	2	.48
Intention, mean (SD)	3.70 (0.61)	3.72 (0.54)	3.70 (0.65)	3.68 (0.65)	0.10	2	.90
Physical activity level (low, moderate, and high), mean (SD)	54.12 (35.07)	52.72 (36.28)	55.29 (35.20)	54.69 (34.00)	0.18	2	.83

Table 3. Attrition analysis.

Baseline characteristics	Odds ratio	*df*	*P* value	95% CI
Condition (eHealth, mHealth, control)[a]				
Condition (eHealth)	2.43	1	.007	1.27–4.62
Condition (mHealth)	1.29	1	.44	0.68–2.46
Sex (female, male)	2.16	1	.02	1.12–4.14
Educational level (low, middle, high)[b]				
Educational level (low)	1.40	1	.54	0.47–4.14
Educational level (middle)	1.57	1	.15	0.84–2.92
Age	0.97	1	.009	0.94–0.99
Body mass index	0.98	1	.67	0.91–1.07
Self-efficacy	0.88	1	.53	0.59–1.31
Intention	1.24	1	.40	0.75–2.05
Physical activity (low, moderate, and high)	0.98	1	.18	0.99–1.00
Physical activity (moderate and high)	0.99	1	.049	0.97–1.001

[a]Reference category was the control group.

[b]Reference group was high educational level.

Attrition Analysis

Figure 1 shows the flow of respondents for the overall sample and separately for the 3 study conditions (see Multimedia Appendix 1 [50] for the CONSORT eHealth checklist). Analysis showed that the overall participation rate at follow-up (T4) was 77.5% (289/373). When comparing dropout rates between the 3 conditions, the highest dropout rate was in the control group, in which 71.7% (91/127) of the participants at baseline completed the last follow-up questionnaire. The lowest dropout rate was in the eHealth condition, with a participation rate of 84.8% (117/138).

Attrition analysis (Table 3) showed that respondents were more likely to complete the follow-up assessment when they were in the eHealth condition (compared with the control condition; odds ratio [OR] 2.43, *P*=.007), they were female (OR 2.16, *P*=.02), they were younger (OR 0.97, *P*=.009), and they had lower levels of daily moderate to vigorous physical activity (OR 0.99, *P*=.049). We included the significant predictors of dropout in all further analyses as potential confounders.

Process Analysis

Results of the process analysis indicate that participants in the eHealth condition evaluated the intervention significantly better than did respondents in the mHealth condition for 3 items: receiving messages, reading messages, and the general clarity of the messages (see Table 4). For the other items, we found no significant differences between the 2 groups.

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Figure 1. Flowchart of the participation of respondents.

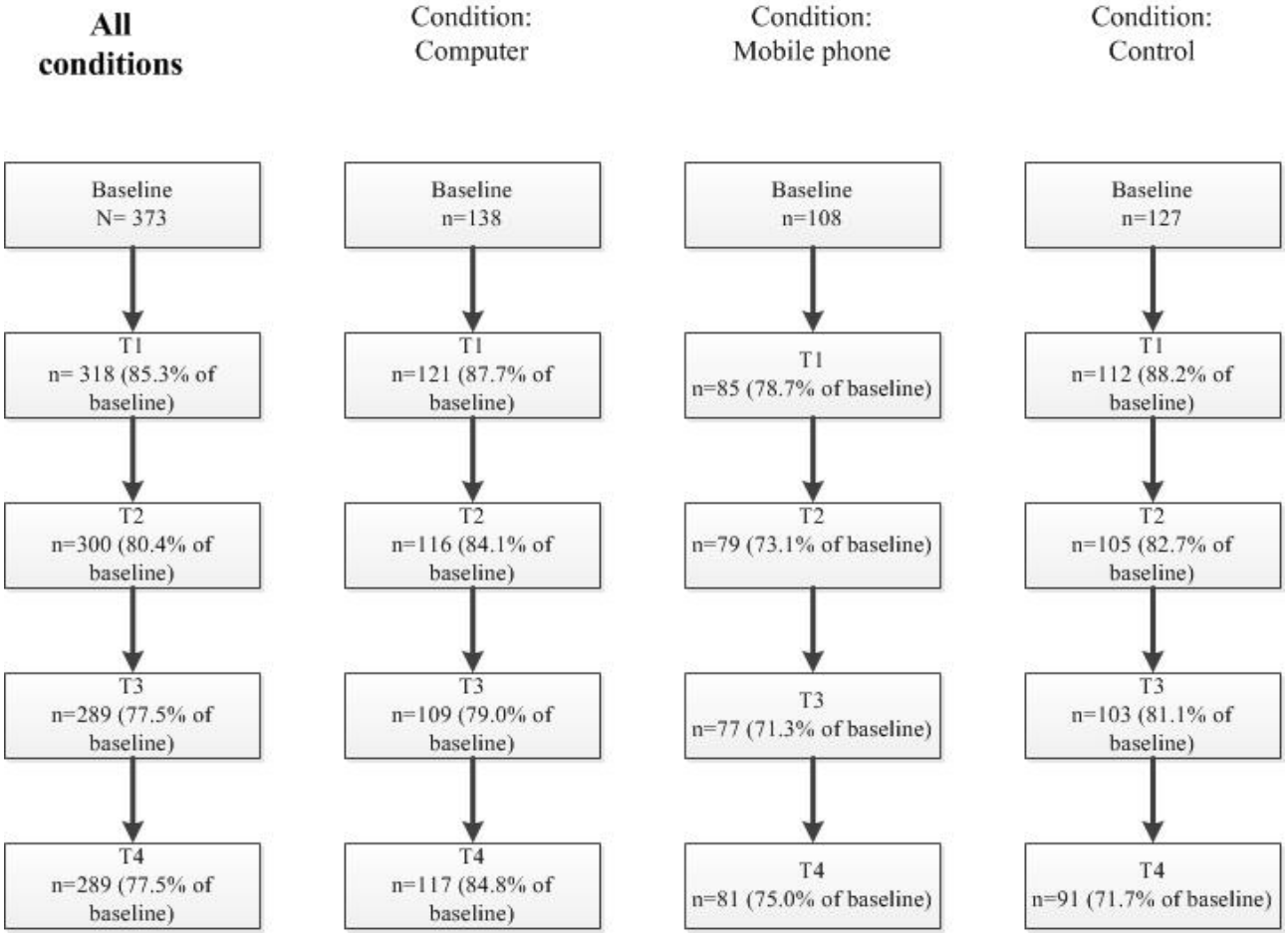


Table 4. Descriptive statistics of the process evaluation.

Variable	Overall sample (n=184) mean (SD)	eHealth (n=109) mean (SD)	mHealth (n=75) mean (SD)	*t* value	*df*	*P* value
Grade given for the whole intervention (range 1–10)	6.35 (1.63)	6.36 (1.60)	6.33 (1.68)	0.10	182	.92
Did you receive the 9 feedback messages?	4.52 (0.84)	4.67 (0.58)	4.29 (1.08)	3.07	182	.002
Did you read the 9 feedback messages you received?	4.60 (0.85)	4.72 (0.59)	4.43 (1.11)	2.34	181	.02
Were the feedback messages believable?	3.43 (0.87)	3.51 (0.83)	3.32 (0.92)	1.46	181	.15
Were the feedback messages interesting?	2.97 (1.05)	2.94 (1.09)	3.01 (0.99)	–0.44	181	.66
Were the feedback messages informative?	3.11 (1.03)	3.02 (1.08)	3.24 (0.96)	–1.43	181	.15
Were the feedback messages clear?	3.90 (0.74)	3.99 (0.74)	3.77 (0.71)	1.99	181	.049
Did the feedback messages help you to be physically active?	2.52 (1.06)	2.48 (1.07)	2.59 (1.05)	–0.66	181	.51
How attractive was the layout of the intervention for you?	3.02 (0.93)	2.99 (0.96)	3.05 (0.88)	–0.45	181	.66

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Table 5. Intervention effects on the total physical activity at follow-up as assessed by linear regression analyses (multiple imputation).

Intervention[a,b]	B[c]	SE	*df*	*P* value	95% CI
eHealth (1) versus control (0)	6.13	3.61	2	.09	–0.98 to 13.23
mHealth (1) versus control (0)	1.92	4.00	2	.63	–5.95 to 9.79
Intervention (1) versus control (0)	8.48	3.77	2	.03	1.06 to 15.90

[a]In the linear regression analyses the following covariates were included: baseline behavior, sex, age, and baseline moderate and vigorous physical activity.

[b]Outcome variable is average daily physical activity (light, moderate, and vigorous).

[c]B: unstandardized regression coefficient.

Effect Analysis

Regression analyses showed statistically significant differences between the intervention conditions and the control group for the total amount of physical activity (see Table 5). After 6 months, participants who used the intervention (ie, mHealth and eHealth together) were significantly more physically active than were participants in the control group (intervention groups: mean 56.35 minutes/day; control group: mean 47.79 minutes/day; B=8.48, *df*=2, *P*=.03, Cohen *d*=0.27). We found a small effect that was borderline significant for the difference between the eHealth group and control condition (eHealth: mean 57.91 minutes/day; control group: mean 47.79 minutes/day; B=6.13, *df*=2, *P*=.09, Cohen *d*=0.21) with regard to total physical activity. We found no effect between the mHealth group and the control group (mHealth: mean 54.78 minutes/day; control group: mean 47.79 minutes/day; B=1.92, *df*=2; *P*=.63, Cohen *d*=0.04) with regard to total physical activity. Secondary analyses with complete cases revealed similar results.

Discussion

Principal Findings

The aim of this study was to evaluate the efficacy, use, usability, and appreciation of 2 different versions (eHealth vs mHealth) of a Web-based computer-tailored physical activity intervention. Contradicting our hypothesis, the eHealth intervention resulted in better usability and appreciation than did the mHealth intervention. Further, we found no significant differences in use and effects between the mHealth and eHealth versions when compared with a control group. These findings imply that mHealth is not necessarily more suitable than eHealth interventions and even suggest that eHealth should still be preferred.

The effect analyses revealed a significant difference in physical activity when comparing the eHealth and mHealth versions against the control condition. Yet we found no differences in effect between the eHealth and mHealth versions. The effect size for the eHealth version suggests a small effect, but the significance level was only borderline significant due to the small sample size. Recent studies also suggested that the use of mobile phone-based interventions may have positive effects on physical activity and weight loss but did not compare the efficacy of mHealth versus that of eHealth [31,47,48]. In line with our findings, it has been suggested that mHealth may be less suitable to achieve behavior change, since participants in an mHealth condition can use the intervention wherever they are at any given time [49]. One explanation may be that mHealth participants may be more prone to distractions than eHealth users. eHealth users may be more committed to take the time to complete their tasks, whereas mHealth users may have been in distracting surroundings and situations such as supermarkets or public transport, which may lead to skipping or misreading messages. However, this explanation needs more research to demonstrate its applicability. The explanation is in line with the assumption of the elaboration likelihood model of Petty and Cacioppo [51]. The model explains that distraction can result in peripheral route processing rather than in more central processing, which is associated with more (enduring) behavior change [51,52].

The higher dropout rate in the mHealth condition can possibly also be explained by the fact that people are more easily distracted when using their mobile phone. A recent study showed that people tend to use their mobile phones during short waiting times (eg, waiting for the bus, waiting in line at a checkout) [53]. This means, on the one hand, that they use the device frequently; on the other hand, it implies that its use can be short and with many interruptions. Previous studies demonstrated that mobile phone use can distract people from other activities such as driving a car [54,55]. However, ongoing activities and the surroundings might also distract the person from the task he or she is doing on the mobile phone. Distraction might lead to worse performance, as well as to forgetting or neglecting the task completely [54,55]. Furthermore, the possibility of distraction might also explain the finding that the eHealth group evaluated the intervention significantly better than did the mHealth group regarding receiving and reading feedback messages, as well as the clarity of the feedback messages. Elaboration likelihood model research has shown that when information is processed via the peripheral route it is less appreciated by the receiver [56,57]. Furthermore, peripheral route processing can lead to lower motivation to engage with the context of the intervention, which would lead to the lower levels of appreciation [57].

Another explanation could be that, while using a mobile phone is often spontaneous and a direct action that is driven by technology, the use of eHealth might be much more user driven. This means that, whereas participants in the mHealth group might have felt obligated to check their message the moment they received it, regardless of time, place, and concentration, eHealth participants consciously chose to start their computer to check their emails. This feeling of autonomously choosing when to engage in the intervention can lead to more intrinsic

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motivation and appreciation of the intervention [58]. A different explanation for the low usability and appreciation could be the difference in the technology itself. The intervention was message based, which might have led to more misunderstanding of the feedback messages within the mHealth group than within the eHealth group [37].

Strengths and Limitations

An important strength is that, to our knowledge, this is the first study that compared an eHealth intervention with an mHealth intervention with regard to efficacy, use, and appreciation.

The first limitation is that all outcome measures were self-reported [59]. Research has shown that self-reported measures, in comparison with objective measures, have both a lower reliability and less validity. However, the IPAQ has been proven to be a reliable and valid measurement of physical activity [46]. Yet replication with other, more objective assessments for measuring physical activity, such as accelerometers, is recommended.

The second limitation is that it was necessary to replace missing values with multiple imputations. Although multiple imputations are often used, there is discussion about how to correctly apply this technique [60]. However, we found the same results regardless of whether we performed the analyses with the multiple imputation or with the completers-only dataset.

The third limitation is that our process analyses were not accompanied by qualitative measurements. For example, by asking participants why they found messages less clear, we could have gained insight into whether the difference between groups was based on technical difficulties only or could be attributed to the other factors.

The fourth limitation is that, because the tested intervention was message based, the results are difficult to generalize to the broader field of mHealth and eHealth.

The fifth limitation is that participants were all recruited from an online panel and were a random sample from the panel. This might make it difficult to generalize the findings from participants who are used to participating in scientific research to the broader population.

Lastly, as pointed out above as well, our sample size was limited. Each condition had approximately 100 participants, and power analyses revealed that we needed at least 141 participants per group to detect standardized effects of 0.20. As the results showed that effect sizes were indeed roughly 0.20, replication of this study with a larger sample is recommended to be able to demonstrate more statistically significant results.

Conclusion

Based on our results, we can conclude that the eHealth version outperformed the mHealth version of a Web-based computer-tailored physical activity intervention with regard to usability and appreciation, but not with regard to effectiveness.

The eHealth intervention excelled with regard to usability and appreciation compared with the mHealth intervention, and there are indications that the eHealth intervention may have been used more often. However, a study by Morrison et al [61] showed the advantages of combining mHealth and eHealth. They reported that, although their mHealth version did not function as an alternative to eHealth, it enhanced the intervention with regard to perceived accessibility, mobility, and on-the-go gadgets.

We recommend performing more research to assess and develop interventions that combine mHealth and eHealth technologies.

Acknowledgments

The authors thank Sander Matthijs Eggers for his valuable comments and his statistical feedback during the writing of the manuscript. The contents of this publication are solely the responsibility of the author and do not necessarily represent the views of any institution or funding agency.

Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.1.

[PDF File (Adobe PDF File), 1005KB - jmir_v18i11e278_app1.pdf]

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Abbreviations

ANOVA: analysis of variance
BMI: body mass index
IPAQ: International Physical Activity Questionnaire
OR: odds ratio
SMS: short message service

Edited by G Eysenbach; submitted 08.06.16; peer-reviewed by L Morrison, I Montagni; comments to author 10.08.16; revised version received 22.08.16; accepted 22.08.16; published 09.11.16.

Please cite as:
Gomez Quiñonez S, Walthouwer MJL, Schulz DN, de Vries H
mHealth or eHealth? Efficacy, Use, and Appreciation of a Web-Based Computer-Tailored Physical Activity Intervention for Dutch Adults: A Randomized Controlled Trial
J Med Internet Res 2016;18(11):e278
URL: http://www.jmir.org/2016/11/e278/
doi:10.2196/jmir.6171
PMID:27829576

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Original Paper

Infusing Technology Into Perinatal Home Visitation in the United States for Women Experiencing Intimate Partner Violence: Exploring the Interpretive Flexibility of an mHealth Intervention

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Abstract

Background: Intimate partner violence (IPV) is common during pregnancy and the postpartum. Perinatal home visitation provides favorable conditions in which to identify and support women affected by IPV. However, the use of mHealth for delivering IPV interventions in perinatal home visiting has not been explored.

Objective: Our objective was to conduct a nested qualitative interpretive study to explore perinatal home visitors' and women's perceptions and experiences of the Domestic Violence Enhanced Home Visitation Program (DOVE) using mHealth technology (ie, a computer tablet) or a home visitor-administered, paper-based method.

Methods: We used purposive sampling, using maximum variation, to select women enrolled in a US-based randomized controlled trial of the DOVE intervention for semistructured interviews. Selection criteria were discussed with the trial research team and 32 women were invited to participate. We invited 45 home visitors at the 8 study sites to participate in an interview, along with the 2 DOVE program designers. Nonparticipant observations of home visits with trial participants who chose not to participate in semistructured interviews were undertaken.

Results: We conducted 51 interviews with 26 women, 23 home visiting staff at rural and urban sites, and the 2 DOVE program designers. We conducted 4 nonparticipant observations. Among 18 IPV-positive women, 7 used the computer tablet and 11 used the home visitor method. Among 8 IPV-negative women, 7 used the home visitor method. The computer tablet was viewed as a safe and confidential way for abused women to disclose their experiences without fear of being judged. The meanings that the DOVE technology held for home visitors and women led to its construction as either an impersonal artifact that was an impediment to discussion of IPV or a conduit through which interpersonal connection could be deepened, thereby facilitating discussion about IPV. Women's and home visitors' comfort with either method of screening was positively influenced by factors such as having established trust and rapport, as well as good interpersonal communication. The technology helped reduce the anticipated stigma associated with disclosing abuse. The didactic intervention video was a limiting feature, as the content could not be tailored to accommodate the fluidity of women's circumstances.

Conclusions: Users and developers of technology-based IPV interventions need to consider the context in which they are being embedded and the importance of the patient-provider relationship in promoting behavior change in order to realize the full benefits. An mHealth approach can and should be used as a tool for initiating discussion about IPV, assisting women in enhancing their

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safety and exploring help-seeking options. However, training for home visitors is required to ensure that a computer tablet is used to complement and enhance the therapeutic relationship.

ClinicalTrial: Clinicaltrials.gov NCT01688427; https://clinicaltrials.gov/ct2/show/NCT01688427 (Archived by WebCite at http://www.webcitation.org/6limSWdZP)

(J Med Internet Res 2016;18(11):e302) doi:10.2196/jmir.6251

KEYWORDS

intimate partner violence; screening; home visitation; nurses; mhealth; intervention; technology; interpretive flexibility

Introduction

Intimate partner violence (IPV) is recognized globally as a serious public health issue, with 1 in 3 women having experienced either physical or sexual violence from a partner [1]. Due to the adverse health outcomes, health care providers frequently, but often unknowingly, come into contact with women affected by IPV, thus providing opportunities for screening and intervention [2,3]. Debates about universal screening for IPV have resulted in conflicting recommendations for health care providers. The World Health Organization advocates symptom-prompted inquiry for IPV, while the US Preventive Services Task Force recommends universal IPV screening of women of childbearing age [4,5]. Nevertheless, research shows that women want health care providers to listen, provide sensitive and nonjudgmental inquiry about their needs, respect their wishes, and facilitate access to services [6].

Pregnancy and the postpartum can be a time of increased vulnerability for abused women because of changes in women's physical, social, emotional, and economic needs [7]. A review of studies found that 1% to 30% of pregnant women experienced physical violence during pregnancy, with most estimates being between 3% and 11% [8]. Higher rates of IPV have been reported during the postpartum period compared with during pregnancy [9]. In the United States, perinatal home visitation is a community health strategy that has been shown to improve outcomes for families and prevent child maltreatment and neglect [10]. The long-term nature of the relationship between the home visitor and the family provides favorable conditions in which to screen women for IPV and provide support. The home visitor is able to observe aspects of family life that are not discernible in a clinical setting, which may offer clues to the presence of abuse.

However, assessing for IPV in the home is as challenging as in a clinic setting [11]. Barriers to screening include provider discomfort with IPV questioning, fear of offending women, lack of training, confidentiality issues, and time restrictions [12-14]. Mobile health technology (mHealth) such as mobile phones and other wireless computing devices may offer a solution to some of these problems, as they can allow for more confidentiality, may be beneficial for women who are unwilling to disclose abuse to a health professional, and may help to standardize the way IPV assessments and interventions are delivered [15].

Greenhalgh and Swinglehurst contended that technology in health care is often introduced with expectations of higher quality, more efficient and safer care, and empowerment for patients [16]. Empowerment is a major goal of IPV interventions, and there is some evidence that such approaches can be embedded within technology. A study using a Web-based IPV intervention (Internet Resource for Intervention and Safety, IRIS) conducted in the United States drew on Dutton's theoretical framework of empowerment [17] by creating a safety decision aid that enhanced women's choice making and reduced their decisional conflict [18]. Adapted versions of the safety decision aid are being tested in Australia and New Zealand [19,20]. Additionally, studies conducted in clinical settings in North America found significantly higher rates of disclosure of abuse using computerized screening than using health care provider screening methods [15,21]. However, to our knowledge, the use of mHealth IPV screening in perinatal home visiting has not been investigated. This innovative approach warrants further exploration of how home visitors and women integrate technology-based IPV interventions in a nonclinical context, where the development of a trusting relationship provides the foundation for the care provided.

The technology literature reveals polarized positions regarding the relationship between technological artifacts and human practices. This has resulted in commentators focusing on technology as either a causal agent of change, whereby human behavior and organizations are influenced by technology (technological determinism), or constructed and interpreted flexibly through human agency (social constructivism) [22]. The inherent interpretive flexibility of technology refers to its capacity to sustain the divergent opinions of different user groups, both during its construction and in the way that it is eventually used. In using technology, users are influenced by individual and social factors that lead them to interpret and appropriate it in different ways. This is evident in empirical evidence that the application of identical technologies in similar organizations can have an impact in different ways [22,23]. However, researchers have highlighted that the interpretive flexibility of technology is not limitless, that the composition of technical objects can constrain the ways in which technology can be interpreted [23,24], and that the extreme positions capturing the relationship between technology and humans present a false dichotomy. There is growing consensus among researchers that technology is both shaping of and shaped by its social context [22].

This study explored the relationship between technology and humans in relation to the Domestic Violence Enhanced Home Visitation Program (DOVE), an empowerment intervention to prevent IPV during pregnancy, which has been integrated into perinatal home visiting programs in the United States [25]. A US multisite randomized controlled trial based in Virginia,

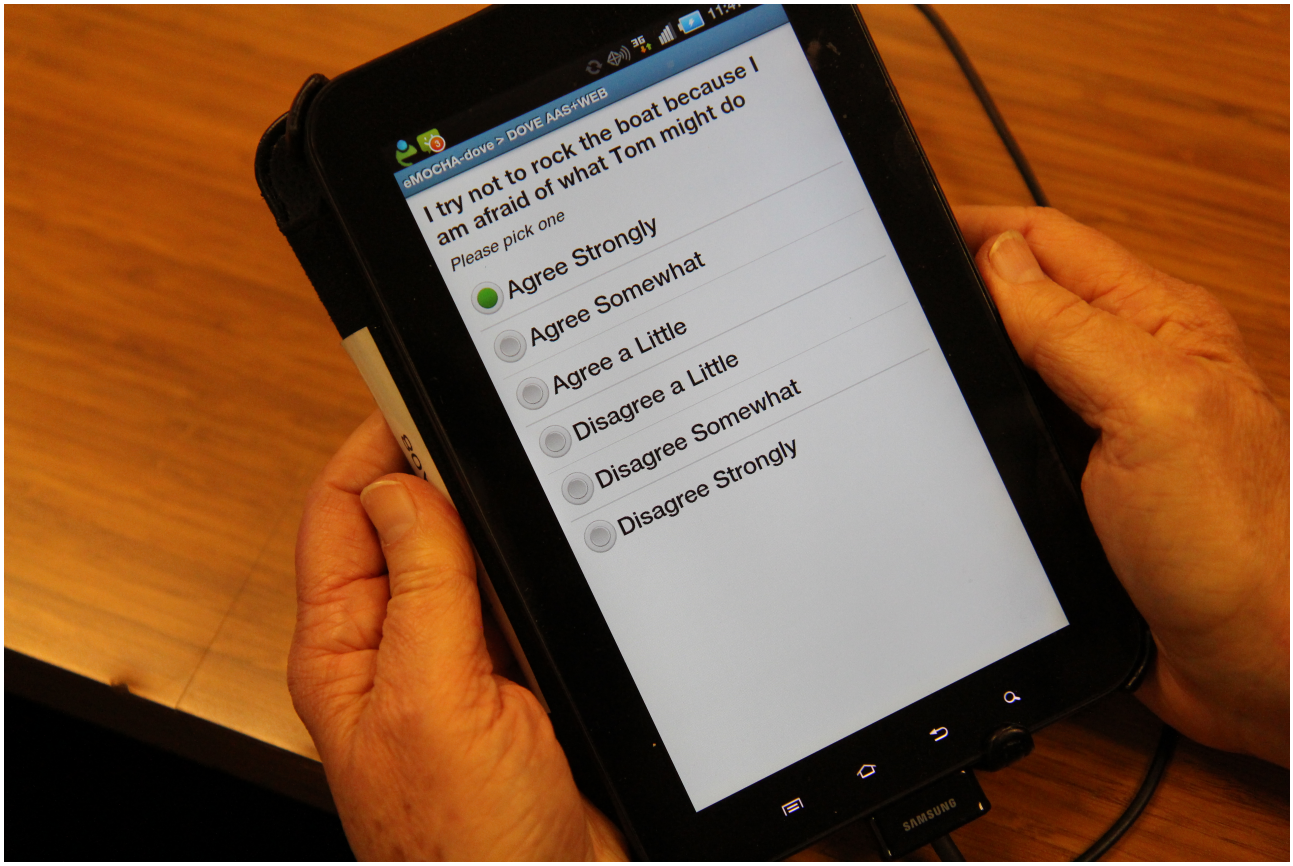
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Missouri, and Maryland (Baltimore) compared a home visitor-led method of screening for IPV and delivering an empowerment intervention, with an mHealth version of DOVE. In the home visitor method, women were screened for IPV with paper versions of the Abuse Assessment Screen [26] and Women's Experience with Battering scale [27]. Women who scored positive for IPV in the year before the current pregnancy were eligible to receive the empowerment intervention, a home visitor-led discussion of the DOVE pamphlet, which was offered on 6 occasions at 1-month intervals. The pamphlet included information on the definition and types of IPV, the cycle of abuse, IPV during pregnancy and the health consequences, assessment of the risk factors for homicide using the Danger Assessment scale [28], safety planning, and information about community resources. In the second method, the mHealth platform electronic Mobile Open-source Comprehensive Health Application (eMOCHA) developed by Johns Hopkins Center for Clinical Global Health Education was used to deliver the same materials via mHealth, except for the safety plan that the home visitor developed with the woman. A prerecorded video presented information contained in the DOVE pamphlet. Figure 1 presents a screen shot of one of the items on the Women's Experience with Battering scale and Figure 2 presents a screen shot of the Danger Assessment scale.

Home visitors were provided with training in IPV and the DOVE protocol using both methods. Women who were pregnant or up to 3 months postpartum were introduced to DOVE at a safe and appropriate time, which was left to the discretion of the home visitor. Women assigned to the computer tablet were free to complete the screening questions alone and were not obliged to discuss their answers with their home visitor immediately. However, the research team informed home visitors if a woman had experienced IPV in the year before her current pregnancy and therefore was eligible to receive the DOVE intervention, which was offered at a follow-up visit. Women were provided with study information and gave consent to using the computer tablet, which then randomly assigned them to the home visitor or computer tablet method. All materials were available in English and Spanish. The computer tablet remained in the possession of the home visitor and was never left in women's homes.

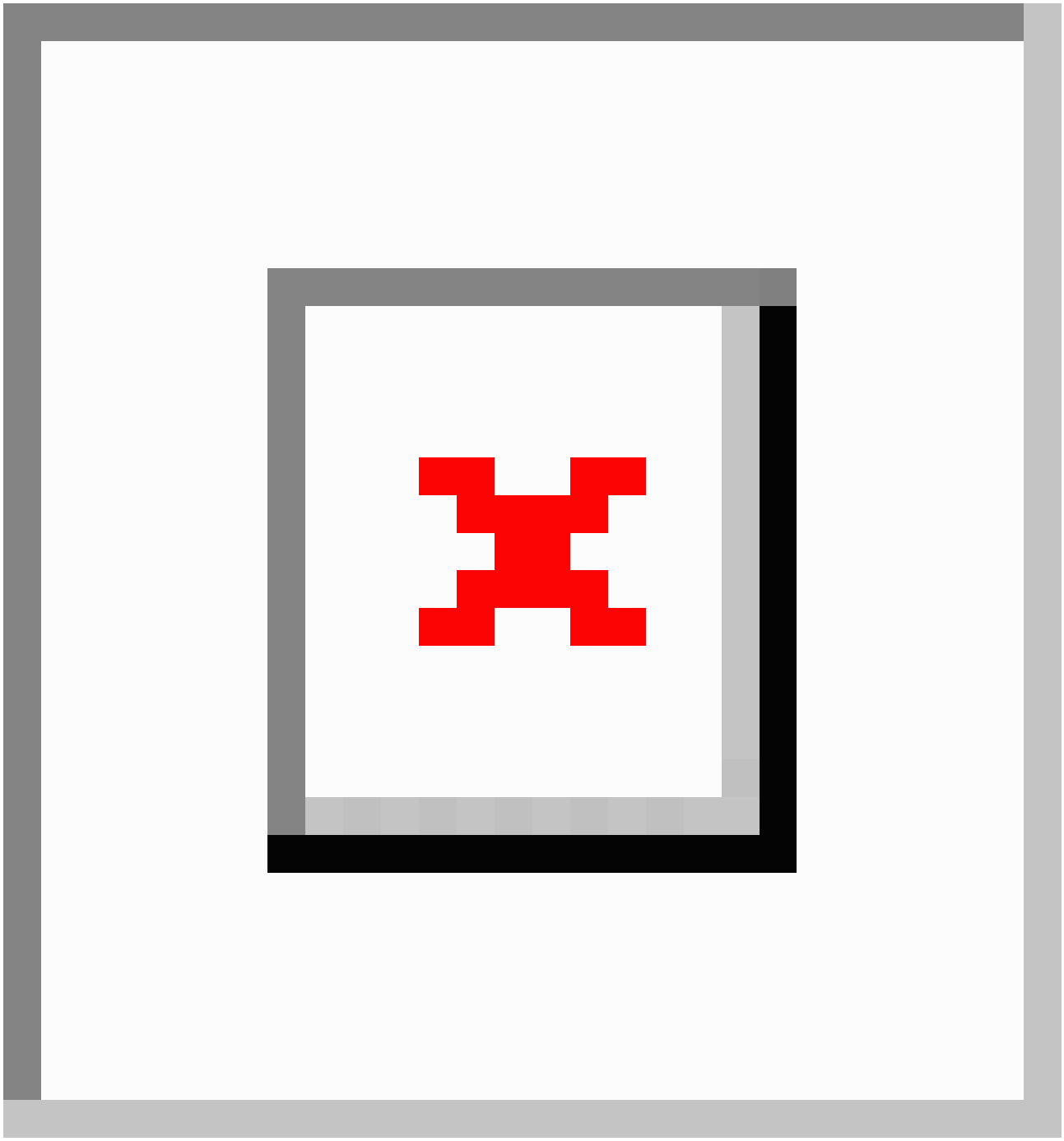
The aim of this study was to explore perinatal home visitors' and women's experiences of screening for IPV and receiving DOVE in the form of either mHealth technology (ie, a computer tablet) or a home visitor-led method. Furthermore, we aimed to understand how their perceptions of the technology resulted in differences in the outcomes of its use.

Figure 1. Domestic Violence Enhanced Home Visitation Program (DOVE) screenshot of one item from the Women's Experience with Battering scale. Image credit: University of Virginia, School of Nursing 2016.



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Figure 2. Domestic Violence Enhanced Home Visitation Program (DOVE) screenshot of the Danger Assessment scale. Image credit: University of Virginia, School of Nursing 2016.



Methods

The nested qualitative interpretive study was conceived after design and implementation of the DOVE trial. The study is underpinned by an interpretivist paradigm, which posits that reality is multiple and relative [29,30]. Using this paradigm permitted us to argue that women's understandings and experiences of DOVE were diverse and socially constructed, influenced by factors such as the interactions generated within the context, values, culture, and time. According to Greenhalgh and Swinglehurst, interpretivists view technological interventions as part of complex social practices involving different actors, which must be understood in terms of the interpretation of the social practices that the actors bring to using technology [16]. As such, it was important to understand the care setting in which the DOVE technology was used, the meaning that it held for different users, how it affected the home visitor-client relationship, and the diverse ways in which it was interpreted and used in context.

Data Collection Methods

Interviews

Between November 2013 and August 2014, the first author (LJB) conducted semistructured interviews with perinatal home visitors and women enrolled in DOVE. Interviews lasted between 1 and 2 hours and used a topic guide that explored a

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wide range of areas. However, this paper presents findings related to (1) screening for IPV at home using either method, (2) safety and confidentiality, and (3) aspects of the home visitor-client relationship that affected discussion about IPV and how the technology transformed this relationship through different interpretations of the technology's use. Interviews with women and home visitors continued until data saturation was achieved.

We also interviewed the 2 program designers of DOVE who were responsible for working with the research team to create an mHealth version of the DOVE intervention, which would also capture research data for the trial. The program designers provided support for technical problems in the field and for making adaptations to the program. The interview provided contextual information about assumptions underpinning the design; computer tablet features and usability; technical difficulties experienced by end users and how these were resolved; and views on the potential for future adaptation.

Nonparticipant Observations

In June 2014, the first author (LJB) undertook nonparticipant observations of home visits at one rural site to gain insight into the context of care, including the physical environment, routine aspects of perinatal home visiting care, and home visitor-client interactions and behavior. Condensed field notes were written immediately after each observation and an expanded account was written at the end of the day [31]. Observation fieldwork notes included descriptive data along with the researcher's own reflections and interpretations.

Study Procedures and Ethics

We used purposeful sampling using maximum variation to select women based on different factors that might influence their experience of DOVE, which would provide "information rich cases for in-depth study" [32]. This was discussed in advance with the trial research team, which led to sampling women in rural versus urban locations; women who used the home visitor paper method versus the computer tablet; women who had experienced IPV versus women who had not; and age (to include younger and older women). At a later stage of the study, we attempted to sample Spanish-speaking women, as the interim results from the screening (by either method) showed that many of these women were not disclosing experiences of IPV.

The trial coordinator provided a list of 47 women enrolled to the DOVE trial who had consented to participating in a qualitative interview, along with information on the above factors. Of these, 32 women were invited to participate (of whom 6 declined) and 15 could not be contacted for various reasons (ie, telephone number no longer in use, a male constantly answering the phone, or a woman not returning messages). Interviews with women took place in their homes if it was safe to do so, or away from the home in the researcher's car. We invited 45 home visitors at the 8 study sites to participate in an interview, which was conducted at their office. The 2 designers of the DOVE computer tablet were interviewed together via Skype.

We obtained written consent from all participants, who received a gift voucher (US $15 for home visitors and program designers, and US $30 for women) for their assistance. The study was approved by the University of Virginia Institutional Review Board for Social and Behavioral Sciences (2011-0243-00) and (2014-0075-00) and the European Union ethics review panel (February 13, 2013; proposal number 329765).

Analysis

Interviews were digitally recorded and transcribed verbatim. Field notes from observations were typed up. We used NVivo 10 software (QSR International Pty Ltd) to facilitate data analysis. Thematic analysis was used to identify, analyze, and report on patterns within the data [33]. The initial coding framework in NVivo was guided by the interview schedule themes and was deductive. Deeper exploration and interrogation of the data was inductive, allowing additional themes and their subcategories to emerge [34]. To ensure consistency in coding, 3 women's interviews and 2 home visitor interviews were coded by CB, DLS, and AMB using the framework, and discrepancies were discussed [34]. As a further check for consistency, LB reviewed a range of quotes representing each theme in the first draft of this paper. Interviews conducted in Spanish were translated into English, and the recording and transcript were compared for accuracy by a Spanish-speaking research nurse. In the quotes presented, IPV + refers to women who disclosed IPV in the year prior to their current pregnancy and IPV– refers to women who did not disclose IPV in the year prior to their current pregnancy in response to screening during the DOVE trial. During the analysis, data from the different sources were compared and integrated in relation to the key themes. Quotes presented are taken from the interviews, and data from observations are indicated throughout the text. Pseudonyms are used in the presentation of the results.

Results

Participant Characteristics

We interviewed 51 participants (23 home visiting staff, 26 women, and 2 DOVE computer program designers) and conducted 4 nonparticipant observations. Table 1 presents the sociodemographic characteristics of 26 women interviewed who were enrolled in DOVE.

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Table 1. Sociodemographic characteristics of women enrolled in the Domestic Violence Enhanced Home Visitation Program (DOVE) (N=26).

Sociodemographic variables	n	%
Age range (years)		
16-19	4	15
20-23	11	42
24-27	7	27
28-35	4	15
Ethnicity		
White	12	46
African/African American/black	8	31
Mixed ethnic origin	4	15
Not reported	2	8
Language		
English	23	88
Spanish	3	12
Location		
Urban	7	27
Rural	19	73
Marital status		
Married	1	4
Single	17	65
Partnered, not married	8	31
Educational level attained		
7th to 9th grade	1	4
10th to 12th grade	7	27
High school graduate/GED[a]	7	27
Some college or trade school	10	38
College graduate	1	4
Number of live births at interview		
1	17	65
2	4	15
3	3	12
4	1	4
5	1	4
Number of partners in the year before current pregnancy		
1	16	62
2	6	23
>2	4	15
IPV[b] abuse status from screening		
IPV in year before current pregnancy	18	69
No IPV in year before current pregnancy[c]	8	31
DOVE method		
Home visitor, paper based	18	65

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Sociodemographic variables	n	%
Computer tablet	8	35

[a]GED: General Education Development.

[b]IPV: intimate partner violence.

[c]Two of the women reported experiencing IPV more than 1 year prior to their current pregnancy.

Of the 23 home visitors, 9 were from urban sites and 14 were from rural sites. Some home visitors disclosed their age, while others preferred to select an age band. The age range was between 25 and 66 years. Length of time practicing as a home visitor was between 6 months and 20 years.

Nonparticipant observations were conducted with 4 African American women, 1 aged 21 years, 2 aged 20 years, and 1 aged 35 years. These observations were facilitated by their home visitor, also African American, who preferred not to disclose her age.

Themes From the Interviews

The relationship between the home visitor and the client is central to the care the home visitor provides and the foundation for promoting positive parenting behavior. The first set of results focuses on key aspects of the relationship that affected the experience of IPV screening, in order to enhance our understanding of how the introduction of the computer tablet transformed these experiences either negatively or positively.

The Pivotal Role of the Home Visitor-Client Relationship

The close bond that home visitors developed with mothers was a key factor in engaging them in home visiting activities and bringing about meaningful change in parenting behavior. It was also regarded as essential to facilitating discussion of IPV.

> *[The most important aspect of home visiting work] is building the relationship because if you don't have the relationship then you don't have anything to work with.* [Home visitor, ≥46 years, rural]

For some women the relationship seemed to replicate familiar bonds of connectedness, which was reflected in their descriptions of their home visitor as being like "a mother figure" or a "close friend." This was also apparent in the nonparticipant observations of home visits, in which interactions and exchanges were warm and caring in nature. For instance, Tina, a home visitor, would bring her clients clothes, toys, and books from the donations that the home visiting team received. The close bond was expressed directly by women and emphasized the importance of interpersonal communication.

> *I have confidence in her as a person. She's a very nice person and caring and you feel affection for her quickly.* [Carolina, client, 33 years, rural, IPV–]

Regardless of how DOVE was administered, there was concern among home visitors that asking about IPV might damage the relationship they had carefully built with women and that they could potentially lose them from the home visiting program. Their desire to support women, while not wanting to intrude into their personal lives, posed a dilemma for some.

> *There's always the concern, you know, will the family or the woman of the household feel like you're being too invasive and then want to pull away from the program?* [Coleen, home visitor, 27 years, rural]

Women regarded IPV screening as an opportunity to talk to someone other than family and friends, whose advice might be unwelcome. It made them feel "cared for" that someone wanted to know if they were "going through a hard time." Furthermore, the screening helped to raise awareness about and destigmatize IPV, thereby making it "more of a common thing" to talk about. This view was shared by women in rural and urban locations, by older and younger women, and among the 3 Spanish-speaking women.

> *DOVE really helped a lot…Some women could tell you right off the bat "look he beat me." But some women could be just like me and it takes time. I think if they do it and the home visitor comes in and they're graceful and supportive, I think it will help [women] a lot. I feel like it helped me a lot and to trust people again.* [Joanne, client, 21 years, rural, IPV+]

Waiting for the Right Moment in the Relationship

Feeling trust in the home visitor facilitated disclosure of IPV, and women's comments emphasized the cognitive and affective aspects of interpersonal trust. Trust was cultivated through repeated interactions, and women assessed trustworthiness on many dimensions, including prior experience or knowledge of the home visitor, the home visitor's tone of voice, not feeling pressured to discuss details of the abuse, reassurances of confidentiality, belief in the home visitor's intentions as genuinely caring, their ability to listen, and not appearing to be uncomfortable with the issue. Women also talked about trust based on "instincts," "vibes that I can read off of somebody," or whether their home visitor's demeanor resembled that of someone else they had trusted in the past. Ostensibly, women's disclosure of IPV was a staged process whereby they assessed their home visitor's reactions before sharing more information about the abuse.

> *It takes me a long time to trust somebody. When Rachel [home visitor] first started coming here I didn't like her. I didn't like talking or anybody messing with my daughter. I didn't like people talking to me about past things. But she was very graceful with it. She didn't rush me to want to talk to her. She did it at my own speed and that made me know that she cared…She would ask "what was the worst part about being with Jason?" and she said "you know you don't have to go into detail, if you can just give me a brief summary, it'll help out a lot." She wasn't all in your face and she had a soft spoken voice where I felt very comfortable.* [Joanne, client, 18 years, rural, IPV+]

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Women assigned to the computer tablet for screening were not obliged to share their answers with their home visitor immediately, although the home visitor would later be informed by the research team if a woman had screened positive and therefore was eligible to receive the DOVE intervention. In the following quote, a woman reflects on the advantage of the computer tablet compared with the home visitor method when trust has not yet been established.

> *If I did not trust her I would not have done this…if that were the case then I would like the tablet. Then I could have answered the questions and I don't have to worry if she had seen them.* [Kimberley, client, 20 years, rural, IPV+]

Home visitors felt that, regardless of the method used, finding the right moment in the relationship to introduce DOVE affected women's willingness to engage with it. A period of trust and rapport building was also necessary for the comfort of home visitors in finding the right moment to introduce IPV using the computer tablet or the in-person method.

> *R: Did you feel there were any risks? How did you feel putting the information in the computer tablet?*
>
> *I: No, 'cause when she came she was partly a friend…She knew I was not from here and that I was not familiar with a lot of things. So she said if you need anybody you can talk to me. And she said, okay you can trust me, I'm not going to tell anybody. It's just me and you, but I can help you. Here are some people you can talk to.* [Bernice, client, 20 years, urban, IPV+]
>
> *I have to make them comfortable with me and that usually takes a couple of visits…even after seeing them for a second time you still haven't gained their trust. Even if you introduce it, it's not a topic they want to be discussing right now. Even if there's nobody home and they can talk, they'll say "no."* [Hayley, home visitor, 36-45 years, urban]
>
> *Eye contact is definitely one way [to assess trust]. Where I'll sit, I think that's a physical thing that right at the beginning you know they always will sit away from me. Quite far away from me and as the visits progress, eventually they'll sit beside me. Sometimes I'll ask permission, "can I sit beside you because we need to look at something together?" It measures a lot of things I think.* [Gina, home visitor, 50 years, urban]

During the nonparticipant observations of home visits, Tina spoke about the importance of being flexible and engaging with "the woman's agenda" on the day of the visit, which sometimes required delaying other assessments, including the introduction of DOVE. During the observation of Rhianna's home visit, her main concern was finding alternative accommodation, as the roof of her mobile home was leaking. It was difficult for Tina to maintain Rhianna's attention during the child development assessments, yet Tina carefully negotiated their differing agendas in a way that was sensitive to Rhianna's needs on the day by listening to her concerns.

The Role of Technology in Reducing Anticipated Stigma

The computer tablet appeared to offer women a greater sense of anonymity and privacy, thereby encouraging more openness in answering the abuse questions. One home visitor reported that her client did not disclose abuse on a paper-based IPV assessment that was routinely used within the home visiting program, but disclosed multiple types of abuse in the DOVE study using the computer tablet. The potential reasons for this are revealed in the following comment, where a woman discloses that her fear of being judged led her to withhold certain information when her home visitor screened her for IPV.

> *I: Oh well, she was talking about fights…that made me feel a little uncomfortable. I was unsure whether or not to tell her the truth or just pass on the question.*
>
> *R: What did you think might happen if you told her the truth?*
>
> *I: What she may think about me.* [Martha, client, 26 years, urban, IPV+]

In using the computer tablet in the way it was originally conceived for the DOVE trial (ie, as an alternative to being screened for IPV by a home visitor), women did not have to engage in discussion immediately, and this seemed to reduce their anxiety about a negative reaction as described in the following comments.

> *There are just some things you feel ashamed saying, no matter how trustworthy that person…And with a computer there's no emotion…and you can just say whatever you need to say and you won't feel like you're being judged…it was like a security blanket.* [Lisa, client, 20 years, rural, IPV+]
>
> *A lot of people don't like to talk and express themselves so [the computer] brings it more out of a person even if they're afraid.* [Jennifer, client, 30 years, urban, IPV+]
>
> *Maybe us asking those questions could be the first time it's ever been brought up. So if they feel safe enough to do it on the tablet, feeling like it's a little anonymous, it starts to break down those walls and maybe next time they'll want to talk about it.* [Coleen, home visitor, 27 years, rural]

Not all women felt ready to discuss the abuse once it was disclosed. This was due, in part, to their fear of things being taken out of their control, feeling vulnerable about the possible consequences of disclosure, or not wanting to discuss abuse that was not current. The computer tablet may have helped limit the extent to which women re-experienced painful memories that can occur through discussion.

> *Some women don't like to talk about it because maybe it's too painful and I think with those women the tablet might be better because they don't have to verbalize it…When you verbalize it, like it leads to more conversation you know of what happened. And sometimes I think they have to relive what they went through.* [Esther, home visitor, age unknown, urban]

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I: I think the tablet was a good idea because most people got tablets now, it's convenient. I did it by myself.

R: Did you want to discuss it after?

I: No, I didn't' feel like there was nothing really to discuss since I wasn't going through it at [that] point in time. [Tammy, client, 23 years, urban, IPV+]

I saved it [in the computer tablet] and I gave it back to her and she asked me if there was anything I wanted to tell her. I told her a lot, but not all of it. I told her how long it had gone on. I told her that his abuse ended with me losing a baby…I was a little fearful, I was a little scared…It doesn't matter if it happened a month ago or ten years, when you talk about it, it still kind of brings a little bit of fear in your mind and that's what I was feeling. [Lisa, client, 20 years, rural, IPV+]

Impact of Technology on Emotional Connectedness and Disclosure of IPV

The interviews with women and home visitors revealed divergent interpretations of how the DOVE technology was used in practice, resulting in very different accounts regarding its impact on connectedness in the relationship. Although home visitors saw many benefits to using the computer tablet, some were apprehensive about its potential impact on their relationship with women. According to the program designers, a key assumption underpinning the design of the computer tablet was that it would collect more accurate information, as the questions were delivered in a standardized way and the anonymity would encourage disclosure. In the following comment, one of the designers reflected on how the computer tablet might affect interpersonal communication.

You know if in fact relationship building is so crucial…you know my only concern was the client goes off, they complete the forms, they do all the work on the tablet themselves. They hand the tablet back. Would the community worker truly sit and still have communication with that client or would they have let the tablet do all the work for them…would there be a loss in that relationship? [Program designer 02]

Home visitors and women talked about the need to convey empathy and compassion when asking about IPV and questioned whether the computer tablet would be an impediment to this.

I don't like it [the computer tablet] but I'm a fixer and I'm a healer. I've heard people want to tell [their] stories over and over because they're still processing them and so I feel like people need to tell. But that doesn't mean [the tablet] won't work for others. [Carol, manager, ≥46 years, rural]

It's cold…it's just her interacting with a machine. So there's no sympathy, there's no condolences. There's no, I want to say loving interaction. No, um, it's like no comfort, no support you know. [Shaun, home visitor, 25–35 years, urban]

You can let more out [when the home visitor asks] than using the computer. I mean both is fine, but I think you should be able to talk about it instead of using a tablet. [Suzanne, client, 26 years, urban, IPV+]

I think I actually would have rather talked to Carol [home visitor] because when you talk to your home visitor you build a relationship with them and you start to get comfortable with them. [Lisa, client, 20 years, rural, IPV+]

In the following comment, a woman reflected on the fact that she was unable to explain her responses to the abuse questions in the computer tablet, as she felt there was an element of mutual aggression within her relationship.

I: [The tablet] was easy. It seemed easier than it would have been to actually speaking to somebody. 'Cause when I'm talking with somebody I can ramble on, where with the tablet I could just easily put it in. The only thing that would have maybe made it easier is like if I could explain some of my answers. Like I said, it's a mixed relationship, there's [?] from both parties you know, there's anger and stuff. So to be able to explain that yes, this happened, but it happened this way.

R: Was the computer tablet a helpful way to share your experiences of partner abuse?

I: Well, I mean it kind of varies you know…if you have time to sit down and be able to talk to a person that sometimes helps women better than to do it on the tablet. [Lauren, client, 28 years, rural, IPV+]

For some home visitors, the technology appeared to conflict with their philosophy of care, which they described as "a relationship-based program" and "engaging the whole family if they want to be engaged." This was also evident in the nonparticipant observations of Tina's home visits, in which she involved parents in conversation about their lives and concerns regarding their children before completing formal assessments. Her observations of parent-child interaction and activity in the home also formed an important part of her evaluations. Together these provided her with a more nuanced understanding of women's circumstances. For example, Tina described her client Keisha (21 years, rural) as "stable" in terms of having secure accommodation, keeping up with health appointments, and receiving support from grandparents. However, based on her observations, Tina confided that she sensed "underlying negativity" from Keisha toward her baby, an unwanted pregnancy resulting from a short-term relationship. Tina alluded to Keisha's lack of desire to read to her baby, to encourage talking and crawling, and her proclivity to set goals that focused entirely on her own needs.

The nature of the interpersonal relationship also had implications for how women chose to disclose IPV, which ranged from overt disclosure to subtle hints about abuse, which they elaborated upon during further visits. One home visitor said he relied on "observations, the things that moms tell me, demeanor, attitude…if she's not herself" as a more nuanced way of assessing for IPV. The DOVE technology eliminated this complex process of waiting for the right moment in the relationship to ask about or disclose abuse, which was

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advantageous to women in terms of being able to access help quickly. However, it seemed to obscure home visitors' access to the unspoken clues such as body language, eye contact, tone of voice, and other gestures, which created feelings of redundancy for some. In this respect, the technology was seen a potential barrier to conversations that might provide home visitors with a deeper understanding of their clients' lives. Some home visitors interpreted women's use of the earbuds with the computer tablet as a request for privacy, and some home visitors appeared to be reluctant to engage women in a discussion about their responses to the questions.

> *I: When Stephanie [home visitor] brought the DOVE [computer tablet] to me I was open with her and let [her] know the things that go on in the home. But she never asked me you know what answers I put to the questions or anything.*
>
> *R: How did you feel about that?*
>
> *I: Fine. I mean she didn't ask…If she had asked I definitely would have [told her].* [Lauren, client, 28 years, rural, IPV+]
>
> *If they have the headphones on [while using the computer tablet], sometimes I really wonder you know? You've provided information, but there's been no discussion about it. So to see where mom's understanding is, I think I struggle with that one.* [Stephanie, manager, ≥46 years, rural]
>
> *There's something impersonal about that tablet…This is one of the most personal things that you can discuss with a woman…when she bares her soul to you, tells you what's going on, it's something that touches your soul. So the impersonalness of the tablet bothered me a bit.* [Alyson, home visitor, ≥60 years, urban]

In contrast to this perspective, some home visitors felt that the computer tablet helped "open the door" to deeper discussion about abuse and other sensitive issues. This was dependent on the approach that they adopted, women's willingness to allow their home visitor to participate in the process, and the quality of the relationship. Some women chose to approach the computer tablet as a shared activity and wanted their home visitor to sit with them while they completed the abuse and risk assessments or watched the intervention video.

> *I think [using the computer tablet] in the home is a good thing because you can actually sit with the person face-to-face, be open to them, and then you can get feedback right away, tell them everything and they can help you. After everything [the home visitor] had to grade it and then she'll say maybe if you get this answer it means something is wrong [referring to abuse score]. Like if you get a 16 it's not good.* [Bernice, client, 20 years, urban, IPV+]

Home visitors' strategies for maintaining interpersonal connection included asking women whether they wanted to discuss anything after using the computer tablet, suggesting that they review and discuss the abuse assessment scores, or surreptitiously monitoring women's reactions to the abuse questions for signs of upset. One of the older home visitors revealed that she used her own lack of experience with technology as a way of encouraging young women to open up to her with the computer tablet *(* "it's like I'm saying you're really tech savvy with this and it's sort of like a prop you know. Like we're going to talk about this, but you get to use this tablet"). One of the program designers described the DOVE technology as a "hybrid intervention" where "there is going to be human interaction if you feel that someone is in distress."

> *The two moms [are in] the intervention process and [using the computer tablet] opened up conversations, especially about previous relationships. One of the families, I knew about the violence with the father of her first child. So it's really opened up and gave us a chance to talk about how her relationship now is different and how the past relationship with violence impacted on her daughter's life.* [Pauline, home visitor, 49 years, rural]
>
> *R: Would you have been okay to leave [your responses] in the tablet and not talk?*
>
> *P: No, not at that point. We talked to make sure I was okay and stuff. I like to express myself now…like it helps me more to talk about the domestic violence.* [Jennifer, client, 30 years, urban, IPV+]
>
> *The challenge is how to keep it personal. If [women] answer positive on the tablet and then you just close the tablet and "oh thank you" and put it away then you've just told her, all I needed was for you to answer the questions. I'm not really here to help you. You have to say okay so this is how you answered and this is how you scored, let's talk more about that. The computer can't do that part, all it can do is take down the information and it's up to the nurse or home visitor to expand upon it and actually get her the assistance that she needs.* [Ann, home visitor, ≥46 years, rural]

The following results relate to external factors that had an impact on how home visitors and women integrated the technology into home visits. This includes negotiating safety and confidentiality in the home environment, and computer tablet design features and usability.

Computer Tablet Usability and Design Features

It took time for the home visitors to integrate the computer tablet into daily practice, describing their record-keeping procedures as "primarily paper driven." Women of all ages appeared to be more confident with the technology and mostly asked for help with understanding the questions. Some home visitors felt it was easier to keep track of things with the paper method, and that there was greater risk of something going wrong with the computer tablet.

> *I think I'm more comfortable with paper. I'd say I'm old fashioned. I think because I know that all I have to do is keep up with it. You know there's not a chance of something going wrong or something not saving. So I think I feel like I have more control over the paper copies.* [Coleen, home visitor, 27 years, rural]
>
> *I didn't think much of it 'cause there's a lot of stuff on tablets nowadays. It's all getting a little more*

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> *technological. I really didn't think anything of it. I thought it was cool.* [Tammy, client, 19 years, rural, IPV–]

The rural sites were more susceptible to loss of Internet connectivity, which would interrupt the process or delay transfer of information to the university's server. The program designers reported that updates to the computer tablet were changed from manual to automatic at an early stage of the study, but problems persisted because some home visitors kept their computer tablet switched off when they were not using them. One of the program designers felt that, on reflection, more time should have been included in the training to provide home visitors with "a bit more knowledge of mobile networks and how the Google system works". Furthermore, they felt that a clean version of the Android system should have been designed for DOVE, as network speed and automatic updates was also affected by bloatware (ie, the preinstalled apps). The trial coordinators were available to deal with computer tablet issues, but it was often necessary to drive long distances to the rural sites to resolve problems. Although a small pilot test was undertaken with clients, the program designers suggested that a more extensive period was needed for end user input during the development and pilot-testing stages.

> *They were doing [DOVE] then turning [the tablets] off, imagining that the information was being uploaded as it was being done. But because the network is not that good, that wasn't happening…so the information would stay in the tablets for several days.* [Program designer 02]

> *You need to use your tablet often for the tablet to keep connectivity with the Google Play Store and sometimes these tablets sit in a drawer and they miss updates because they're turned off. They lose the token that Google gives the tablet to keep it authenticated…If you don't have that token you will not access the market, you cannot get your update. So skipping updates is really bad when you're dealing with this kind of research software…I would have given them a bit more network knowledge. We didn't teach them about that…I mean they're nurses and they're not supposed to know those things.* [Program designer 01]

Women and home visitors appreciated some features of the computer tablet; for example, it helped to reduce the cognitive load by presenting women with one question at a time. It also had audio capability, as the DOVE research team anticipated that some of the women would have low literacy, and these features were beneficial to those who experienced difficulties reading long forms. However, one woman who used the computer tablet commented on the relative benefits of using paper assessments, which she felt would have allowed for more considered responses to the questions.

> *I think I would prefer paper so I can go and look back like when you're on one question you might [think] "oh well maybe I should have answered that one different." Because maybe another question helps better explain…I can go back and see is this really how I feel? Instead of the tablet you just get one question at a time and you can't see them all [together].* [Carrie, client, 29 years, rural, IPV+]

The computer tablet's Internet capability allowed for different interpretations of its function for helping women in other areas of their life, providing further evidence of its interpretive flexibility. One home visitor revealed that she downloaded videos of different health topics for use during visits, another used it to access Web-based assessment tools for women who wanted to return to education, and one woman said that she was shown a Web-based video about the prevalence and causes of IPV.

> *We don't have tablets usually so I used the tablet to do some personality tests of my clients who wanted to be in school.* [Natalia, home visitor, 47 years, rural]

> *She showed me a video on the tablet on the statistics of [domestic violence] and the age range that it normally happens and why it happens. It was like a YouTube video, but was statistics and girls speaking about it and that sort of thing* [Joanne, client, 18 years, rural, IPV+]

A limiting design feature was the DOVE intervention, which was a prerecorded video of someone presenting the DOVE pamphlet. The program designers explained that the trial design required that the computer tablet replicate a home visitor-led discussion of the pamphlet. Therefore, it was not possible to incorporate any interactive features or algorithms for tailored messaging, beyond those relating to the Danger Assessment scale score, which informed women of their level of risk of lethal violence and prompted them to talk to their home visitor. The video also ensured that the intervention was delivered to women in a consistent manner, as one program designer revealed that there were concerns that with the home visitor method some "weren't really spending much time and were just handing the brochure over and not really reviewing it with [women]." Some women found the video too long or difficult to absorb, and questioned the need to watch it again on subsequent visits. There was more flexibility to tailor the intervention content to women's current needs in the home visitor-led discussion. The repetition of the intervention on 6 occasions was based on the assumption that messages needed to be reinforced in order for women to make changes. Home visitors felt that the video was "not engaging" and that administering a static intervention did not reflect women's changing needs and priorities. One home visitor suggested varying the content and including videos of survivors' stories, as the home visitor stated that this strategy had been impactful in educating women in the prevention of sudden infant death syndrome. After watching the video once, some women chose not to view it again when it was offered at later visits or skipped the informational section to focus on the Danger Assessment scale, which helped them to reassess their level of risk of homicide.

> *I guess that video you're supposed to watch it every time. I thought you should only watch it the first time. 'Cause I'm like why do they want you to watch the same thing? I asked Natalia [home visitor] if I could just skip the video…I'm like how many times am I*

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> *supposed to watch it?...I guess the [Danger Assessment scale] is useful depending on what you're dealing with at home. Your answers will change because you're not always dealing with the same thing at the same period you're answering those questions…Some of the stuff was informative, like I never thought of stashing away money and that's the situation I found myself in.* [Carrie, client, 29 years, rural, IPV+]

> *I really feel that the tablet could be better used…They could do case studies…there's something comforting about knowing that there are other women who have experienced the same as you. My client looked at me one time, and she said "how many more times do we have to do this?" I understand that repetition is part of a learning program. But at some point when you see that this client has moved from here to here, there are other things that you can do.* [Alyson, home visitor, ≥60 years, urban]

Both of the program designers discussed possibilities for future adaptation of DOVE, including the use of shorter educational messages tailored to different levels of risk women were encountering and interactive features.

> *I would think about what types of risks are actually being assessed there…what levels of risk make a difference and what levels of education are needed for those risks. Then I would create educational vignettes that were specific, short, and tailored to those risks so that I could trigger them when needed…There's so much more that can be done with imagery than is needed with text…and potentially inputting some interaction within it.* [Program designer 02]

Despite having reservations about the repetitiveness of the intervention video, participants perceived some aspects of the information presented as being helpful. For example, in the following quote, a woman describes using the cycle-of-violence information to assess her new nonabusive relationship.

> *I: Was there anything in particular you liked about the video?*

> *R: There is a young lady, she talks about the stages of different things to look out for and what to do…Yeah, I still go over it, the honeymoon stage. I do it with my new partner. Sometimes I think of my past to my new future. In the cycle it talks about, oh I apologize, I love you, I'm going to do this, everything. 'Cause like I said I went through a big trauma…like right now I have real big trust issues. But that was the thing, the cycle that they tell you you're going through.* [Jennifer, client, 30 years, urban, IPV+]

Safety, Confidentiality, and the Legitimacy of Asking for Time Alone

An advantage of the computer tablet was its built-in safety mechanism, an icon that switched from the DOVE program to a baby video in the case of an unexpected interruption. This safety feature was greatly appreciated because only the home visitor could reactivate DOVE with his or her unique identification number. In addition, if women wanted privacy when using the computer tablet, they could use earbuds. Despite the relative anonymity of the computer tablet, seeing women in a confidential space remained a challenge for home visitors. This was apparent in the observation of Rhianna's (20 years, rural) home visit, which was conducted in a cramped bedroom with her mother and her mother's 4 young children present. It was a struggle for Tina to keep her engaged, as there were constant distractions and interruptions. Some of the women were living in mobile homes or small apartments with friends or family where space was lacking, and it was difficult to obtain absolute privacy where a discussion about IPV could take place comfortably. Furthermore, home visitors' accounts of overbearing partners revealed that it was not unusual for abusers to direct their hostility toward the home visitor.

> *I have a client who was abused physically, choked while she was pregnant into unconsciousness. And of course I can't enroll her [in DOVE] because her husband…he's there for her every move…and she has to arrange her doctor's appointments when he's off from work.* [Alicia, home visitor, ≥46 years, urban]

> *I've had some clients that the abuser is still around and I could only visit during a certain time on a certain day because he would not be around. And that was very uncomfortable for me and I know it was for her because one day he walked in unexpectedly. They kind of hang around usually like in a corner in the kitchen where they can overhear. It's all a matter of control and intimidation.* [Alyson, home visitor, ≥60 years, urban]

When asked how they might procure confidential time with women, home visitors suggested strategies such as taking women to their car, and meeting them at the library or obstetrician's clinic. Regardless of the method used to administer DOVE, women appreciated the home visitor's reassurances of confidentiality. Concerns about the computer tablet confidentiality were related to information being inadvertently transferred to the wrong people, and there was a perception that information in the tablet might be open to others, while information given to the home visitor would be kept confidential.

> *Well I kinda had this thought in my head…what if it's not going to the people they said it's going to and then he does find me and then I'm screwed…If I were to tell somebody [in person], I think it would go directly to that person or the people that need to know about it. But with the tablet, technology's kinda finicky sometimes and it has glitches and you don't really know where it's going.* [Lisa, client, 20 years, rural, IPV+]

> *Everything you put on the computer everyone can see it. It's probably better letting the home visitor do it because Miss Laura [home visitor] said that if somebody tries to ask her about me, she can't tell them.* [Amy, client, 16 years, rural, IPV+]

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In summary, although both the computer tablet and home visitor method clearly had benefits for disclosure of abuse, the nature of the relationship between the home visitor and the woman played a role in how they experienced screening for IPV. The malleability of the DOVE technology was dependent upon how home visitors and women chose to interpret its function and role in the care process, and partly due to its design features.

Discussion

Principal Findings

Home visitor-led and mHealth approaches to screening women for IPV and offering interventions can be integrated successfully into perinatal home visiting. However, both approaches require good interpersonal skills, and the development of a trusting relationship was an important aspect of ongoing communication and support regardless of the method used to obtain disclosure of IPV. Although the computer tablet was conceived as an alternative to the interpersonal approach to inquiring about IPV, home visitors and women played a role in how the technology was used and gave it new meaning by maintaining interaction. Through their interpretation of its use, some home visitors and women were able to transform the technology from an *impersonal* artifact to a shared activity. Instead of creating distance, the computer tablet became the conduit through which the interpersonal connection between the home visitor and the woman could be deepened. However, others perceived the computer tablet as a barrier to communication and trust building. The DOVE technology appeared to reduce women's anticipated stigma because they did not worry about negative reactions to their responses, nor did they feel obliged to discuss their responses with the home visitor immediately. Certain design features within the DOVE technology appeared to constrain its interpretive flexibility, such as the didactic intervention video, which home visitors found difficult to tailor to women's changing circumstances or feelings toward their partner. Since the content was fixed, it was less amenable to alternative ways of using it. Although home visitors and women felt that the video content was helpful, they were less enthusiastic about the way it was delivered and repeated.

Comparison With Prior Work

The multiple interpretations of the computer tablet reveal an important aspect of the social shaping of the DOVE technology, which can be understood within the social construction of technology (SCOT). From this perspective, technological artifacts are open to multiple interpretations, which influences their development during the embryonic phase and how they are eventually used in practice [35]. A defining feature of the original conception of SCOT is the idea of relevant user groups who can construct radically different meanings of a technology, known as the technology's interpretive flexibility [36]. However, Orlikowski argued that the "interpretive flexibility of any given technology is not infinite," as the material characteristics of technology can constrain human action [23]. This appeared to be the case with the didactic DOVE intervention video, which was a limiting feature of its design. It is well documented that abused women are faced with complex decisions and that safety seeking is a gradual process involving multiple steps or strategies [37]. In our study, home visitors and women identified the need for tailored interventions that reflect women's changing needs. This was also found in an Australia study of a Web-based safety decision aid for women experiencing IPV. The intervention translated aspects of a brief IPV counselling intervention offered by general practitioners into tailored messages, motivational interviewing, and nondirective problem solving into a Web-based format. Women appreciated having an objective assessment of their situation and felt reassured that their concerns were being taken seriously [19]. Outside of the field of violence, Hall and colleagues' work on the development of cancer support videos articulated the need for video messages to be short and relatable. They emphasized the need to capture the varying concerns and coping strategies of patients at different stages of the illness. This enabled them to create targeted, tailored videos that could reflect a person's experience during different periods of time [38].

Studies of mHealth technology addressing other sensitive issues, such as safer sex, human immunodeficiency virus (HIV) infection prevention, substance abuse, and depression, have demonstrated its utility in reducing feelings of stigma that can occur during face-to-face counselling [39-42]. This resonates with a clinic-based US study that found that not all women who screened positive for IPV using a computer wanted to share their answers with their health care provider [15]. In our study, the reduced anticipated stigma reported by women using the computer tablet is a positive finding because they were able to avoid the complicated "dance of disclosure" that often occurs when women talk to their health care provider about abuse [43]. Cultural beliefs about IPV can contribute to abused women developing stigmatized identities that focus on victim blaming. In turn, women may internalize these negative beliefs, which can be a barrier to disclosure and help seeking [44]. Disclosure of IPV is often a staged process, and women in this study required time to develop a trusting relationship with their health care provider before divulging detailed information beyond the initial disclosure [45]. Therefore, mHealth technology can facilitate early disclosure and help seeking.

The importance of the relationship between the home visitor and the woman in facilitating behavior change needs careful consideration when infusing technological interventions into perinatal home visiting. Women who experience IPV often feel vulnerable and afraid. Therefore, the necessity of provider empathy and compassion take on added importance because these qualities are basic to good communication and providing a supportive response. Sensitive inquiry for IPV by health professionals followed by a nonjudgmental response can change the perceived acceptability of IPV among women, which is considered a valuable intervention [46]. This raises questions about the extent to which technology can replicate or complement this.

In midwifery, practitioners have expressed concern that technology may be detrimental to client care as it becomes a replacement for human contact. Technology is represented as "other" to the real work of midwives and the more holistic care of being with the woman [47]. Kennedy and Shannon's exploration of the process of midwifery care revealed how midwives achieved balance between low and high technological

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environments and perceived themselves as "instruments" of care through their presence with the woman [48]. In our study, some home visitors felt disconnected from women while they used the computer tablet because they were unable to gage their client's feelings. Similarly, some women using the home visitor method said they appreciated being able to talk to their home visitor about the abuse because it helped them to release and process emotions. However, divergent views emerged, as the DOVE technology was not necessarily an impediment to the interpersonal relationship but facilitated communication about abuse and other sensitive issues. The potential for mHealth to enhance patient-provider communication has been reported elsewhere. In a study of an mHealth HIV/sexually transmitted infection and drug abuse prevention intervention for primary care, adolescents involved in its development suggested the inclusion of a drug use and sexual risk assessment to facilitate difficult conversations with clinicians [49]. Similarly, the inclusion of the Danger Assessment scale in DOVE provided a way for women using the computer tablet method to discuss increased levels of risk of lethal violence with their home visitor. This complemented the discussion of the tailored safety plan that was always initiated by the home visitor.

Home visitors used multiple strategies to infuse IPV screening and the technology into practice, for example, by judging the right moment when trust had been established; monitoring nonverbal communication; approaching the computer tablet as a joint activity and offering to discuss abuse scores; and respecting women's wishes to use the tablet alone or not discuss their disclosure immediately. Yet, regardless of the method used, it was sometimes necessary for home visitors to prioritize women's immediate concerns and delay IPV inquiry until a more opportune moment arose. This echoes the work of Jack and colleagues, who stated that client-centered care is central to good practice and that not addressing a client's immediate concerns may deter her from discussing her experiences of IPV with her home visitor [13]. This emphasizes the need for health practitioners to remain adaptive to the woman and her situation.

Screening for IPV in the home is not without its challenges. In a clinical environment a certain degree of privacy between the practitioner and patient is expected and can also be created. However, negotiating confidential space within the home was challenging, and some home visitors expressed discomfort in requesting this. Home visitors reported feeling vulnerable when entering the homes of clients where there was a known history of risk behaviors such as drug abuse or criminality. While mHealth apps aim to provide access to tailored health information technology and have the potential to alleviate global health burdens, there are concerns about risk to information security and privacy, which have come under scrutiny. This can impede users' willingness to share information [50]. The DOVE computer tablet offered privacy and included a safety icon that switched the program to a baby video if there were interruptions at home. Yet, regardless of the method used, women still needed explicit reassurance from their home visitor that their participation would remain confidential, particularly from their partner, and that information would not be accessible to others. This emphasizes the important role of home visitors in gaining women's trust and vouching for the trustworthiness of the technology.

Strengths and Limitations

The researcher (LJB) was an international visiting fellow who was not involved in the design of the DOVE trial, nor in the training and support of the home visitors. This unique position of "outsider" helped to elicit data that were diverse and rich. While the study revealed several important findings, it was subject to limitations. The study would have benefitted from the inclusion of undocumented migrant women whose opinions on the use of technology to record abuse experiences may have been less favorable due to concerns about personal information being reported to the authorities. At the time of the interviews, more women were randomly assigned to the home visitor method, which resulted in a smaller number of women using the computer tablet in the overall sample. The imbalance among women who had experienced IPV in the year prior to the current pregnancy was smaller (7 versus 11) than among those who had not (1 versus 7). The inclusion of additional computer tablet-using women may have yielded more diverse views, particularly if this occurred at a later stage of the study when home visitors felt more comfortable integrating the technology. Purposive sampling is not free from bias, and interpretation of the findings is limited to the population under study, in this case infant and early-childhood home visiting programs in the United States where there is continuity of the care provider.

Conclusions

The DOVE computer tablet was introduced into a nonclinical setting in which the home visitor and the woman could develop a consistent and strong interpersonal relationship. While the computer tablet was sometimes regarded as disruptive to the process of relationship building, it was also perceived as beneficial in opening up communication about a highly sensitive topic. It is important to consider end users and the context into which IPV technology is being embedded to ensure that it complements and enhances the therapeutic relationship. Technological interventions are more likely to be accepted and used if they are underpinned by theory and involve end users during the design and testing phases. An mHealth intervention in perinatal home visiting is an important tool for assisting women in disclosure of IPV, considering help-seeking options, and enhancing their safety. However, this must be accompanied by training to help home visitors successfully integrate the tool into their practice.

Acknowledgments

The nested qualitative study was funded by the European Commission as part of a Marie Curie International Fellowship (329765). The DOVE trial is funded by the National Institutes of Health (NIH/NICHD 071771). The authors wish to thank the women, home visitors, and program designers who generously shared their time and experiences. We also wish to acknowledge the DOVE

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trial coordinators in the schools of nursing at the University of Virginia (Meg Norling, RN) and Johns Hopkins University (Iye Kanu, RN; Kimberley Hill, MS) for their assistance.

Conflicts of Interest

None declared.

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Abbreviations

DOVE: Domestic Violence Enhanced Home Visitation Program
eMOCHA: electronic Mobile Open-source Comprehensive Health Application
HIV: human immunodeficiency virus
IPV: intimate partner violence
IRIS: Internet Resource for Intervention and Safety
SCOT: social construction of technology

Edited by G Eysenbach; submitted 21.06.16; peer-reviewed by W Trick, A Taft, K Hegarty, N Trabold, R Giallo; comments to author 04.08.16; revised version received 17.09.16; accepted 28.10.16; published 17.11.16.

Please cite as:
Bacchus LJ, Bullock L, Sharps P, Burnett C, Schminkey DL, Buller AM, Campbell J
Infusing Technology Into Perinatal Home Visitation in the United States for Women Experiencing Intimate Partner Violence: Exploring the Interpretive Flexibility of an mHealth Intervention
J Med Internet Res 2016;18(11):e302
URL: http://www.jmir.org/2016/11/e302/
doi:10.2196/jmir.6251
PMID:27856405

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Original Paper

Practical Issues in Developing a Culturally Tailored Physical Activity Promotion Program for Chinese and Korean American Midlife Women: A Pilot Study

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Abstract

Background: With advances in computer technologies, Web-based interventions are widely accepted and welcomed by health care providers and researchers. Although the benefits of Web-based interventions on physical activity promotion have been documented, the programs have rarely targeted Asian Americans, including Asian American midlife women. Subsequently, culturally competent Web-based physical activity programs for Asian Americans may be necessary.

Objective: The purpose of our study was to explore practical issues in developing and implementing a culturally competent Web-based physical activity promotion program for 2 groups of Asian American women—Chinese American and Korean American midlife women—and to provide implications for future research.

Methods: While conducting the study, the research team members wrote individual memos on issues and their inferences on plausible reasons for the issues. The team had group discussions each week and kept the minutes of the discussions. Then, the memos and minutes were analyzed using a content analysis method.

Results: We identified practical issues in 4 major idea categories: (1) bilingual translators' language orientations, (2) cultural sensitivity requirement, (3) low response rate, interest, and retention, and (4) issues in implementation logistics.

Conclusions: Based on the issues, we make several suggestions for the use of bilingual translators, motivational strategies, and implementation logistics.

(J Med Internet Res 2016;18(11):e303) doi:10.2196/jmir.6454

KEYWORDS

Web-based intervention; physical activity; midlife; women; Asian American women; Korean American women; Chinese American women

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Introduction

Increasing use of the Internet by racial/ethnic minorities has prompted health researchers to be interested in using the Internet as a method for data collection and as a medium for interventions for racial/ethnic minorities. For example, Asian Americans as a racial/ethnic group use computers more than any other racial/ethnic groups [1-3]. About 66% of Asian Americans reportedly use smartphones [3,4], and about 50% of them were reported to use tablets [5]. Thus, it is natural to assume that a study or an intervention using the Internet would work very well in this specific population.

Web-based interventions, furthermore, are reported to be effective for isolated or marginalized people with stigmatized conditions (eg, human immunodeficiency virus infection, depression) and for underserved people such as racial/ethnic minorities and rural populations [6,7]. The literature even supports that Web-based programs would be more beneficial for racial/ethnic minorities than for white people [6,7]. Indeed, Web-based programs reportedly have great potential to narrow racial/ethnic disparities in health and illness experience and to reduce barriers to care by providing information and support to racial/ethnic minorities [6,7]. Furthermore, socially marginalized or deprived people (eg, those with low income) are reportedly more interested in eHealth than are others, and Internet resources are valued by those who cannot easily establish equal and honest relationships with their health care providers in clinical settings (eg, racial/ethnic minorities) [8-13].

Despite these well-known benefits, racial/ethnic minorities, including Asian Americans, are reported to use Web-based programs at a minimal level [14-22]. As a plausible reason, it has been pointed out that Web-based programs have rarely been tailored to racial/ethnic minorities [14-22]. Thus, researchers have reported the necessity for culturally tailored Web-based programs for racial/ethnic minorities to enhance the appeal and accessibility of the program to these groups [20,21,23-25].

Indeed, few existing Web-based physical activity programs were culturally tailored to Asian Americans despite their great presence on the Internet [6,26-31]. Rather, most of these programs targeted patients with diabetes, adolescents, or general adult populations [16,22,32]. For example, Wanner et al developed and tested a Web-based physical activity intervention for a general online population with positive results [9]. Massoudi et al developed an app for personal health records that delivered a physical activity promotion intervention for sedentary adults, also with positive findings [8]. However, none of these existing programs were tailored to any racial/ethnic minority midlife women [29,30].

The purpose of our study was to identify practical issues in developing and implementing a culturally tailored physical activity promotion program for 2 groups of Asian Americans—Chinese and Korean American midlife women. We targeted midlife women in this study because physical activity in midlife is a significant predictor of better health in later years [33]. Also, midlife women are at increased risk of cardiovascular diseases, type 2 diabetes, obesity, hypertension, and all-cause mortality partially due to high physical inactivity [34-36]. First, we provide background information by concisely summarizing the study's methods used to identify the issues. Then, we describe and discuss practical issues found during the study process. Finally, we propose implications for future research based on the discussion of these issues.

Methods

This was a pilot study to determine the effectiveness of a Web-based physical activity promotion program among Chinese American and Korean American midlife women. This study consisted of 2 sections: a usability test and expert review (phase 1) and a preliminary randomized trial (phase 2).

In phase 1, for a usability test, the first 5 Asian American midlife women who participated in previous studies of the research team and who indicated their interests in participating in additional studies were involved in a 1-month-long Web-based forum. The participants were required to come to the forum site, use the program, and post messages with their evaluation of the program within a month. They were asked to evaluate the program on 7 topics, including the general structure of the program, color, designs, and menus of the program, content included in the program, need for technical support and difficulties encountered, links to Internet resources, and other potential issues. Then, we analyzed the users' posted messages using a content analysis method [37].

The expert review was done by 5 experts in women's health and Asian American health from our institution. Cultural experts, as well as content experts, were essential for the expert review because the program aimed to be culturally tailored to Asian American midlife women. Then, the experts were provided with the Web address of the program and asked to evaluate the program and send their evaluation by email or by phone within a period of 2 weeks. Then, we analyzed their evaluations using a content analysis method [37].Based on the results from phase 1, the research team made decisions on the directions for program refinement.

For phase 2, we recruited 69 self-reported Chinese or Korean American midlife women. This phase was a randomized repeated-measures pretest-posttest (pretest, post-1 month: time point 1; and post-3 months: time point 2) control group study. The control group did not use the program, but used Internet resources related to Chinese or Korean Americans' daily life. The intervention group used the program and Internet resources related to Chinese or Korean Americans' daily life. The Internet resources were those related to daily life concerns and issues of Chinese or Korean Americans (eg, news from Mainland China, Taiwan, or South Korea, Chinese or Korean American businesses in the United States, cooking, and traveling). This phase used multiple instruments, including several questions on background characteristics and health and menopausal status, the Questions on Attitudes toward Physical Activity, Subjective Norm, Perceived Behavioral Control, and Behavioral Intention [38], the Physical Activity Assessment Inventory [39], and the Kaiser Physical Activity Survey [40]. The reliability and validity of all the instruments have been established among Chinese and Korean Americans [41,42].

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During the study process, we wrote memos on the practical issues that we identified and our inferences on potential reasons for the issues. We also had weekly group discussions and kept the minutes of the discussions. The memos and minutes were reviewed and analyzed using a content analysis method [37]. No specific software was used for the data analysis due to the small volume of the data. Rather, line-by-line coding, categorization, and theme extraction were used to conduct the content analysis [37]. Each word was a unit of analysis.

Results

We classified our content analysis findings into 4 idea categories: (1) bilingual translators' language orientations, (2) cultural sensitivity requirement, (3) low response rate, interest, and retention, and (4) issues in implementation logistics. In the following section, we present and discuss the issues according to the idea categories. Multimedia Appendix 1 also summarizes the practical issues and related implications.

Discussion

Practical Issues

Bilingual Translators' Language Orientations

As in the interventions using traditional methods, cultural tailoring in this Web-based intervention required the use of multiple languages. To culturally tailor the Web-based program for Chinese and Korean American midlife women, we used 3 languages for the program: English, Chinese (Mandarin), and Korean. We chose these 3 languages because they are the major languages spoken by Chinese or Korean American midlife women [43].

The program had 3 Web-based components: (1) message boards, (2) educational sessions and one-on-one coaching, and (3) resources. Before starting the study, we prepared the educational sessions and resources in the 3 languages. First, 4 bilingual researchers (2 Chinese-English bilingual researchers and 2 Korean-English bilingual researchers) translated the educational modules and resources into Chinese (traditional Mandarin) and Korean. Then, 4 bilingual researchers checked the accuracy of the translation. We did not use the standard back-translation process [44] for the educational modules and resources because the volume of content was too large.

Bilingualism can lead to some degree of deviance in translated meanings. For example, those from another culture who can speak fluent English do not inevitably have the same cultural beliefs and values of native speakers [44,45]. Also, bilingual translators can bring in some words straight from their second language and use the words and stylistic devices from their second language [44]. Subsequently, the same words can be understood and interpreted differently by different bilingual translators, which can often make scientific translation difficult [46].

Indeed, the main issue that we had in developing the 3 different languages versions of the Web-based program was related to bilingualism [44]. Our issue specifically concerned the equivalence of the bilingual translators' level of language proficiency in both languages. Although all the translators were identified as bilingual in 2 languages (Chinese and English or Korean and English), some translations tended to be oriented to English sentence structures and wording, while others tended to be oriented to the other languages (Mandarin Chinese or Korean). Thus, the translations could result in awkward sentence structure and wording depending on their language orientations. Thus, for all translations, 2 other bilingual research team members double-checked the translations and wording in the educational modules and forum messages for coaching and support.

Cultural Sensitivity Requirement

As in culturally tailored traditional interventions [47,48], cultural sensitivity was essential in developing and implementing the culturally tailored Web-based intervention. First, some cultural issues resulted in difficulties in recruiting research participants. One of the major reasons for the recruitment difficulty was potential participants' cultural attitudes toward midlife. Many eligible women, particularly those in their 40s, did not want to participate in the study because they did not perceive themselves as midlife women. They felt that midlife women meant those who were much older than them, although they were actually in the midlife age range. Although this attitude can be found in other racial/ethnic groups, it was interesting to find it in Asian American midlife women because traditional Asian cultures gave high respect to elders. With increasing life expectancies and cultural changes in Asian countries [49], Asian (especially Korean) midlife women's perception of midlife has become quite different from that in traditional Asian cultures. Furthermore, due to negative attitudes toward aging in Asian American cultures, as well as in modern Asian cultures, some women felt offended when we approached them for this study (targeting midlife women), even though this was a Web-based intervention study.

The second hurdle in recruitment was the educational modules and resources related to depressive symptoms that were offered to the intervention group. One of the women dropped out suddenly, so we contacted her to figure out the reason for her dropout. Interestingly, her reason was that she did not want to be involved in any studies with content related to depression. The educational modules were each categorized into 3 topics, such as depression, menopausal symptoms, and physical activity. The reason for introducing the topics of depression and menopause in the program was their relevance to physical activity of midlife women; and one module under each of these topics was specifically designed to inform the relationships of physical activity with depression and menopause. The woman who dropped out may have done so because of the stigma attached to depression in Asian culture [48]. We inferred that her main purpose in joining the study was to promote her physical activities and that she might have perceived the depression topic in the education modules as deviating from her original purpose. Also, due to the cultural stigma attached to depression, she might have misconceived the depression module as a signal to label her as a patient with psychological and psychiatric disorder.

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Another culture-related issue was the women's own perception of their level of physical activity. Because the women perceived any activities as physical activities, they thought they were adequately doing physical activities through their daily life. For example, they even perceived their breathing as physical activities. Indeed, a previous study by Im and Choe found that Korean American midlife women's definition of physical activity was broad; the women thought only death was physical inactivity, while all other activities could be physical activities [50]. This cultural definition of physical activity was an inhibitor in promoting the women's physical activity in the study.

Cultural sensitivity was also required in approaching the informal and formal gatekeepers of the Web-based communities for Asian Americans. As a recruitment strategy, we targeted Asian churches across the United States. A research assistant sent emails to the churches' pastors to ask for their help by announcing the study to their Web-based communities and congregations. However, a problem arose when the research assistant used only English when contacting the churches. We received a response from 1 of the pastors, who gave us advice and tips for effective communication with Asian churches whose services were delivered in Asian languages. To increase the possibility of recruiting church members to the study, he recommended the use of Asian languages (eg, Chinese Mandarin or Korean) in emails; otherwise, pastors would be more likely to ignore or delete the emails, considering them to be advertisement or spam emails. Also, receiving just an email would not make pastors want to help the research. Instead, as the pastor suggested, we needed to call or visit the churches in person and explain the study before asking for help.

A plausible reason for the gatekeepers' high rate of responses to culturally matched research assistants using their original languages is that the study announcement and communication in their first languages could resonate highly with Asian Americans. Also, collectivism is the moral stance in many Asian cultures, including Chinese and Korean [48]. Asian Americans often give special attention to languages and activities specific to their cultural group. Furthermore, using Asian languages in communication increased potential participants' sense of belonging, thus increasing the willingness to participate in the study. In addition to their interest in culture-specific activities, Asian Americans also showed special interests in researchers with the same cultural background. For example, one participant in the Chinese group expressed her and her social group's willingness to support projects conducted by researchers from the same cultural group.

Low Response Rate, Interest, and Retention

Web-based recruitment is supposed to be easier than recruitment through traditional methods (eg, mail or phone announcement) due to speedy and flexible communication [51]. However, in this study, recruitment and retention were challenging. Studies have reported high dropout rates in Web-based interventions because the participants could disappear from the website without any difficulty [52]. Indeed, in this study, the dropout rate by the post-3-month survey was 30.43%.

We suspected that the high participation burden for the intervention group (given the amount of participation reimbursement) with a long study period and many requirements from the Web-based program contributed to participants' withdrawal. The intervention group joined the weekly Web-based forums and completed 3 questionnaires until the end of the study. Also, the intervention group was asked to review 3–4 educational modules and leave questions or thoughts on each module every week. It took approximately one and a half months to cover the entire educational modules. After the first round of the Web-based forum ended, we repeated the same Web-based forum one more time for the intervention group until we invited the participants to fill out the post-3-month survey. One participant who officially withdrew from the study noted the time constraints because she had a full-time job and experienced difficulties setting aside enough time to fulfill the study requirements. Similarly, another participant stopped responding to the research team after being informed of the total number of required educational modules and every week's commitment to the forum. Others who expressed their interests in the study asked whether a US $30 gift certificate would be offered each time they completed the questionnaire; after hearing that US $30 was the total amount of reimbursement, they decided not to join the study. Therefore, we incorporated additional motivation strategies to prevent further dropouts, such as weekly reminders by emails, a random draw of a US $50 gift card at the completion of the post-1-month survey, and a US $100 gift card at the completion of the post-3-month survey.

The response rate to individual coaching and support by email was also low. A plausible reason is that the intervention group was already overwhelmed by several responsibilities to participate in the forum and did not want to be involved in additional individual coaching or support. Social desirability bias [53] might have affected their participation. Through the individual coaching and support, an interventionist helped the participants set their own goals to promote physical activity, checked their progress each week, provided emotional support, and discussed barriers preventing the participants from increasing their level of physical activity. The participants could feel pressured every time the interventionist assessed how far they had come closer to the goals or why they had not achieved their goals. Participants might have thought they were being judged by the interventionist and blamed for not doing their best. Subsequently, feeling pressured that they should become a good participant complying with the study requirements might have made them not want to participate in the individual coaching and support at all. Also, participants' characteristics might have influenced the individual coaching and support process. This study limited participation to relatively healthy people who were online by screening out those with current and past medical conditions and even with a family history of cardiovascular diseases. Thus, the healthy participants might have not been highly motivated to increase their physical activity through the individual coaching and support.

Logistic Issues in Web-Based Implementation

We had several logistic issues in implementing the Web-based intervention. First, we anticipated that participants would be successfully enrolled into the study within a predetermined enrollment period. In reality, however, their entry points into

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the study were different and sporadic, which made it difficult to streamline the intervention schedule. Given the limited study period as a pilot study, it was unrealistic just to wait until the intervention group was filled with 25 participants. Thus, we grouped the participants by their enrollment time (those enrolled at similar time points were grouped into a cohort) and then started the intervention until we recruited another cohort. However, even within the same cohort, the starting point of the intervention varied among the participants.

A second issue in implementing the Web-based program was timing, although the Web-based program could be accessed at any time without any geographical restrictions. Because of delays in many administrative aspects of the study, we started the data collection in November. Around the American Thanksgiving holidays, it was difficult to recruit and retain experts for the expert review. Also, it was difficult to recruit and retain Asian American midlife women for the usability test. Several email reminders were needed to get their feedback on the program. Then, because of Christmas holidays, we needed to stop data collection in December. In January, we began to recruit Asian American midlife women through Internet communities. It was still difficult to get responses from the webmasters and Web owners at the beginning of January. Also, there were unexpected Asian holidays (eg, Lunar New Year's Day) that we did not originally consider in the study implementation, but that turned out to be important to consider during the implementation process.

This study adopted an interactive Web-based platform that was similar to the Facebook platform in order to encourage active discussion and social networking among the participants. Our study website, as in Facebook, allowed the latest postings to appear at the top of the message board. Through several rounds of the forum, we learned that the Facebook-type platform was not working well for the Web-based intervention, where participants' entry points into the intervention had a wide range even within a single intervention cohort. Specifically, old postings on the message board continued to be pushed down and quickly disappeared because the first page could accommodate only a limited volume of postings. Under this condition, it was very difficult to build up discussions and accumulate comments for each question, especially when multiple cohorts engaged in separate forums with different topics every week. Thus, the interventionist needed to keep posting the questions for newer cohorts on the forum site, although the same questions had already been asked in the past for older cohorts.

Suggestions for Future Research

Based on the findings, we propose the following suggestions for future research using a full-scale intervention. First, for effective recruitment, it would be critical to assess the characteristics of recruitment sites, either Web-based or offline. In addition, we highly recommend a combined use of Web-based and offline recruitment methods because recruitment only through the Internet may not work anymore due to changes in dynamics (eg, an increasing number of Internet frauds) [54].

Second, as in traditional culturally tailored interventions, bilingual translators with adequate language proficiency in both languages are essential. As our findings indicated, bilingual translators frequently have unbalanced language skills between the 2 languages; they may be more proficient in one language than the other. Thus, having at least one bilingual translator with adequate proficiency in each language is important to ensure the adequacy of translation.

Third, as in traditional culturally tailored interventions, cultural attitudes toward several major concepts and topics related to the study need to be carefully examined. As this study indicated, cultural sensitivity was essential to approach the study population because of several unexpected issues. Usually, Web-based interventions are regarded as stigma-free because of non-face-to-face interactions with research participants [29,31,55]. Thus, many researchers have suggested the use of Web-based interventions for underserved populations with stigmatized conditions and assumed that the participants would not care about their stigmatized condition in Web-based interactions [29,31,55]. However, we found that participants were hesitant to participate in the study because of the cultural stigma attached to several different topics (eg, midlife, depression) that we never expected to cause stigma to the study population in a Web-based environment.

Fourth, more carefully planned motivation strategies need to be adopted. As discussed above, researchers' perceived adequacy of motivational strategies could be quite different from those of the research participants. The amount of participation reimbursement needs to be carefully set after consulting with some potential participants. In our study, we thought that US $30 would be adequate to motivate participation in the study without any ethical concern (eg, the potential of exploiting low-income persons), but the participants thought that US $30 was too low for their participation.

Fifth, potential issues related to logistics in implementing Web-based interventions need to be carefully considered in the planning stage. Timing and technology-related issues have frequently been reported as disadvantages of Web-based studies in the literature [53-57]. Because of the longitudinal nature of our study, timing was much more important. Once the intervention started, there was no way to stop it while maintaining its continuity despite the upcoming holidays. Thus, timing would be much more important in longitudinal interventions than in one-time interventions. Thus, before starting an intervention, it would be essential for researchers to check culture-specific holidays, as well as national holidays.

Conclusions

We identified 4 practical issues in developing and implementing a culturally competent Web-based physical activity promotion program for 2 groups of Asian American midlife women (Chinese American and Korean American). The equivalence of bilingual translators' level of language proficiency in both languages was an issue. Although this was a Web-based intervention study, we also identified several issues related to cultural sensitivity in the use of specific terms and the content of the intervention. We also found low response rates, a low level of interest in the study, and low retention rates despite the use of multiple strategies to motivate the participants. Finally,

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we found several unexpected issues in implementation logistics (eg, the screen display format).

Based on the findings, we suggest several strategies to overcome these issues; that is, using both Web-based and offline recruitment methods, including bilingual translators with adequate language proficiency in both languages, carefully considering cultural attitudes toward several major concepts and topics related to the study, and carefully planning motivation strategies and implementation logistics. Yet the findings and suggestions need to be carefully interpreted and adopted because of several limitations of the study (eg, recruitment and subject bias, small sample size, and the short timeline).

Acknowledgments

The study was supported by Chang Gung Medical Research Foundation (Grant #CMRPF190061-63 & ZZRPF3C0011) and Ministry of Science Council (MOST 103-2511-S-255 -008 & MOST 104-2511-S-255-006).

Conflicts of Interest

None declared.

Multimedia Appendix 1

[PDF File (Adobe PDF File), 23KB - jmir_v18i11e303_app1.pdf]

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Edited by G Eysenbach; submitted 09.08.16; peer-reviewed by A Booth, G Heath; comments to author 22.09.16; revised version received 24.10.16; accepted 29.10.16; published 21.11.16.

Please cite as:
Chee W, Kim S, Chu TL, Tsai HM, Ji X, Zhang J, Chee E, Im EO
Practical Issues in Developing a Culturally Tailored Physical Activity Promotion Program for Chinese and Korean American Midlife Women: A Pilot Study
J Med Internet Res 2016;18(11):e303
URL: http://www.jmir.org/2016/11/e303/
doi:10.2196/jmir.6454
PMID:27872035

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Original Paper

Web-Based Antismoking Advertising to Promote Smoking Cessation: A Randomized Controlled Trial

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Abstract

Background: Although hundreds of millions of dollars are spent each year on public health advertising, the advertisement content, design, and placement are usually developed by intuition rather than research.

Objective: The objective of our study was to develop a methodology for testing Web-based advertisements to promote smoking cessation.

Methods: We developed 10 advertisements that varied by their content (those that empower viewers to quit, help viewers to quit, or discuss the effects of smoking). We then conducted a series of Web-based randomized controlled trials that explored the effects of exposing users of Microsoft's Bing search engine to antismoking advertisements that differed by content, placement, or other characteristics. Finally, we followed users to explore whether they conducted subsequent searches for smoking cessation products or services.

Results: The advertisements were shown 710,106 times and clicked on 1167 times. In general, empowering advertisements had the greatest impact (hazard ratio [HR] 2.6, standard error [SE] 0.09 relative to nonempowering advertisements), but we observed significant variations by gender. For instance, we found that men exposed to smoking cessation advertisements were less likely than women to subsequently conduct smoking cessation searches (HR 0.2, SE 0.07), but that this likelihood increased 3.5 times in men exposed to advertisements containing empowering content. Women were more influenced by advertisements that emphasized the health effects of smoking. We also found that appearing at the top right of the page (HR 2.1, SE 0.07) or at the bottom rather than the top of a list (HR 1.1, SE 0.02) can improve smoking cessation advertisements' effectiveness in prompting future searches related to smoking cessation.

Conclusions: Advertising should be targeted to different demographic groups in ways that are not always intuitive. Our study provides a method for testing the effectiveness of Web-based antismoking advertisements and demonstrates the importance of advertisements that are tailored according to specific demographics.

(J Med Internet Res 2016;18(11):e306) doi:10.2196/jmir.6563

KEYWORDS

smoking cessation; online advertising; computational advertising

Introduction

In the United States alone, tens of millions of public health dollars are spent annually on advertisement campaigns in the belief that it is possible to change smoking behaviors [1]. For example, the Centers for Disease Control and Prevention's Tips From Former Smokers campaign, which ran in 2013, cost roughly US $48 million [2]. However, it is difficult to know which advertisements are effective and which are not. Research into the effectiveness of advertisements often relies on weaker

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scientific evaluation methods, such as before-and-after designs [3] or designs that measure very long-term population-level effects.

As public health advertisements move onto the Web, however, it has become possible to conduct randomized controlled trials (RCTs)—the gold standard in research design—of smoking advertisement content and characteristics. This can be done by exposing users to advertisements, and then following these users on the Web to measure the influence of these advertisements on the users' health risk behaviors as observed in their searches [4-6]. For example, investigators can measure subsequent searches, key words used in online posts or emails, shopping behavior [7], or exercise behavior (eg, as measured by global positioning systems), providing a robust picture of the outcomes associated with Web-based advertisements. This can be done quickly and at a fraction of the cost of a real-world trial.

The private sector has long used such inexpensive experiments to test products [4-6]. For instance, Google and Microsoft often test the impact of website design or user interfaces by randomly exposing participants to different design concepts and then observing participants' responses. For example, the *New York Times* tested the effects of various font types on readers' perceptions of the validity of the same block of text by randomly changing the font and then surveying the readers about their perceptions of the text [8]. Likewise, researchers have experimentally manipulated the number of positive or negative posts that users saw on Facebook, and then examined the emotional content of users' subsequent posts [9].

Search engine queries are known to reflect real-world behaviors [10]. As such, researchers have used search engine queries to infer behaviors in the real world, both health related and otherwise [11], and their effect on future health outcomes. The use of Web-based advertising to measure health outcomes was pioneered by Eysenbach [12]. Web-based advertisements have also been used to measure sentiment to behaviors on the Internet [13] and to increase consumer demand for smoking cessation interventions [14]. However, the use of Web-based advertising to induce a behavioral change and its measure through search engine queries has not, to our knowledge, been attempted thus far.

In theory, a mix of Web-based advertisements can be developed and targeted to specific populations. Users can then be randomly shown advertisements within this mix to determine whether they had the intended effect on the intended audience. Using these data, it should be possible to continuously refine advertisements such that they can have ever-increasing effectiveness in changing individual behavior.

Therefore, the goal of this study was to take the first step toward proving this concept by developing a methodology for testing Web-based advertisements to promote smoking cessation. We conducted an RCT showing how 10 advertisements developed by a public health practitioner could influence the likelihood that Internet search engine users would subsequently conduct searches related to smoking cessation. We then asked whether some advertisements are more effective than others, and explored variation by demographic group.

Methods

Overview

We conducted an RCT using the Bing Ads system (Microsoft Corporation, Redmond, WA, USA) to randomly display 10 different advertisements, and then followed exposed or unexposed participants to explore whether they were more likely to subsequently search for ways to quit smoking. The control intervention was "usual care," meaning users were served whatever advertisements the Bing Ads system would have otherwise served.

We asked a public health professional to design textual advertisements. These advertisements conformed to basic public health communications campaign theory. They were designed without the assistance of an advertising firm to better reflect real-life public health advertisements, which are usually not designed with such expertise. We then categorized the advertisements into 1 or more of 3 categories according to whether the text (1) empowered participants to quit ("empowering"), (2) suggested ways to quit ("helping"), or (3) discussed the effects of smoking on one's health ("effects"). We then linked these advertisements to the most commonly visited smoking cessation websites (as determined by Microsoft's search engine, Bing). These antismoking sites were operated by a government body, a nongovernmental organization, or a private entity, and thus were chosen because of the perceived difference in authority of each organization type.

Advertisements

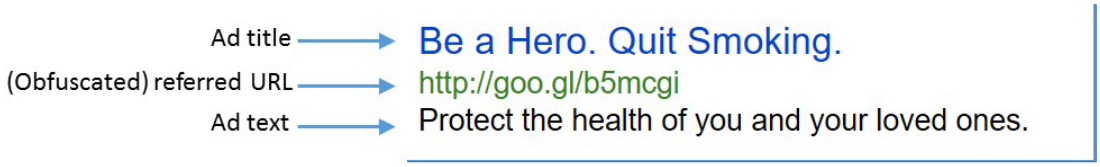
The advertisements contained text and took the form of a title, a body, and a link to a URL (Table 1). We used a full factorial design such that we tested all combinations of title/body and URL. The advertisements were only shown to people who searched from computers located in the United States, and who performed searches on the Bing search engine (Microsoft Corporation). Figure 1 shows a sample advertisement. We note that the market share of Bing in the United States is around 19%, according to recent estimates [15]. The correlation between the number of Bing users per county in the United States and the number of people in that county according to the 2010 US Census is R^2=.83 (P<.001). Thus, it is estimated that Bing users are a representative sample of the US population.

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Table 1. Smoking cessation advertisement title and subtitle text and classification.

Title	Subtitle text	Classification
Stop It!	Smoking lowers quality of life and causes illness and death. Quit now.	Effects
Be a Hero. Quit Smoking.	Protect the health of you and your loved ones.	Empowering
Smoking Makes You Ugly	See the effects of smoking on your looks and health.	Effects
Quit Smoking Your Way	Find a quit method that will work for you!	Helping
Free Help to Quit Smoking!	Tips and tools to help you quit smoking. Choose what's best for you!	Helping
Stop While You Still Can	Tobacco use is responsible for 1 in 5 deaths in the US. Quit smoking.	Effects
Who Says Quitting is Bad!	Learn about the immediate benefits of quitting smoking.	Helping
Want to Ruin Your Life?	Smoking harms nearly every organ of the body. Smoking also kills.	Effects
Quitting Smoking Is Hard	Having a plan to quit smoking makes it easier. Get help to prepare one.	Empowering, Helping
Need Motivation to Quit?	Learn from former smokers who have smoking-induced illness and disability.	Helping

Figure 1. Sample advertisement promoting smoking cessation aimed at users of the Bing search engine.



Textbox 1. List of terms matched in users searches on "from smoking" on the Bing search engine.

1. cancer from smoking
2. birth defects from smoking
3. yellow teeth from smoking
4. black lungs from smoking
5. hairy tongue from smoking
6. hole in throat from smoking
7. diseases from smoking
8. hole in neck from smoking
9. damaged lungs from smoking
10. wrinkles from smoking

The advertisements were shown when users' searches were matched by (1) broad terms (eg, those searches containing the words "smoking" or "cigarettes") or (2) specific terms (eg, "smoking causes black lungs"). These specific terms were identified by finding the 10 most common queries submitted during November 2014 to the Bing search engine that contained the phrase "from smoking." Textbox 1 shows the list of terms.

The advertisements were randomly shown either directly underneath the search text ("top of the page") or to the right of the search results ("right of the page"). The advertising system sometimes presented our advertisements in addition to other advertisements paid for by sponsors. In those cases, a placement at "location 1" meant that the advertisement was shown as the first advertisement in the list, and lower locations implied a lower order within the set of advertisements shown.

The Bing Ads system chose which of the 10 advertisements to show randomly using a random number generator. Each of the 10 advertisements had the same probability of being displayed. While it is likely that most users saw the advertisements, only some users actually clicked on it. Upon clicking, they were led to antismoking sites that we had preselected from government websites, nongovernmental organization websites, or commercial websites. We selected these websites according to their search rankings. Importantly, the sites did not contain

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detailed smoking cessation information. Therefore, we used future searches to test the effect of the advertisements on seeking cessation information, as detailed below.

The advertisements were shown between June 10, 2015 and September 10, 2015.

Statistical Analysis

We extracted all searches conducted on Bing by people who were shown 1 or more of the advertisements we presented from 1 month before the beginning of the advertisement campaign (ie, May 10, 2015) and until 1 month after its completion (October 10, 2015). This was done to obtain a sense of the baseline number of searches and the advertisement types that these searches generated. This way, we could more easily detect a media event (eg, a celebrity death attributable to smoking) in the middle of a campaign and account for variations from baseline that could have occurred as a result.

Searches comprised the text of searches, date and time, and an anonymous user identifier. Where users had a Microsoft account and were signed in, their age and gender, as well as the zip code location of users, were also recorded.

We categorized searches according to their text into a 3-level scale: we assigned a score of 0 to searches that only mentioned "smoking" or "cigarettes," without additional context. We gave a score of 1 to searches that mentioned symptoms associated with smoking, such as "wrinkles from smoking." We gave searches a score of 2 if they mentioned specific diseases associated with smoking, such as "cancer from smoking." We refer to this scale as the query damage scale.

Our primary outcome of interest was whether the user conducted at least one query, filtered to include only those queries indicative of an intention to quit smoking search (IQSS). Such queries were those that included 1 or more of the following terms: (1) direct reference: quit, cessation, stop smoking, smoking withdrawal; (2) smoking cessation medications: nicotine, bupropion, carenicline, Chantix, Buproban, Aplenzin, Wellbutrin, Budeprion, Zyban, clonidine, Catapres, Kapvay, Nexiclon, Clophelin, Nicoderm, Nicorette; (3) electronic cigarettes: e-cigarettes, electronic cigarette, vaporizer, vape, smokeless, vapor; and (4) support: support group, Smokefree, smoke free, American Cancer Society, American Lung Association.

We constructed a Cox proportional hazards model to assess the relation between the likelihood of conducting subsequent IQSS and the independent attributes shown in Textbox 2.

Textbox 2. Independent attributes.

1. Attributes of the advertisements:
   a. Location on the page: either above the search results or to their right.
   b. Whether the advertisement was clicked on.
   c. Type of match between the query and the ad keywords: advertisements can be exact (the exact phrase used for triggering the advertisements is the query) or approximate (the words triggering the advertisement appear in query, as well as other words).
   d. The websites they referred to (government, nongovernmental organization, or other).
2. The search words that triggered the advertisements.
3. User demographics:
   a. Age.
   b. Gender.

The assumption of proportionality was tested and met. To measure advertisement (and advertisement parameter) success, we further computed a conversion fraction, defined as the fraction of advertisement displays that resulted in a future IQSS. We then defined the conversion fraction ratio (CR) as the ratio of conversion fractions when an attribute was present to when it was not. Because the number of participants was very large, we only considered differences of 10% to be clinically meaningful irrespective of the statistical significance of the finding.

Institutional Review Board Approval

Our study was approved by the Microsoft Institutional Review Board and was declared exempt by the Columbia University Institutional Review Board under the understanding that the Columbia University researchers would not have access to the data and would not seek funding for the study.

Results

The advertisements were shown 710,106 times and clicked on 1167 times. Of these showings, 171,297 were linked to 3086 users, who also conducted 663,493 searches on Bing. Table 2 shows statistically significant advertisement and user attributes relative to the hazards of IQSS for those who were exposed to a smoking cessation advertisement of any type relative to those who were not exposed to an advertisement. Table 2 shows that advertisements placed on the top right of the page were twice as likely (hazard ratio [HR] 2.11, standard error [SE] 0.067) to induce subsequent searches indicating IQSS (a search for some kind of smoking cessation product or advice). Additionally, advertisements placed below those that did not have smoking cessation content were more effective than those placed at the top of a list (HR 1.13, SE 0.020 relative to the bottom of a list). Participants were only 1% more likely to subsequently conduct IQSS for each time that they were exposed to an advertisement (HR 1.01, SE 0.001). This suggests that 10 advertisements would

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be needed for a 10% increase in near-term smoking cessation-related searches.

Men were less likely than women to have future IQSS (HR 0.24, SE 0.073). Older participants who were exposed to smoking cessation advertisements were 2% more likely to subsequently search for IQSS for each additional year of the participant's age than were those who were not exposed to such advertisements in a linear fashion (SE 0.002).

Advertisements that had empowering text, those that had text that suggested help, and those that discussed the effects of smoking tended to induce more IQSS. Websites produced by nongovernmental and commercial websites were more likely to induce IQSS than were governmental websites overall.

Table 2. Results of a Cox proportional hazards model with intention to quit smoking search terms as the dependent variable.[a]

Variable	Hazard ratio	SE[b]	*P* value
Ad shown on top of page (to the right)	2.11	0.067	<.001
Ad rank (top to bottom of list)	1.13	0.020	<.001
Number of previous exposures to ad	1.01	0.001	<.001
Empowering ad? (Not empowering)	2.57	0.092	<.001
Helping ad? (Not helping)	2.46	0.115	<.001
Ad discussing effects? (Not effects)	1.36	0.138	0.03
Government website (Not government)	0.55	0.106	<.001
NGO[c] website (Not NGO)	0.63	0.094	<.001
Query damage scale	0.55	0.091	<.001
Gender (male)	0.24	0.073	<.001
Age (years)	1.02	0.002	<.001

[a]Hazards reflect exposure to the treatment (smoking cessation advertisement) relative to the control (no advertisement) by selected advertisement characteristics (reference characteristic). Only statistically significant variables are shown.

[b]SE: standard error.

[c]NGO: nongovernmental organization.

Recall that the CR refers to the likelihood of IQSS when an attribute is present relative to when it is missing. A higher CR indicates that more users shown the advertisement subsequently conducted an IQSS. As Figure 2 shows, men were 3.5 times more likely to respond to empowering advertisements than to advertisements in other categories. Men were also more than twice as likely to respond to advertisements provided on government websites relative to other websites. Women were roughly 1.3 times more likely to respond to advertisements that stressed the effects of smoking relative to those that did not.

We further modeled the data to predict which users would likely perform smoking cessation searches in the 2 days following exposure to the advertisement, given their personal attributes, as well as those of their search and of the advertisements. To do this, we built a linear regression model with interactions, estimating its performance as measured by the area under the receiver operating characteristic curve (AUC) using 5-fold cross-validation [16]. The AUC of this classifier was 0.892.

After performing sequential forward feature selection [16], we found that by using 7 of the 13 attributes, we could obtain an AUC of 0.870. The 7 variables were advertisement shown on top, advertisement position, age, gender, empowering advertisement, URL referring to a government website, and the query damage scale.

Table 3 shows statistically significant ($P<.05$, with Bonferroni correction) attributes. The interactions in the model reveal that people of different ages responded differently to advertisement placement. Similarly, different advertising content affected people of different genders and ages in a dissimilar manner. Thus, tailoring the advertisements to specific audiences requires the selection of very specific advertisement wording, placements, and URLs.

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Figure 2. The conversion ratio (CR) during the first 2 days compared with all other times for advertisement attributes ("empowering" ads, ads "helping" participants to quit, and ads showing the "effects" of smoking), website attributes (governmental [gov] and nongovernmental organization [NGO]), and sex. A higher CR implies that more users shown the ad subsequently conducted a search related to smoking cessation. All effects are statistically significant at $P<.05$ (χ^2_1 test), except the following pairs: Helping-Female and Is NGO-Female.

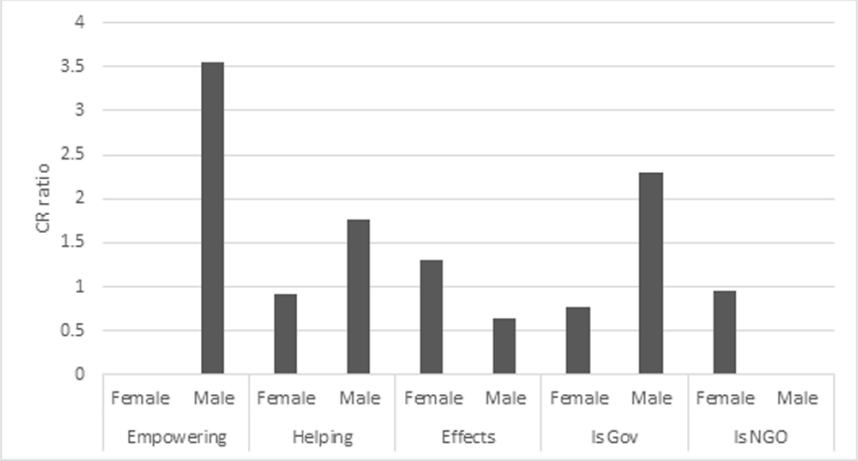


Table 3. Statistically significant attributes and their interactions for predicting future smoking cessation searches.

Variable	Coefficient	SE[a]
Gender	–.0130	0.0027
Ad shown on top	.0208	0.0039
URL designed by government	.0383	0.0041
Age × ad position	.0001	0.00001
Age × empowering	.0009	0.0001
Age × ad shown on top	–.0010	0.00005
Age × government website	–.0008	0.0001
Ad position × damage scale	–.0023	0.0005
Ad position × empowering	.0089	0.0009
Ad position × ad shown on top	.0109	0.0008
Ad position × government website	–.0050	0.0006
Damage scale × ad shown on top	–.0104	0.0020
Empowering × gender	.0202	0.0027
Empowering × ad shown on top	.0172	0.0032
Empowering × URL is government	–.0994	0.0062

[a]SE: standard error.

Discussion

In this study, we explored the effect of various advertisement characteristics on participants' likelihood of conducting future searches related to smoking cessation. Our results show that men were more likely to subsequently conduct smoking cessation searches when exposed to advertisements containing empowering content, but women were more influenced by advertisements that emphasized the health effects of smoking. We also found that women and older people were generally more likely to be influenced by antismoking advertisements, and that placement of smoking cessation advertisements in the middle of a list of unrelated advertisements can improve their effectiveness in prompting future searches related to smoking cessation.

Thus, our results indicate a good deal of variation in the likelihood of future smoking cessation searches that is explained by the characteristics of the advertisements, the characteristics of the participants, and the type of entity that produced the website. Foremost, we found that smoking cessation advertisements that empowered individuals to quit were more effective among men, whereas those that suggested ways to quit were more effective among women. Further, we found that the landing page had implications for users' likelihoods of subsequent smoking cessation searches.

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Overall, our findings suggest that targeting Web-based advertising may improve the effectiveness of those advertisements. Therefore, it is possible that relatively simple alterations in ad-serving algorithms can improve public health. Likewise, the landing page can also differ depending on the characteristics of the user. Based on our results, we would want to rely more on government websites as landing pages when the searcher is young, for instance. That women are more susceptible to Web-based advertisements (irrespective of their placement or content) is encouraging, as this is the group for which mortality has been on an unprecedented rise due to smoking [17].

There were some important limitations to this work. Mainly, our study was limited by a lack of comprehensive data. First, it is unclear that subsequent searches actually translated into changes in smoking behavior—and without such data, our understanding of the health consequences of advertising is limited. Second, our demographic targeting was less specific than we would have liked. In the ideal, it would be possible to use information stored on users' computers to devise Bayesian prediction algorithms. Such algorithms can be used to devise typologies for individual users (not just age and gender), and then to design much more targeted advertisements for such users.

However, there remains a clear challenge in understanding the influence of Web-based advertising on public health. Although private corporations conduct tens of thousands of such experiments each year, academics are required to obtain the consent of all participants in human subjects research. Even with informed consent, the privacy challenges associated with working with potentially identifiable data are daunting. For these reasons, academics who would be naturally positioned to better understand the public health consequences of Web-based advertising targeting cannot directly engage in such research. In this way, institutional review standards that have not pivoted to accommodate the volume and availability of data in the Internet age limit the role of those trained and experienced in public health research.

Our findings—that the characteristics of the advertisement's content, the placement of the advertisements, and the entity producing the advertisement should vary by the demographic characteristics of the searcher—are an important first step in demonstrating the power of Web-based advertising. Future research should seek to refine advertisements based on demographic data, as well as to improve their design and delivery with the support of advertising professionals. Ultimately, this work has the potential to improve the effectiveness and efficiency of public health advertising to promote healthy behavior and mitigate chronic disease.

Acknowledgments

All funding for this research was provided by Microsoft Research. The investigators performed this work as part of their salaried research.

Conflicts of Interest

The authors report no conflicts of interest.

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Abbreviations

AUC: area under the receiver operating characteristic curve
CR: conversion fraction ratio
HR: hazard ratio
IQSS: intention to quit smoking search
RCT: randomized controlled trial
SE: standard error

Edited by CL Parra-Calderón; submitted 28.08.16; peer-reviewed by V Agarwal, D Lee; comments to author 20.09.16; revised version received 25.09.16; accepted 28.10.16; published 21.11.16.

Please cite as:
Yom-Tov E, Muennig P, El-Sayed AM
Web-Based Antismoking Advertising to Promote Smoking Cessation: A Randomized Controlled Trial
J Med Internet Res 2016;18(11):e306
URL: http://www.jmir.org/2016/11/e306/
doi:10.2196/jmir.6563
PMID:27872032

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Original Paper

Clinical Relevance of the First Domomedicine Platform Securing Multidrug Chronotherapy Delivery in Metastatic Cancer Patients at Home: The inCASA European Project

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Abstract

Background: Telehealth solutions can improve the safety of ambulatory chemotherapy, contributing to the maintenance of patients at their home, hence improving their well-being, all the while reducing health care costs. There is, however, need for a practicable multilevel monitoring solution, encompassing relevant outputs involved in the pathophysiology of chemotherapy-induced toxicity. Domomedicine embraces the delivery of complex care and medical procedures at the patient's home based on modern technologies, and thus it offers an integrated approach for increasing the safety of cancer patients on chemotherapy.

Objective: The objective was to evaluate patient compliance and clinical relevance of a novel integrated multiparametric telemonitoring domomedicine platform in cancer patients receiving multidrug chemotherapy at home.

Methods: Self-measured body weight, self-rated symptoms using the 19-item MD Anderson Symptom Inventory (MDASI), and circadian rest-activity rhythm recording with a wrist accelerometer (actigraph) were transmitted daily by patients to a server via the Internet, using a dedicated platform installed at home. Daily body weight changes, individual MDASI scores, and relative percentage of activity in-bed versus out-of-bed (I<O) were computed. Chemotherapy was administered according to the patient medical condition. Compliance was evaluated according to the proportions of (1) patient-days with all data available (full) and (2) patient-days with at least one parameter available (minimal). Acceptability was assessed using the Whole Systems Demonstrator

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Service User Technology Acceptability Questionnaire. Linear discriminant analysis was used to identify the combination of parameters associated with subsequent unplanned hospitalization.

Results: A total of 31 patients (males: 55% [17/31]; World Health Organization Performance Status=0: 29% (9/31); age range: 35-91 years) participated for a median of 58 days (38-313). They received a total of 102 chemotherapy courses (64.7% as outpatients). Overall full compliance was 59.7% (522/874), with at least one data available for 830/874 patient-days (95.0%), during the 30-day per-protocol span. Missing data rates were similar for each parameter. Patients were altogether satisfied with the use of the platform. Ten toxicity-related hospitalizations occurred in 6 patients. The combination of weighted circadian function (actigraphy parameter I<O), body weight change, and MDASI scores predicted for ensuing emergency hospitalization within 3 days, with an accuracy of 94%.

Conclusions: Multidimensional daily telemonitoring of body weight, circadian rest-activity rhythm, and patient-reported symptoms was feasible, satisfactory, and clinically relevant in patients on chemotherapy. This domomedicine platform constitutes a unique tool for the further development of safe home-based chemotherapy administration.

(J Med Internet Res 2016;18(11):e305) doi:10.2196/jmir.6303

KEYWORDS

domomedicine; chronotherapy; actigraphy; MDASI; telemonitoring

Introduction

Incremental advances in the treatment of cancer are responsible for its progressive transformation into a chronic condition, with a similar level of impact on the individual patients' quality of life, health, and well-being as other chronic diseases [1-3]. However, health care providers have not kept pace in developing the design of their management packages for cancer patients to fit the model of care for chronic diseases [1,2]. An important aspect of the chronic diseases model of care is delivery of treatment and review of symptoms assessed in the patient's home and usual environment [4-8]. To best achieve this goal in cancer patients receiving often complex and toxic multidrug chemotherapy, it is important that the care model integrates the need for adequate safety [4,9,10]. Thus, an oftentimes complex compendium of procedures given to home-dwelling patients might be required [11]. Consequently, current practice usually involves chemotherapy administration at least partly within the hospital setting either as inpatient or outpatient, which can affect patient's quality of life and increase the financial burden on patients and national health systems [5,9]. However, the integrated home care and support proposed with the domomedicine approach could offer an alternative to the present care system [12]. Domomedicine is defined as all procedures and care, sometimes complex, given at the patient's home or in his or her social and professional activities, at least comparable in quantity and quality to those delivered in hospital, based on modern technologies, and it aims at promoting medical progress [12].

Improvements in treatment safety and patient well-being have been the mainstay for the development of the delivery methods that enable tailoring chemotherapy delivery according to circadian clocks in cancer patients. Toward this goal, cancer chronotherapy protocols use dedicated multichannel programmable-in-time pumps [13,14]. Thus, chronotherapy usually involves the chronomodulated delivery of chemotherapeutic agents according to circadian rhythms in nonhospitalized patients [13,15]. Doublet and triplet chronomodulated regimens have been safely administered at the patient's home, resulting in improved tolerability and efficacy [16-19].

Recent progress in information and communication technologies can provide health care professionals with continuous data flow on symptoms, quality of life, toxicity, behavior, and circadian function from remote patients remaining within their own environment [7]. Toward this goal, we integrated daily telemonitoring of multidimensional objective and subjective parameters into a dedicated electronic home-based platform connected to the oncology department via a central server. We assessed the feasibility of such an approach and its acceptability in the clinical setting of advanced patients receiving multidrug chronomodulated chemotherapy at home. The clinical relevance of this domomedicine patient-centered system was further evaluated to provide a first estimate of its ability to predict unplanned emergency hospitalizations. The study was conducted within the framework of the inCASA European project (ICT-PSP). Its overall goal was the development of citizen-centric technologies and a service network to improve the health condition and daily life of patients suffering from a chronic disease, thus minimizing hospitalizations.

Methods

Patients and Setting

Patients aged more than 18 years with any cancer type requiring chemotherapy for at least one month were screened for the study at the Chronotherapy Clinics in the Medical Oncology Department of Paul Brousse Hospital in Villejuif, France. Eligibility further required the availability of an Internet connection at home and signed written informed consent. The inCASA electronic platform and the related equipment were installed at the home of each registered patient for a minimum of 30 days. The platform was connected to the Internet Protocol network. Each patient was instructed on how to use the platform for the daily transfer of biomedical data, and was given a form with telephone contacts information for technical or health-related issues.

While on study, patients could receive either conventional chemotherapy or chronotherapy according to medical decision.

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World Health Organization (WHO) Performance Status (PS) score was estimated for all patients before each treatment to support medical decision. WHO PS is a 0-5 score (0 indicating perfect health and 5, death) used to quantify cancer patients' well-being and functional status [20]. All conventional treatments were administered in hospitalization or in outpatient clinics. Chronotherapy was delivered using a multichannel programmable pump (Melodie, Domocare, Montmirail, France) at home or during hospitalization, according to patient preference or medical decision.

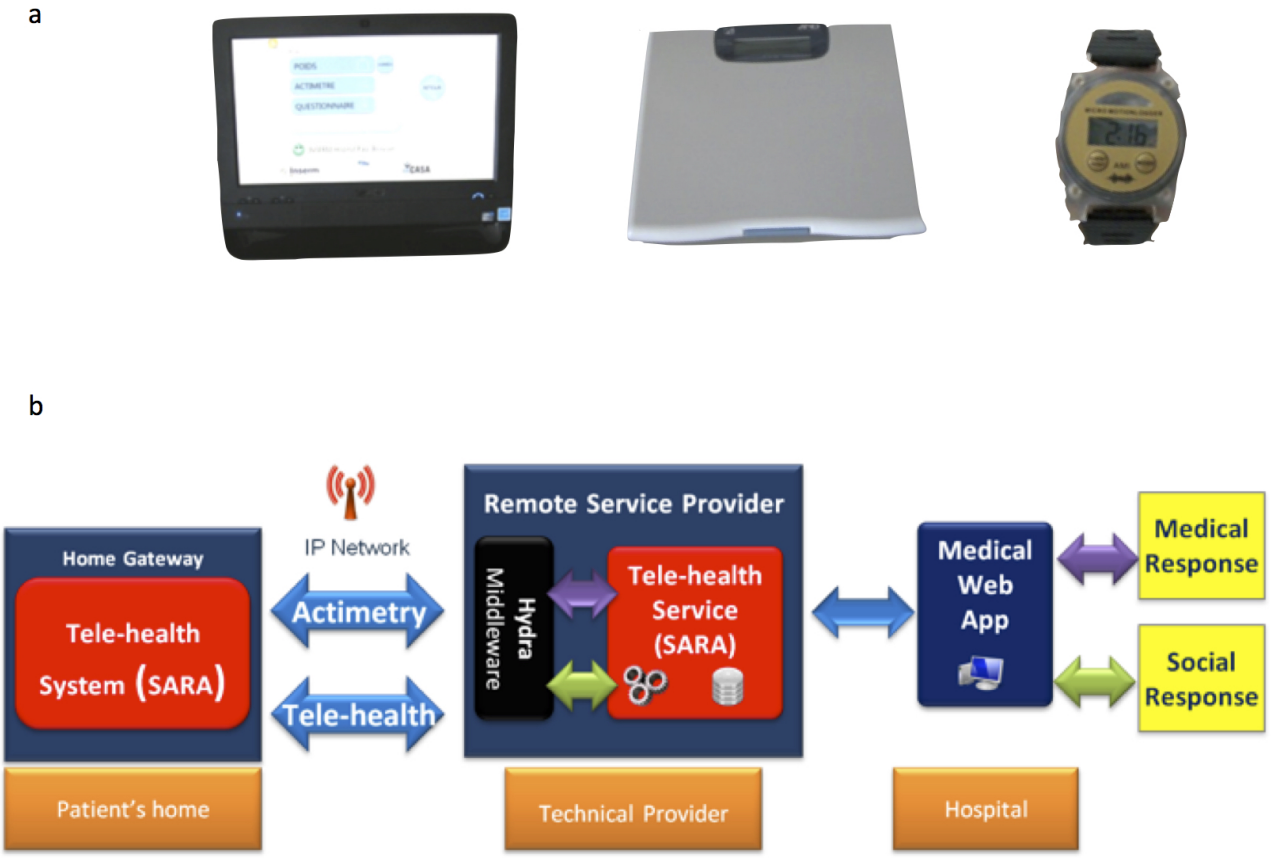
The study was approved by the local institutional review board and conducted according to the Declaration of Helsinki [21]. Each patient signed a written informed consent form.

Technical Equipment

The inCASA platform was composed of (1) a touch screen computer (ASUS Eeetop ET1611, ASUSTEK, Taipei, Taiwan) equipped with the SARA software (Telefonica Investigacion y Desarrollo SA, Granada, Spain); (2) a body weight scale (UC321-PBT, A&D Medical, San Jose, CA, USA), which was connected to the computer via Bluetooth through the SARA application; and (3) a wrist-watch accelerometer (actigraph) (Micro MotionLogger, Ambulatory Monitoring Inc, Ardsley, NY, USA), whose collected data on wrist accelerations (per 1-min epoch) were transmitted via an infrared USB dongle connected to the computer (Figure 1a).

The SARA software included an electronic version of the MD Anderson Symptom Inventory (MDASI) questionnaire for self-assessment of 13 frequent core symptoms and 6 items assessing interference with activities of daily living. Daily self-rated MDASI items, self-measured body weight, and 24-h rest-activity records were automatically transmitted to a server through the Internet via the SARA software and the LinkSmart Middleware (Figure 1b).

Figure 1. inCASA platform elements: (a) patient's equipment (computer, scale, and actigraph); (b) information system technical architecture.



Study Design and Remote Monitoring Protocol

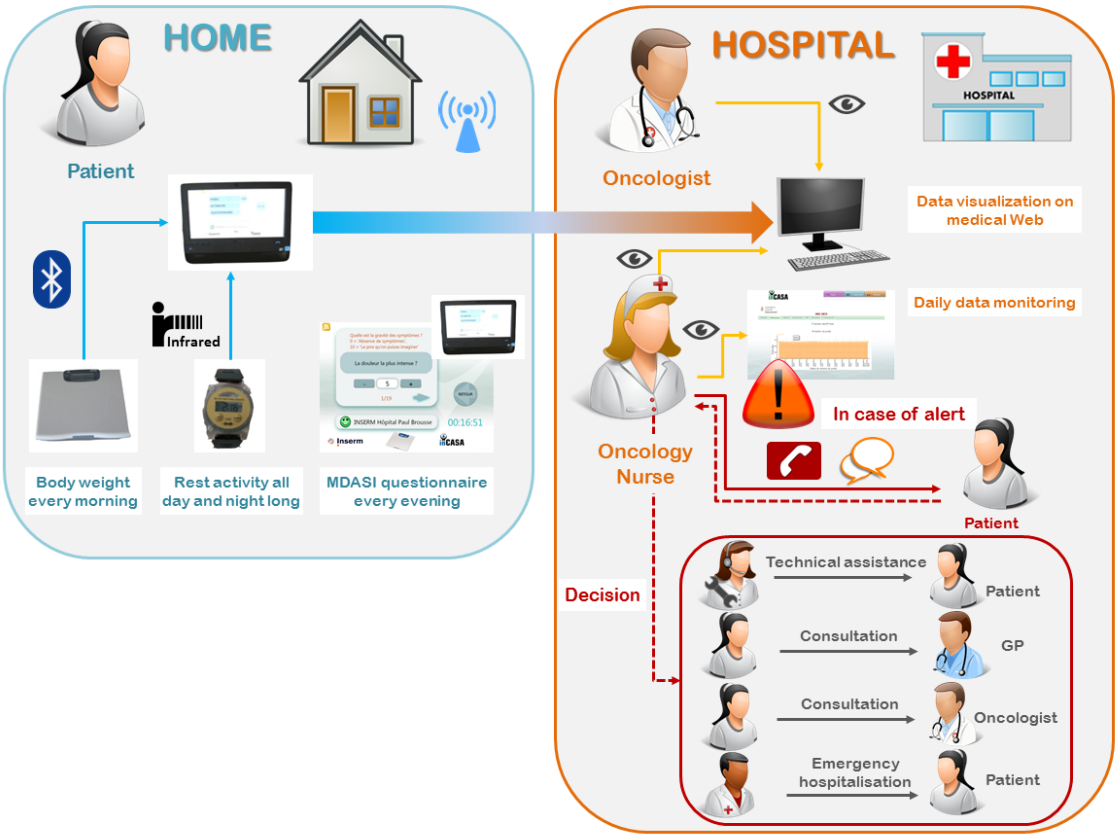
Patients were instructed to weigh themselves each morning, fill out the on-screen MDASI questionnaire each evening, continuously wear the wrist actigraph, and download the data in the evening, before or after completing the questionnaire. All the data were then transmitted daily via the Internet to the secured central server. They could be securely accessed anytime by the oncology nursing or medical staff with a dedicated graphical display (Figure 2). The per-protocol recommended study duration was 30 days for each patient. Patients were asked to extend the duration of their participation to the study for further 30 days or more, depending upon their wishes and platform availability.

Patients were asked to contact the hospital or their general practitioner (GP) as they would have normally done in case of a health concern. Nonetheless, in case of a lack of data transmission for more than 24 hours, high symptom severity, quick body weight loss, or apparent deterioration of the circadian activity pattern, the oncology nurse usually phoned the patient and organized any appropriate intervention. This could involve telephone reassurance, a home visit by a technician or a nurse,

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a patient visit to the GP or to the oncologist, or an emergency visit at the outpatient clinics or in hospitalization (Figure 2).

Figure 2. Outline of study design and remote monitoring procedures. Source of icons: pixabay.



Platform Use Compliance

The overall compliance to the platform was assessed by calculating longitudinal individual patient-day reporting rates. These were defined as the total number of days in which data were obtained divided by the duration of the period during which the platform was available for use for each participant. These rates were calculated for each parameter (body weight, MDASI, and actigraphy) separately, for at least one parameter per patient-day, and for all 3 parameters together. Furthermore, given the 3-day time frame for emergency hospitalization prediction, we also calculated the percentage of patients with a full set of data (actigraphy, body weight, and MDASI) available at least once during a sliding window of 3 days. Longitudinal analysis was performed during the initial 30 days (primary endpoint), and for the following 30 days (on-study days 31–60), whenever applicable.

The study did not include specific and structured questioning about the reasons for missing data; however, during routine consultations, the medical oncologists (PI, AU, MB, MH, JFM, and FL) were encouraged to offhand discuss the noncompliance issue with the patients.

Platform Evaluation

Participants rated their perception and satisfaction regarding the service delivered using the Whole Systems Demonstrator Service User Technology Acceptability Questionnaire (SUTAQ) [22] at study completion.

Unstructured, narrative interviews of the hospital nurses involved (RBD, VP, and MM) were performed by the main study investigators (AA, PI, and FL) to evaluate their global perception of the clinical relevance of the platform and acknowledge specific issues.

Collected Data Analysis

The daily percentage of body weight change was calculated with reference to baseline values obtained over at least three days before the initial course of on-study chemotherapy. The 19 MDASI item scores were used without any predefined threshold. The rest-activity pattern was analyzed using the Action 4 software (Ambulatory Monitoring Inc). The dichotomy index I<O was selected as being the most clinically relevant in cancer patients, according to prior work [23-31]. I<O was computed as the percentage of activity epochs when in-bed, whose values were lower than the median level of activity when out-of-bed [32]. A normal dichotomy index is one approaching 100%, indicating restful sleep in bed at night and regular and lively activity during the day, out of bed. Values of I<O in healthy controls are rarely <98% [32,33]. Here, I<O was calculated over 72 h, with 3-day sliding windows, throughout the whole time series in each patient.

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Descriptive analyses were performed for the overall distribution and individual longitudinal patterns of body weight change, of the 19 MDASI items separately, and of I<O.

Emergency Hospitalization Prediction

Time series were analyzed using Matlab (The Mathworks, Natick, MA, USA), and ranked for relevance regarding prediction of emergency hospitalizations. First, handling missing data in each of the 21 time series (19 MDASI items, body weight loss, and I<O) from each patient were interpolated according to their localization: missing data localized at the beginning (or at the end) of the time series were assumed as having the value of the first (or the last) measured value, respectively; a linear interpolation was used to compute missing data within two measured data segments. We initially tested several interpolation approaches (bi-cubic, harmonic, likelihood, and principal component analysis-based) for our sensitivity analyses, but the final results were roughly similar to those using the simple linear method (data not shown). Second, we calculated the dynamic patterns of change over time by subtracting the parameter value of each day from the average of the same parameter on the three previous days. Finally, linear discriminant analysis (LDA) was used on these computed values to determine the combination of parameters whose 3-day dynamic patterns best predicted for an unplanned hospitalization (target event). The predefined time frame for prediction was set at the 3 days preceding each emergency hospitalization event.

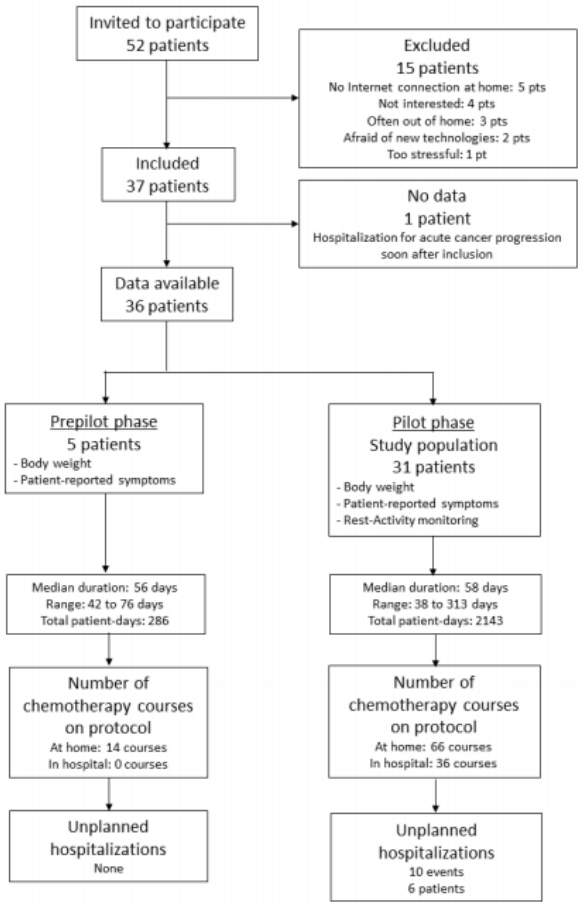
Results

Study Patients' Cohort

A total of 52 patients were screened as potentially eligible from October 2011 to August 2013 (Figure 3). Eight were not registered for technical reasons, and 7 declined participating. One patient was repeatedly hospitalized for prolonged spans because of acute cancer progression just after inclusion and could not provide any data. Five patients participated in the prepilot phase. The results reported here regard the 31 patients included in the pilot phase.

Patients aged 35-91 years (median: 61 years) participated in the study for a median duration of 58 days (range: 38-313 days). Most of them were treated for colorectal, pancreatic, or breast cancer (Table 1). The majority of patients had undergone prior surgery and received prior chemotherapy. A total of 102 chemotherapy courses were administered to the 31 patients while on-study. Six patients (19%) received 20 courses of conventional chemotherapy at the hospital (20% of courses). The remaining 25 patients (81%) were treated with 82 courses of chronomodulated chemotherapy, of which 66 (80%) were administered at home.

Figure 3. Study flowchart (Consort diagram).



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Table 1. Clinical features of the study population.

Patient characteristics	n (%)
Gender	
Male	17 (55)
Female	14 (45)
Age (years)	
35-45	4 (13)
45-55	4 (13)
55-65	11(36)
65-75	5 (16)
75-85	5 (16)
85-95	2 (6)
Median (range)	61 (35-91)
World Health Organization performance status	
0	9 (29)
1	11(36)
2	2 (6)
3	2 (6)
Not available	7 (23)
Primary tumor site	
Colon	8 (26)
Rectum	4 (13)
Pancreas	9 (29)
Breast	5 (16)
Prostate	2 (7)
Lung	1(3)
Liver	1(3)
Ovary	1(3)
Number of metastatic sites	
0	7 (23)
1	24 (77)
Comorbidities	
None	24 (78)
Diabetes	5 (16)
Hepatitis B	1 (3)
Chronic heart failure	1(3)
Prior surgery for	
None	3 (10)
Primary tumor	20 (64)
Metastases	8 (26)
Prior chemotherapy	
No prior chemotherapy	3 (9)
Adjuvant only	11 (36)
Metastatic only	1 (3)

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Patient characteristics	n (%)
Both	16 (52)
Number of prior chemotherapy protocols for metastatic disease	
None	13 (42)
One	4 (13)
Two or more	12 (39)
Unknown	2 (6)
Chronotherapy protocol while on inCASA	
Total number	25 (81)
ChronoIFLO4[a]	13 (42)
Other chrono triplets	2 (7)
Other chrono doublets	10 (32)
Conventional chemotherapy protocol while on inCASA	
Total number	6 (19)
Triplet	1 (3)
Doublet	2 (6)
Monotherapy	3 (10)
Protocol courses given on inCASA	
Total number	102 (100)
At home	66 (65)
At hospital	36 (35)
Median number per patient (range)	3 (1-14)

[a]ChronoIFLO4 is the chronomodulated combination of irinotecan, oxaliplatin, 5-fluorouracil, and leucovorin [19].

Study Compliance

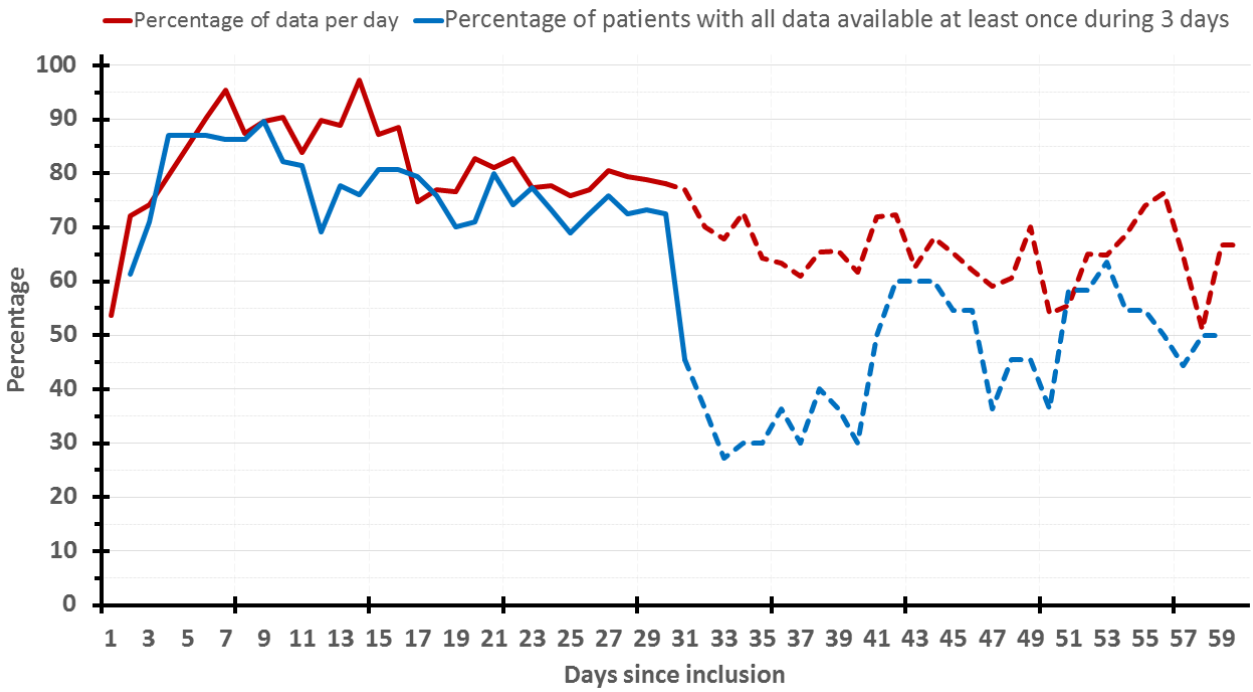
During the initial 30-day period (per-protocol), patients provided complete daily data (body weight, MDASI, and actigraphy) for a total of 522 days out of the 874 theoretical patient-day data (930 total minus the 56 days of elective or emergency hospitalizations). Hence, overall full compliance was 59.7%. Individual general compliance for each parameter was as follows: 81.7% (714/874) for body weight, 78.1% (683/874) for MDASI, and 74.7% (653/874) for actigraphy. At least one parameter for each patient-day was available in 95.0% (830/874) cases. Moreover, at least one complete set of daily data for the 3 parameters was available at least once every 3 days in 77.2% of the cases. Altogether, compliance remained rather good and stable over the per-protocol 30-day span (Figure 4). However, in the longer term (days on study 31-60), data availability decreased for those patients who opted for continuing the study beyond the per-protocol time span (Figure 4). In particular, over this subsequent 30-day span, complete daily data were provided for 38.7% (264/683) patient-days. Respective figures were 64.4% (440/683) for body weight, 61.3% (419/683) for MDASI, 62.1% (424/683) for actigraphy, and 83.0% (567/683) for at least one of them. Finally, 55.1% of patient-days had at least one complete set of data at least once every 3 days, during days on study 31-60 (Figure 4).

Individual patient compliance (available out of theoretical data) ranged from 0% to 85.7%, with a median of 56.3%.

The most common reasons for missing data, outside planned or emergency hospitalizations (125 patient-days), were informally reported to be technical problems, out-of-home trips, and patient forgetting or feeling too sick.

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Figure 4. Long-term longitudinal compliance rates. The red curve shows the percentage of available data per day (MDASI counted as one), and the blue one, the percentage of patients with all data (actigraphy, body weight, and MDASI) available at least once during 3 days. The solid curves plot the initial 30 days (per-protocol period), and the dashed ones, the following 30 days (day 31-60). MDASI: MD Anderson Symptom Inventory.



Platform Evaluation

Fifteen patients completed the SUTAQ questionnaire, which was offered at mid study course to 22 patients (results detailed in Table 2). The general satisfaction rate was 84%. The system was perceived to enhance care for 80% of the patients; 87% of the participants indicated that it did not interfere with their life or privacy. However, 67% of them considered that it could not be used as a substitution for the current health care. No patient in the study offhand recounted any major issues appreciated in the platform to the physicians, nurses, or technicians. Whenever specifically questioned, patients expressed generally positive comments on the platform, as a usable additional health care tool, in agreement with the subgroup completing SUTAQ.

All 3 surveyed hospital nurses involved in this study spontaneously reported the perception that the system globally improved the follow-up of the health condition of the patients, in comparison to the current standard procedure. They also acknowledged, nevertheless, that some technical problems interfered with their experience, especially when recurring in the same patient, and proposed that dedicated personnel ought to be allocated to such domomedicine task. Finally, the system usability was altogether recognized by the 3 nurses independently as operational for larger-scale deployment.

Table 2. Perception and satisfaction results[a].

	SUTAQ[b] items					
Outcomes	Enhanced care	Increased accessibility	Privacy and discomfort	Care personnel concerns	Kit as substitution	Satisfaction
Mean item score	3.8	3.0	4.2	3.6	3.1	4.2
General satisfaction with the item	77%	60%	83%	72%	62%	84%
Number of patients satisfied with the item	12	7	13	10	5	14
Percentage of patients satisfied with the item	80%	47%	87%	67%	33%	93%

[a]Responses to the SUTAQ questions were measured using a 5-point Likert scale.

[b]SUTAQ: Service User Technology Acceptability Questionnaire.

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Table 3. Distribution of objective and subjective collected data during the study.

Parameters	Median	1st; 3rd quartiles	Range (min to max)
Objective			
Body weight change (%)	–0.4	–2.0; 0.9	–10.5 to 6.0
I<O (%)	98.3	96.6; 99.1	82.5 to 100
Subjective			
MDASI[a] symptom items			
Pain	2	0; 4	0 to 10
Fatigue	4	2; 5	0 to 10
Nausea	0	0; 2	0 to 10
Disturbed sleep	2	0; 4	0 to 9
Distress	3	1; 5	0 to 10
Shortness of breath	2	1; 5	0 to 9
Problem with remembering things	1	0; 2	0 to 8
Lack of appetite	2	0; 5	0 to 10
Drowsiness	2	0; 4	0 to 8
Dry mouth	1	0; 5	0 to 10
Sadness	2	0; 5	0 to 9
Vomiting	0	0; 0	0 to 10
Numbness or tingling	1	0; 3	0 to 10
MDASI interference items			
General activity	4	2; 5	0 to 10
Mood	2	0; 4	0 to 9
Work	5	2; 6	0 to10
Relations with others	2	0; 4	0 to 9
Walking	3	1; 5	0 to 10
Enjoyment of life	3	2; 5	0 to 10

[a]MDASI: MD Anderson Symptom Inventory.

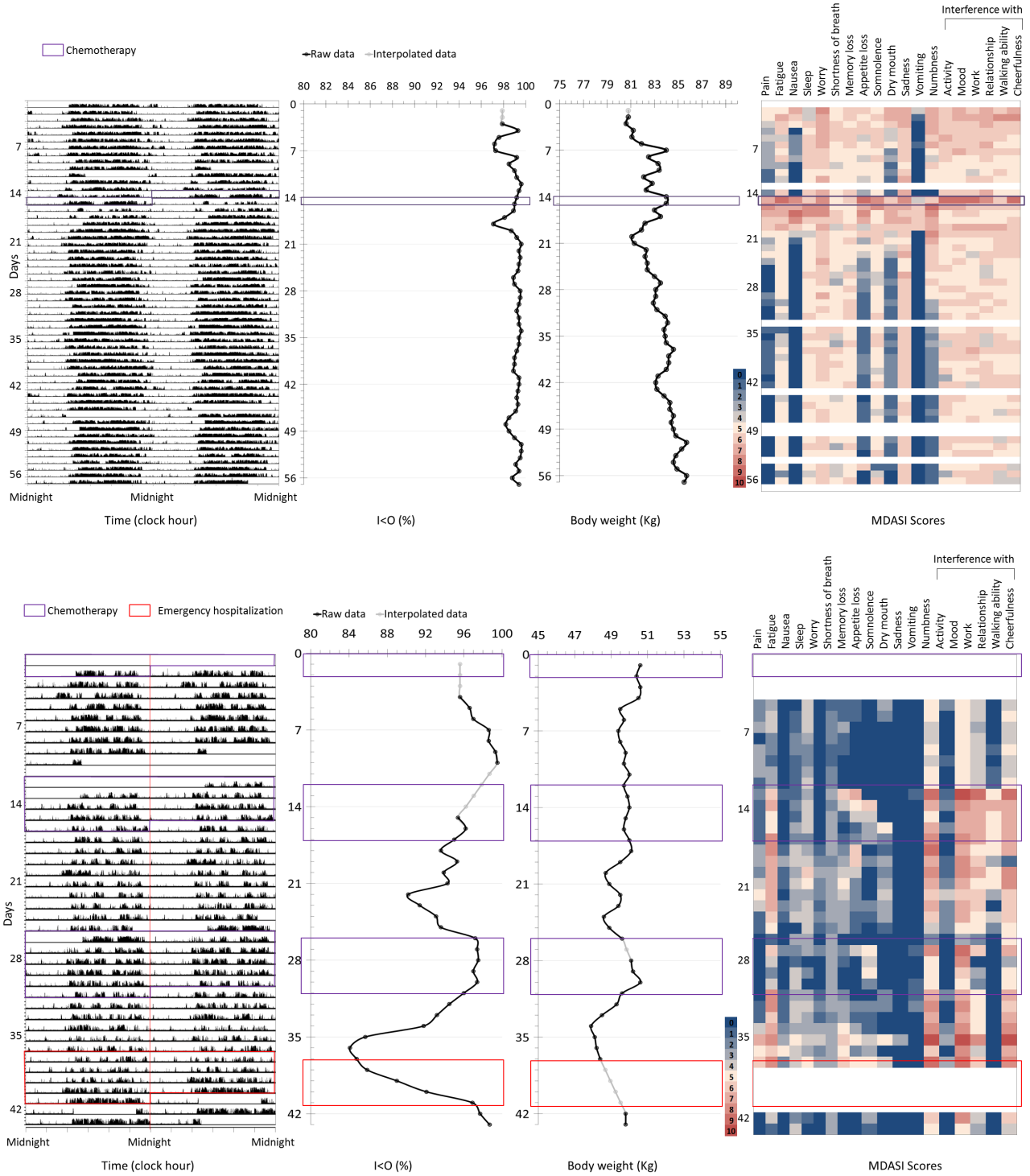
Descriptive Analysis of Collected Data

The quartiles and extreme values of body weight change, I<O, and individual MDASI items for all patients throughout the whole study span are shown in Table 3.

The dynamics of rest-activity patterns, computed I<O values, body weight changes, and MDASI items scores are depicted for 2 representative patients over 57 and 44 days, respectively (Figure 5).

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Figure 5. Representative examples of the multidimensional data available for 2 patients over 57 (top) and 44 (bottom) monitoring days, respectively. From left to right: first panels: actigraphy recording (midnight-centered double plot; Y-axis: activity counts per minute); second panels: corresponding daily I<O values; third panels: daily body weight change; fourth panels: daily MDASI items (heat map; white represents missing values, blue through yellow to red, increasing values from 0 to 10). Purple boxes represent the days during which chemotherapy was administered. In the bottom plot, the red box represents the duration of an emergency hospitalization. MDASI: MD Anderson Symptom Inventory.



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Emergency Hospitalizations

An emergency hospitalization event occurred after 9.8% (10/102) chemotherapy courses in 6 patients (19%). Thus, 5 participants underwent a single unplanned hospitalization, and 1 patient was hospitalized 5 times. Table 4 details the most relevant characteristics of these hospitalization events. Appropriate symptomatic treatment was administered as indicated, with discharge at home in all cases.

Table 4. Clinical features of patients involved and events regarding unplanned hospitalizations.

Patient characteristics	n (%)
Gender	
Male	2 (33)
Female	4 (67)
Age in years, median (range)	60 (52-91)
Chemotherapy protocols followed by unplanned hospitalization, n=10	
Type of delivered chemotherapy	
Chronotherapy	9 (90)
Conventional chemotherapy	1 (10)
Location of treatment delivery	
At home	5 (50)
At hospital	5 (50)
Hospitalizations, n=10	
Number per patient	
Only one hospitalization	5 (83)
More than one hospitalization	1 (17)
Hospital stay (days), median duration (range)	6 (2-9)
Causes	
Gastrointestinal symptoms with general physical deterioration	5 (50)
Febrile neutropenia	3 (30)
Sepsis	1 (10)
Asthenia with poor general condition	1 (10)

Early Warning Signals Predicting Emergency Hospitalizations

A global decrease in average daily rest-activity I<O values was observed over the 2 weeks preceding an unplanned hospitalization (Figure 6a). No such trend was obvious for body weight changes (Figure 6b). Some patient-reported symptoms, such as interference with work or lack of appetite, appeared to worsen on average before an unplanned admission, while others, such as problem with remembering things, did not display congruous changes over the same time span (Figure 6c).

LDA identified the model with the relative weights for the dynamic patterns in circadian rest-activity I<O parameter, body weight change, and MDASI scores, which best predicted for a subsequent emergency hospitalization during the following 3 days (Table 5). Testing the model on the whole dataset (initial 30 days for learning and additional 30 days for validation) yielded a sensitivity of 55.5%, a specificity of 94.6%, a positive predictive value of 12.7%, and a negative predictive value of 99.3% (Table 6). Hence, global accuracy was 94.0%. Sensitivity analyses confirmed the results of the main predictive model, with the highest loading weight assigned to I<O and a cluster of MDASI items connected to interference with relations, daily activities, and appetite.

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Table 5. Coefficients of all the 21 items (ranked) of the final predictive linear discriminant analysis (LDA) model.

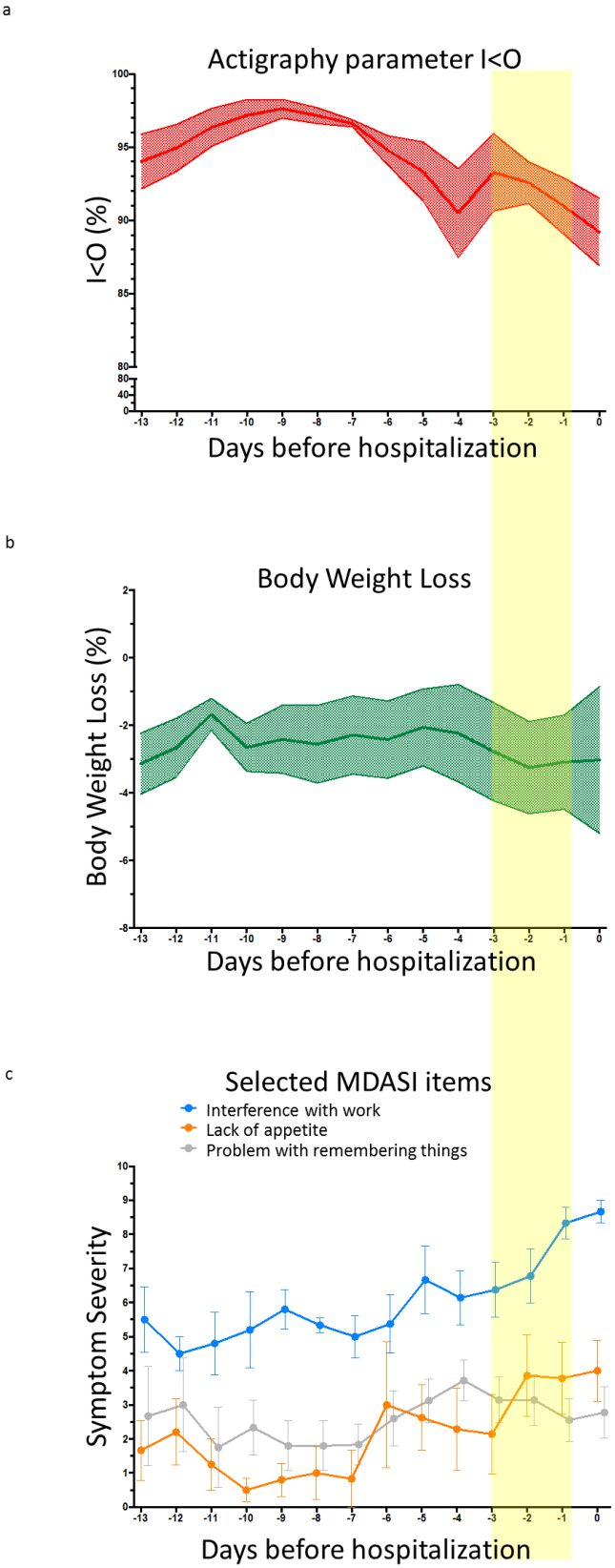
Parameter	Coefficient
Shortness of breath	–0.945
I<O	0.772
Relations with others	0.634
Work	–0.492
Disturbed sleep	0.473
Drowsiness	–0.466
Sadness	0.435
Distress	–0.351
Problem with remembering things	–0.335
Vomiting	0.283
Numbness or tingling	0.221
Mood	0.198
General activity	0.153
Nausea	–0.136
Enjoyment of life	–0.128
Dry mouth	0.097
Walking	0.089
Lack of appetite	–0.089
Pain	0.065
Body weight change	–0.025
Fatigue	–0.009

Table 6. Confusion matrix regarding prediction of unplanned hospitalization.

Patient/day	Actual event	
Predicted	Yes	No
Yes	10	69
No	8	1203

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Figure 6. (a) Average (and standard error of the mean) daily I<O values, (b) body weight change, (c) and 3 selected MDASI items in the 2 weeks preceding unplanned hospitalizations (n=10). The yellow bar highlights the 3 days preceding the emergency hospitalization, used for the predictive analysis (LDA). MDASI: MD Anderson Symptom Inventory, LDA: linear discriminant analysis.



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Discussion

Main Results

Continuous telemonitoring of circadian rest-activity rhythm, jointly with daily body weight and self-reported symptoms, was implemented for the first time in the home of patients receiving chemotherapy for advanced cancer. The inCASA domomedicine platform was found to be adequate for such purpose, since it was well accepted by the patients and provided an unprecedented amount of multidimensional data over prolonged time spans. Furthermore, the integration of the subjective and objective data translated into accurate information able to predict subsequent emergency hospitalization (Table 6). Thus, such novel telehealth system carries out a number of potential clinical applications.

Comparison With Prior Studies

The inCASA platform was home located and Web-based, but it did not require to log-in, in contrast to other telehealth studies [5,34-36]. The multiparameter monitoring performed here was not limited to patient-reported outcomes, as it is usually the case [5,34,35,37]. In contrast, teletransmitted parameters also included objectively measured body weight and wrist activity pattern (Figure 2). This required technical innovations for minimizing patient discomfort and maximizing compliance. Both parameters were chosen on the basis of previous results relating altered circadian rest-activity rhythm to poor outcomes [23,25,27], body weight loss to circadian disruption [24], and both parameters to poor survival outcome on chronotherapy [38]. The proper tracking of the dynamic changes in these parameters entailed the need for daily measurements, whereas other authors have proposed evaluations of symptoms and quality of life once a week or at each clinic visit [4,5,34,35,39,40]. With an overall 59.7% per-protocol compliance rate, and with 95% of the days having at least one data, our study demonstrates the feasibility of cancer patients' empowerment for gathering and teletransmitting both subjective and objective health-related data. Moreover, the compliance appeared altogether stable over time during the per-protocol span (Figure 4), inferring possible long-term use. However, the sustainability of such platform in daily clinical practice cannot be definitely foretold with this study, as it did not include cost-effectiveness analysis or payment stakeholders' involvement.

Limitations

Although the platform workflow was well accepted by patients altogether, some technological aspects could be refined to increase both comfort and convenience, thus further improving compliance rates in view of a prolonged use. For example, circadian rest-activity rhythm data could be automatically and seamlessly transmitted to the home-based platform, and thereupon to the central server, resulting in less end-user manipulations. Additionally, hospital nurses indicated the positive impact of timely technical support for the implementation of this patient-centered approach, confirming previous report [41]. On some occasions, patients were unable to provide data due to traveling away from home, suggesting the relevance of lightweight mobile systems for further developments. Thus, a handheld computer was used to record self-reported and objective measures in oncologic outpatients with satisfactory acceptance and reliability [39]. Similarly, smartphone-based apps have been successfully tested for frequent symptom evaluation and toxicity management in patients on chemotherapy [9,42]. Such mobile technology could further enhance long-term compliance, as suggested [35,37]. However, certain features of the solution will need to be modified, including the addition of a log-in component for authentication on the main mobile device, required to be connected to the Web via secure wireless network for data transfer protocol, and the possibility of manually adding body weight. Nonetheless, the wearable device, the interface of the main technical equipment, the server-based system, and the remote monitoring procedures will allegedly not require significant modifications.

Perspectives

Notwithstanding these amendable technical issues, this study identified, for the first time, a combination of subjective and objective parameters whose dynamics predicted the occurrence of emergency hospitalization within 3 days from the event with an accuracy of 94%. Thus, the integrated multiparametric assessment, including body weight and circadian rest-activity rhythm jointly with subjectively rated symptoms, provided a novel framework for the early detection of severe adverse events that will require hospital admission within 3 days. These data allow foreseeing the timely triggering of proactive interventions to improve the safety of treatment administration at home while potentially reducing the financial burden on health care providers [43,44]. Indeed, less frequent emergency room visits were described from adequate nurse-initiated response during routine cancer care involving weekly remote monitoring of self-reported symptoms [36].

This pilot study was mainly observational; hence, no predefined decisional pathway or procedures were implemented according to telemonitored data. Notwithstanding, common sense and prudence led the investigators to off-protocol contact patients in case of missing data, mainly for reasons not requiring medical attention, or, less often, in case of parameter deterioration (Figure 2). In this study we could not quantify the benefit to the patients related to early interventions prompted by observed alterations in I<O, body weight change, or MDASI items, but it was probably realistic to assume that, in some cases, contacting the patient and eliciting a rapid and opportune medical care response could have avoided more severe outcomes, even if these procedures were informally executed (Figure 2).

Such hypothesis of patient benefit from a telemonitoring-guided proactive intervention is being tested within a multicenter domomedicine French study, using a second-generation platform (PiCADo) [12]. The study involves patients receiving multidrug chronotherapy at home, using the acquired expertise and the a posteriori predictive model derived from the current study. Moreover, the forecasting analysis applied in the current study provides an evolving methodological framework, whose prediction ability improves through learning based on data enrichment stemming from forthcoming studies.

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Finally, besides low I<O that defines altered circadian rhythms, the MDASI items most strongly associated with subsequent unplanned hospitalization have been linked to circadian disruption (fatigue, appetite loss, and poor physical, social, and role functioning) [23,24,26,27,45]. Therefore, these findings bolster the clinical relevance and warrant the implementation of circadian rhythms monitoring in medical oncology [15].

Conclusions

The inCASA solution allowed monitoring not only of patient-reported symptoms, but also of circadian rest-activity patterns and of body weight in cancer patients on chemotherapy, while they were at home. These unique and novel data provided useful information to health care and social care professionals for the follow-up of patient's well-being. The ultimate paramount benefit of this approach is the increased safety of chemotherapy administration at home. In our experience, this multidimensional telemonitoring represented an effective, accurate, and refined tool for identifying patients at risk for emergency hospitalization, allowing in the future the development and timely triggering of preemptive, coordinated, and befitting interventions to prevent such unplanned admissions, within a domomedicine approach.

Acknowledgments

The authors wish to thank the European Commission through the ICT Policy Support Programme project inCASA (Contract CIP 250505, FP7), Conseil Régional d'Ile de France and OSEO, Fonds Unique Interministériel 12 (Contract PiCADo), Institut de Recherche en Santé Publique (Contract CLOCK-DOM1), and CASyM (Coordinating Action Systems Medicine) research grants in Systems Medicine.

The study has been presented in part at the 2012 Annual Meeting of the American Society of Clinical Oncology, Chicago, IL, USA, and at the 39th Annual Meeting of the European Society of Medical Oncology, Madrid, Spain.

Conflicts of Interest

None declared.

Authors' Contributions

The study was co-conceived by PFI, AA, JF, and FL. Funding resources were mainly obtained by JF and FL, and the study management was carried out by AA and AK. Technical supervision was assured by SK, AA, and JRS. Methods were designed by PFI, SK, AMD, AA, JB, JF, JRS, and FL. PFI, AU, MB, MH, JFM, and FL included patients in the study. Data were collected and curated by PFI, SK, AA, AU, MB, MH, RBD, VP, MM, DB, AK, JFM, and FL. Data analysis was performed by PFI, SK, AMD, AA, JB, and FL. Data interpretation involved all coauthors. PFI, SK, AA, MA, and FL led manuscript drafting. Its editing and final approval involved all coauthors.

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Abbreviations

I<O: dichotomy index
LDA: linear discriminant analysis
MDASI: MD Anderson Symptom Inventory
PS: performance status
SUTAQ: Service User Technology Acceptability Questionnaire
WHO: World Health Organization

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Edited by G Eysenbach; submitted 06.07.16; peer-reviewed by M Larsen, JH Lee, R Patel; comments to author 04.08.16; revised version received 07.09.16; accepted 20.09.16; published 25.11.16.

Please cite as:
Innominato PF, Komarzynski S, Mohammad-Djafari A, Arbaud A, Ulusakarya A, Bouchahda M, Haydar M, Bossevot-Desmaris R, Plessis V, Mocquery M, Bouchoucha D, Afshar M, Beau J, Karaboué A, Morère JF, Fursse J, Rovira Simon J, Levi F
Clinical Relevance of the First Domomedicine Platform Securing Multidrug Chronotherapy Delivery in Metastatic Cancer Patients at Home: The inCASA European Project
J Med Internet Res 2016;18(11):e305
URL: http://www.jmir.org/2016/11/e305/
doi:10.2196/jmir.6303
PMID:27888171

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Original Paper

Impact of Information Technology–Based Interventions for Type 2 Diabetes Mellitus on Glycemic Control: A Systematic Review and Meta-Analysis

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Abstract

Background: Information technology–based interventions are increasingly being used to manage health care. However, there is conflicting evidence regarding whether these interventions improve outcomes in people with type 2 diabetes.

Objective: The objective of this study was to conduct a systematic review and meta-analysis of clinical trials, assessing the impact of information technology on changes in the levels of hemoglobin A_{1c} (HbA_{1c}) and mapping the interventions with chronic care model (CCM) elements.

Methods: Electronic databases PubMed and EMBASE were searched to identify relevant studies that were published up until July 2016, a method that was supplemented by identifying articles from the references of the articles already selected using the electronic search tools. The study search and selection were performed by independent reviewers. Of the 1082 articles retrieved, 32 trials (focusing on a total of 40,454 patients) were included. A random-effects model was applied to estimate the pooled results.

Results: Information technology–based interventions were associated with a statistically significant reduction in HbA_{1c} levels (mean difference −0.33%, 95% CI −0.40 to −0.26, P<.001). Studies focusing on electronic self-management systems demonstrated the largest reduction in HbA_{1c} (0.50%), followed by those with electronic medical records (0.17%), an electronic decision support system (0.15%), and a diabetes registry (0.05%). In addition, the more CCM-incorporated the information technology–based interventions were, the more improvements there were in HbA_{1c} levels.

Conclusions: Information technology strategies combined with the other elements of chronic care models are associated with improved glycemic control in people with diabetes. No clinically relevant impact was observed on low-density lipoprotein levels and blood pressure, but there was evidence that the cost of care was lower.

(J Med Internet Res 2016;18(11):e310) doi:10.2196/jmir.5778

KEYWORDS

diabetes mellitus; medical informatics applications; technology

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Introduction

Chronic diseases such as diabetes can be managed better by implementing system-wide practices such as the chronic care model (CCM). This model identifies 6 components as essential for chronic disease management: health system organization, delivery system design, self-management support, community resources, decision support, and clinical information systems [1]. The CCM is globally applied to support system changes in diabetes management and places particular emphasis on the use of information technology [2]. Advanced information technologies enhance communication among and between health care providers and patients [3] and improve chronic disease management [4]. Various information technology applications are currently available, including electronic patient registers, electronic decision support systems, electronic medical records (EMRs), telemedicine, videoconferencing, and electronic self-management systems [5]. Advanced informatics technology can aid the monitoring of hemoglobin levels, improve clinical practices, and help eliminate the health problems caused by diabetes [6].

Several systematic reviews evaluated the potential benefits of information technology–based diabetes management interventions, and all concluded that information technology–based interventions could improve diabetes management for adult care [7-11]. However, they did not extend their focus to consider blood glucose measurements using meta-analysis techniques or map interventions incorporating CCM elements. Therefore, this systematic review aimed to determine the effect of information technology–based elements of the CCM on glycemic control in people with type 2 diabetes mellitus (T2DM).

Methods

Search Strategy

A comprehensive literature search was conducted using PubMed and EMBASE for articles focusing on information technology–based diabetes interventions, which were published up until July 2016. A search strategy that combined keywords and Medical Subject Headings (MeSH) using the terms “diabetes,” “diabetes mellitus,” “non-insulin-dependent,” “diabetes type 2,” and “informatics” was used. In addition, international journals were searched manually and the reference lists from retrieved articles were reviewed in order to identify additional, relevant papers (Table 1).

Inclusion and Exclusion Criteria

Titles and abstracts of all studies identified were independently reviewed by 2 reviewers (NSA and NA) from February to July 2016. Any discrepancies between the choices of the 2 reviewers were resolved by another reviewer (SDL). The inclusion and exclusion criteria for the study are presented in the Textboxes 1 and Textboxes 2, respectively.

Table 1. Search strategies.

Database	Search terms	Number of studies
PubMed	1: “Diabetes Mellitus”[Mesh]	22,247
	2: “Medical Informatics Applications”[Mesh]	37,851
	1 and 2	425
EMBASE	2: 'diabetes'/exp AND 'mellitus'/exp	537,195
	1: 'information'/exp AND 'technology'/exp	28,774
	1 and 2	557

Textbox 1. Inclusion criteria for the study.

- The study design specifically evaluated the use of information technology–based interventions for the management of diabetes mellitus or T2DM, but the authors also included studies where information technology was part of a comprehensive intervention in which the impact of the information technology element was reported separately
- The study focused on T2DM or both type 1 and type 2 diabetes mellitus, because T2DM accounts for more than 90% of all diabetes cases [12]
- The study reported glycated hemoglobin (hemoglobin A_{1c} or HbA_{1c}) as an outcome measure
- The study had one of the following study designs: randomized controlled trial, nonrandomized controlled trial, and before-after trial

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Textbox 2. Exclusion criteria for the study.

- Reviews lacking original study data
- Studies that evaluated information technology–based interventions in other chronic diseases
- Studies published in languages other than English or Arabic
- Studies of children with diabetes, as very few have T2DM, or studies of pregnant women with gestational diabetes, as this is not T2DM (even though people with gestational diabetes are at an increased risk)
- Papers using the same data as those already selected for use in the review

Data Extraction and Quality Assessment

Two reviewers (NH-NS) independently reviewed the title, the abstract, and the article. Discrepancies were resolved by consensus or determined by other reviewers (SDL). Information was taken from each study using a predesigned collection form: authors, date of the study, technology type, country, study site, duration of the intervention, type of diabetes, study design, communication type, main user, number of participants, and outcome measures. Relevant missing data were obtained from authors. A qualitative review was performed to extract information about the clinical and process outcome measures: body weight, systolic blood pressure, diastolic blood pressure, low-density lipoprotein (LDL) cholesterol, high-density lipoprotein, process of care, cost of care, patients' satisfaction, smoking levels, and medication adherence. As part of data collection, quality assessment for each included study was conducted using PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines [13]. The studies were assigned a quality score ranging from 0 to 7 based on certain criteria (each item scored 1 point; the total score was 7), as depicted in Textbox 3.

Textbox 3. Criteria for assigning the quality score.

- Whether the study design was randomized
- Whether the study described criteria for selection of participant
- Whether both groups had similar baseline
- Whether the study described the intervention methods
- Whether the study evaluated the interventions after 6 months or more
- Whether the study used intention-to-treat analysis
- Whether the study reported method of blinding

Data Analysis

The outcome measure was the changes in HbA_{1c} levels from baseline to follow-up. HbA_{1c} is recognized as a significant indicator of information technology–based intervention effectiveness in patients with T2DM because it reflects average glycemia over 8 weeks and is strongly associated with diabetes complications [14,15]. A heterogeneity test (random-effects model) was used to evaluate variation between the studies. In addition, meta-analysis was used to assess the effectiveness of information technology–based interventions according to the type of technology used. All analyses were performed using the R Project for Statistical Computing program (AT&T Labs) [16]. HbA_{1c} is recognized as a valuable indicator of treatment effectiveness in patient with T2DM, because it reflects average glycemia over several months, unaffected by self-report bias, and strongly associated with T2DM complications [17].

Results

Study Selection and Characteristics

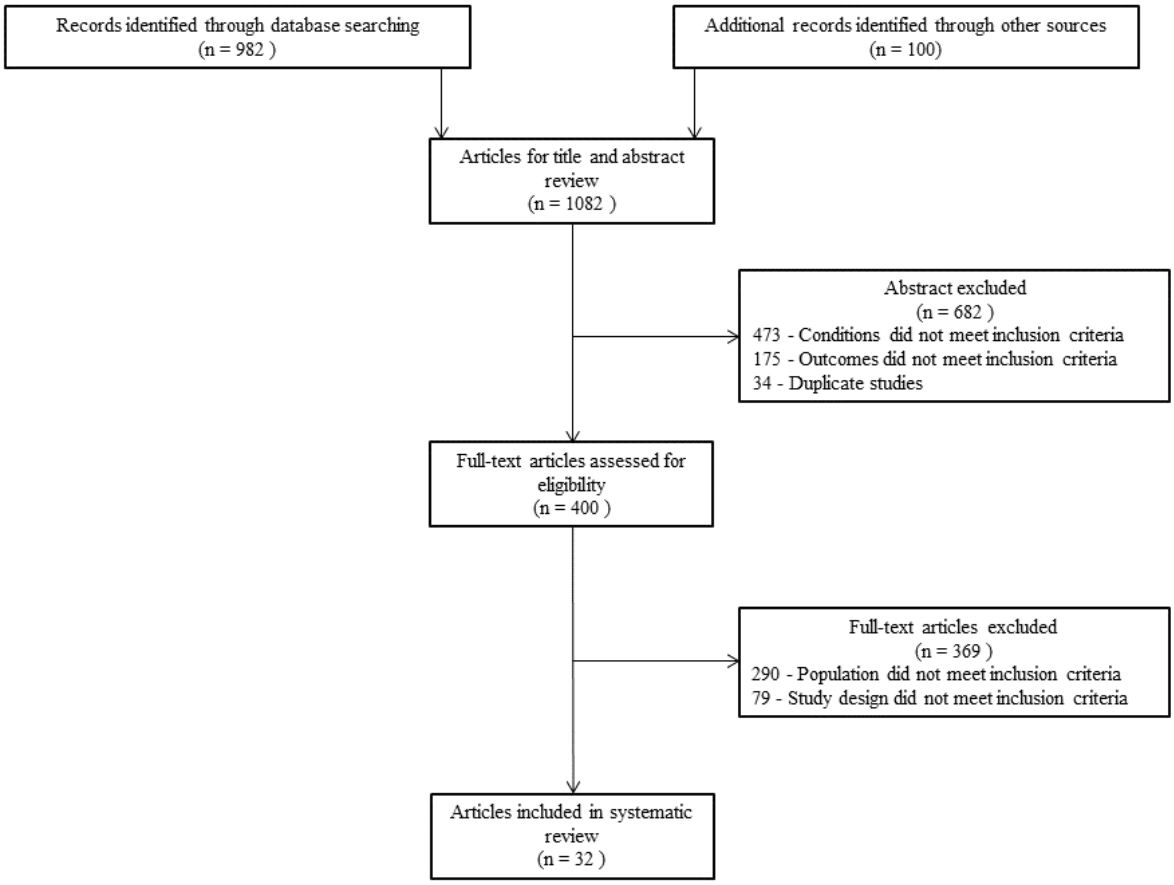
The data search produced 982 studies and a further 100 studies were identified by manual searching and from the references of included articles, giving a total of 1082 studies. A flow diagram of the search and selection process is shown in Figure 1. The data search identified 1082 relevant studies, but 682 studies were excluded after title or abstract analysis. Therefore, 400 full-text studies were assessed for eligibility after excluding 34 duplicates (as well as 648 studies that did not address the topic under consideration). At the final stage of eligibility assessment, 369 articles were excluded, and the remaining 32 studies were included in this review.

All 32 studies selected for the review were published in English. Included studies had a total of 40,454 patients, more than half of them with both type 1 diabetes mellitus (T1DM) and T2DM, the others suffering from T2DM alone. Most of the included studies were conducted in the United States, while the 5 remaining studies were carried out in the United Kingdom [18], Korea [19], Germany [20], the Netherlands [21], and Canada [22], with the majority published after 2005. Study duration ranged from 3 months to 36 months; the main characteristics of the included studies are summarized in Multimedia Appendix 1. The intervention was targeted at monitoring diabetes care. As our meta-analysis was designed to specify, all studies included different types of technologies. The interventions had varying degrees of complexity. Information technology–based intervention strategies included different combinations of transmission of data, reminders, and data storage: 4 studies used a diabetes registry [18,23-25], 3 studies used EMRs [26-28],

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18 articles used electronic patient self-management technology [19,29-45], and the other studies used electronic decision support systems (7 studies) [20-22,46-49].

Figure 1. Study selection process.



Applications of Technologies

Four types of technological applications were identified as constituting the information technology–based intervention: electronic self-management system, electronic decision support system, diabetes registry, and EMRs. In some studies a combination of 2 technologies was identified. However, we categorized the types based on the main technology used in such cases.

Electronic Self-Management System

Out of 32 articles, 18 used electronic self-management tools [19,29-45]. These studies have applied several tools designed for electronic self-management systems, and the technologies have all shown to be successful. In this category, patients made use of the Internet, mobile phones, telemedicine, or other technologies to enhance their self-management, essentially to access diabetes health education programs or to communicate with clinicians.

In this group, the best weighted mean change in HbA_{1c} level, −1.86%, was reported in the study by Smith et al [37]. To elaborate, the baseline HbA_{1c} level was 10.83% (intervention group) and 11.08% (control group; P<.001). HbA_{1c} level in intervention and control groups at 9 months was 7.68% and 10.83%, respectively (P=.02). In this study, patients used the MyCareTeam system, which gives people with diabetes the opportunity to log in and receive information about their condition, provides a portal for patients to log their blood glucose readings, and creates a space in which patients can discuss their condition with physicians and exchange information related to diabetes management. This technology was found to improve long-term glycemic control where a 1% decrease in HbA_{1c} levels is associated with a 35% decrease in nerve damage, vision loss, and kidney disease, a 22% decline in peripheral vascular disease, an 18% reduction in the likelihood of suffering a heart attack, and a 25% reduction in diabetes-related deaths of all types [37].

Decision Support System

Out of 32 articles, 7 used a decision support system [20-22,46-49]. Tools belonging to this system were used to process data and provide recommendations and alerts to providers and their patients. Studies in this category utilized advanced forms of technology such as telemedicine, touch screen, computer-aided assessment, and Web-based diabetes trackers. In this group 71% of studies showed improvements in glycemic levels. The best improvement in HbA_{1c} level in this group was observed in a study by Augstein et al [20] (−0.34% in the intervention group vs 0.27% in the control group; P<.011).

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This randomized trial enrolled adult patients with T1DM or T2DM and who were recruited from 5 outpatient centers. The decision support system tool that was used is the Karlsburg Diabetes Management System (KADIS). This system is an interactive, computerized, personalized decision support system for T1DM and T2DM. It allows for visualization of the current, characteristic daily HbA_{1c} profile, identification of individual weak points, and interactive simulation procedures to predict outcomes of therapeutic strategies and lifestyle changes in HbA_{1c} profiles [20].

Diabetes Registry

Diabetes registry was the primary intervention in 12% (4/32) of the included studies [18,23-25]. The impact of diabetes registries on improving care was difficult to quantify because the registries performed many different functions. Although several studies have demonstrated improvements in the process of care delivery, the mechanism that accounts for this improvement is far from clear. Any improvement in the HbA_{1c} level was modest [18,23-25], and strict entry criteria in another study left very little scope for improvement.

In one study, a pragmatic, cluster randomized controlled trial was conducted over a period of 15 months, with 3608 adult patients with T2DM, older than 35 years, and clients of 58 general practices from 3 localities in England. The intervention was a computerized diabetes register that incorporated the diabetes recall and management system. The registers were based on structured datasets completed on paper forms and laboratory reports. The results revealed that the intervention group demonstrated a decline in the mean level of HbA_{1c}, down to 7.32%. In addition to the improvement of the clinical outcome, the study also demonstrated improvements in the clinical process, including foot examinations, 67.3% (P<.05); dietary advice, 46.3% (P<.05); and blood pressure monitoring, 71.4% (P<.05) [18].

Among the studies, 2 randomized controlled trials did not show a significant improvement in the levels of HbA_{1c} [24,25]. However, the first of these evaluated the effects of a registry-generated audit for diabetes, as well as feedback and patient reminder interventions on diabetes care, for 483 diabetic patients [24]. The registry was integrated electronically with other clinical information systems, automatically queried clinical databases, and reported summaries. After 12 months of evaluation, the study demonstrated that the hemoglobin levels were not different for either the intervention group or the control group.

Electronic Medical Record

Only 3 out of 32 studies utilized EMR as the primary technological equipment [26-28]. The EMR was used as a decision support system or was integrated with Web-based personal health records. Out of the 3 articles in this group, 2 showed improvement in clinical outcomes, with O'Connor et al highlighting the best improvements in HbA_{1c} levels. In this study the impact of EMR was evaluated over 12 months, in 11 clinics, and involving 2556 diabetic patients. The implementation of the EMR was associated with significant improvements in HbA_{1c} level (8.5%-7.9%, P<.011) and systolic blood pressure control but no improvement in LDL cholesterol levels [26].

Types of Technology Used

This systematic review has identified 4 broad categories of T2DM management technologies. Electronic self-management technologies were a major component of studies targeting patients. These technologies may be placed broadly into 4 categories. The first category is the Web-based intervention that is based on interactive websites. Patients upload their data and receive feedback at a time most convenient for them and are not limited to clinic office hours [29-32,36,38,45]. The second category is the telephone-based system, where patients regularly submit data about their conditions and they receive instructions and feedback through telephone calls performed by diabetes clinicians for follow-up or drug adjustment [34,39,40]. The third category is a mobile phone–based system, where patients use their mobile phone to upload their data manually or by connected glucometer, and then all data stored can be transmitted directly to their clinicians [19,42]. The last category is the telemedicine, which is a useful technology for consulting [41].

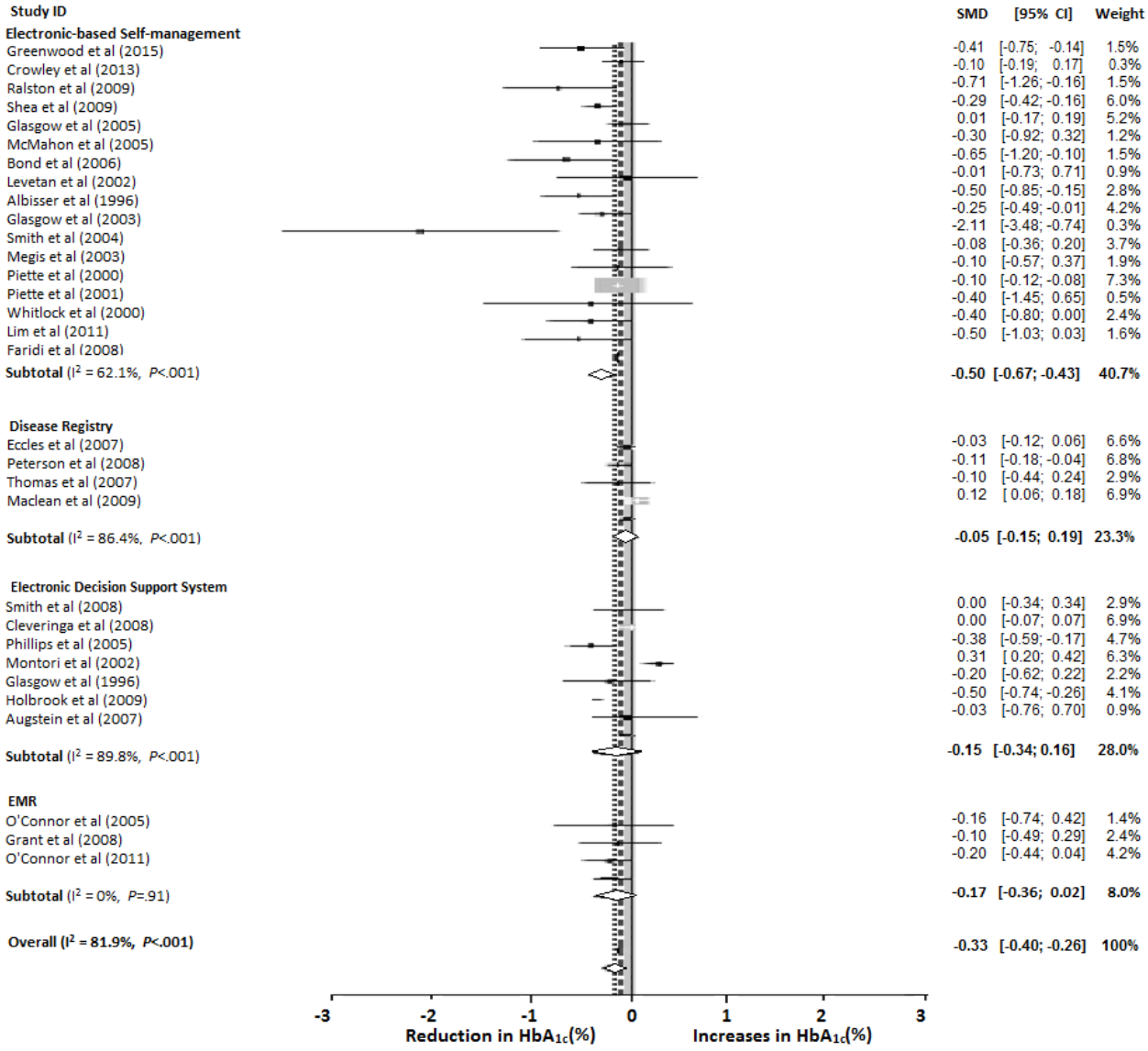
EMRs and disease registries facilitate care providers to conduct clinical audits, provide them with reports for analyzing a patient's key diabetes-related measures, and assist in tracking the patient's progress. Registries are a central component of the CCM within both the public and private health sectors. Previous studies have suggested that their use correlates with improved outcomes for patients with diabetes [50]. The use of a diabetes registry can improve clinical outcomes, including HbA_{1c} levels [18,23,24]. Also, information technology has been used as a decision support system based on several tools such as clinical guidelines, condition-specific order sets, or reminders that linked to specific patient data such as blood pressure, cholesterol level, hemoglobin control, and annual eye and foot screenings, with the advice given to the physicians based on evidence-based guidelines.

The Effects of Information Technology–Based Interventions on HbA_{1c}

The overall effect of different information technology–based interventions on the mean reduction in HbA_{1c} level was 0.33% (95% CI −0.40 to −0.26, P<.001; Figure 2). For the 4 information technology–based interventions, studies focusing on electronic self-management systems demonstrated the largest reduction in HbA_{1c} level (0.50%), followed by those with EMRs (0.17%), an electronic decision support system (0.15%), and a diabetes registry (0.05%).

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Figure 2. The reduction in HbA1c values by the type of information technology–based intervention. EMR: electronic medical record. Horizontal lines: confidence intervals, squares: means, diamonds: pooled estimated measures. SMD: standardized mean difference.



Discussion

Principal Findings

This study reviewed clinical trials that assessed the effect of information technology on glycemic control of patients with T2DM. This systematic review (32 studies, 40,454 patients) shows that information technologies achieved a significant reduction in glycated hemoglobin in patients with T2DM. Significant positive effects on HbA_{1c} levels were found in 30 studies. The subgroup analysis demonstrated that electronic self-management technology had the greatest impact on the health of patients with T2DM, while the diabetes registry had the least effect.

The impact of diabetes registries on improving care was difficult to quantify because the registries performed many different functions: it was unclear if the improvements had been driven by the functioning of the basic diabetes registry or other interventions. In the same way, being certain about the effectiveness of electronic health record systems is challenging because there cannot be a certain relationship with any presumed dependent variable; there is at best an association between technology use and quality and satisfaction [51]. Although some studies have demonstrated improvements in the process of care delivery, demonstrating improvements in HbA_{1c} levels has proved to be more challenging [18,23,24]. In addition, the baseline hemoglobin level in one study was 7.7% in both control and intervention groups [28]. Information technology diabetes interventions may need to be introduced to patients with a baseline HbA_{1c} level equal to or higher than 8.0% in order to effect changes, as was the case in 12 studies reported. This analysis further demonstrated a greater reduction in HbA_{1c} level in patients with a poor HbA_{1c} level as compared with a moderate one (−0.58% vs −0.20%).

These days, information technologies are advancing rapidly and are ubiquitously available worldwide. There is widespread belief that information technology may reduce care costs for patients with diabetes. However, relatively few studies have evaluated the effect of information technology on costs. The secondary outcome measures were summarized qualitatively because they were measured with various instruments. We found that a

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number of information technology studies reported improvements in the process of care and patient satisfaction, which suggests that information technology may be an effective strategy for changing patient behaviors. Additionally, our review demonstrates that there was no clinically relevant effect on LDL and no effect on blood pressure. This finding confirms those from a previous systematic review [7].

For diabetes care to be successfully supported by information technology–based interventions, their use should be embedded in the CCM. This review was able to map these technologies onto the CCM. It found that the most common CCM components used in trials besides the clinical information system were self-management support, delivery system design, and decision support. Health care organization and community resources were not reported. Most of the studies reported using multiple components in their interventions. It was difficult to determine which elements of the CCM benefit diabetic patients the most. However, interventions using self-management support reported the largest improvements in HbA_{1c} levels. Four components of the CCM have a stronger effect on HbA_{1c} levels than do 2 or 3 elements.

Comparison With Prior Work

Several systematic reviews related to health information technology have been undertaken, but they have limited their scope to specific systems such as telemedicine [52], clinical decision support system [53], mobile phone [54], and EMRs [55,56]. No study to date has reviewed a broad range of health information technologies. In addition, previous systematic reviews with less methodological rigor have not performed meta-analysis or have failed to detect significant differences between different types of technological interventions [8,10]. The findings confirm the findings of meta-analyses that stated that changes must be made in multiple areas of CCM elements in order to considerably improve the quality and outcomes of diabetes care [57].

There is evidence to suggest that electronic self-management systems may improve glycemic control in patients with T2DM: this meta-analysis indicated that this type of technology significantly reduced HbA_{1c} levels compared with the control group (pooled mean difference 0.50%, $P<.001$). These results support the conclusion previously reported in 2012 [51]. It appears that clinical outcomes improve more when several CCM components are utilized simultaneously. In a review of 69 studies of diabetes care systems that used a variety of CCM components, the results demonstrated that utilizing all CCM elements may reduce the HbA_{1c} level by 0.46%, which is quite similar to our findings (−0.50%).

Limitations

This review and meta-analysis has several advantages over most, previous systematic reviews of the impact of information technology on diabetes care. We reviewed a large body of literature, assessed the quality of included trials, and contacted authors of some studies to collect missing data. To our knowledge, this systematic review presents the first pooled analysis results of varied information technology types on HbA_{1c} levels among patients with T2DM. Nevertheless, this review also has limitations. We used HbA_{1c} level as the primary outcome measure because of its long-established association with adverse cardiovascular outcomes in diabetes [58]. However, we recognize that an appropriate process of care, as described in the CCM, may be more important in improving health outcomes. In addition, there is the possibility of publication bias as people are more likely to publish positive findings. Selection bias also consists of an exclusive focus on English- or Arabic-language studies, to the exclusion of studies in other languages. Although searches were carefully conducted using major databases and a cross-referencing method, there is the possibility that some publications were not included in the study because of the inclusion criteria. Most of the studies were conducted in the United States, with only a few conducted elsewhere. Considering that many European countries have implemented information technology interventions, it was surprising to note the lack of evaluation of these systems in diabetes care. Inevitably in this study, only HIT that was operational and part of a health system was included in our review. We know that may HIT implementations fail, and that a socio-technical approach and provide insights into why and when HIT can improve the care of patients with T2DM [59,60]. Further research needs to include how and why some implementations succeed and potentially improve health while others fail.

Conclusions

The findings of this review suggest that, in general, information technology interventions improve glycemic control. Patient self-management support appears most promising; EMRs and clinical decision support system appear to confer benefits, but disease registries by themselves do not appear to improve quality. In addition, the results conform to presumptions surrounding the CCM that changes must be made in multiple areas in order to considerably improve the outcomes of diabetes care. However, further investigation is still required to increase our understanding of how, why, and when information technology can improve the care of patients with T2DM. This includes a cost-benefit analysis of using information technology and the other secondary outcomes.

Acknowledgments

This work was part of a PhD dissertation funded by King Saud University.

Conflicts of Interest

None declared.

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Multimedia Appendix 1

Summary of information technology–based interventions for type 2 diabetes.

[PDF File (Adobe PDF File), 54KB - jmir_v18i11e310_app1.pdf]

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Abbreviations

CCM: chronic care model
EMR: electronic medical record
HbA_{1c}: hemoglobin A1c
LDL: low-density lipoprotein
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
T1DM: type 1 diabetes mellitus
T2DM: type 2 diabetes mellitus

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Edited by G Eysenbach; submitted 19.03.16; peer-reviewed by M Prietula, K Fitzner, N Vigano; comments to author 06.07.16; revised version received 13.09.16; accepted 30.09.16; published 25.11.16.

Please cite as:
Alharbi NS, Alsubki N, Jones S, Khunti K, Munro N, de Lusignan S
Impact of Information Technology–Based Interventions for Type 2 Diabetes Mellitus on Glycemic Control: A Systematic Review and Meta-Analysis
J Med Internet Res 2016;18(11):e310
URL: http://www.jmir.org/2016/11/e310/
doi:10.2196/jmir.5778
PMID:27888169

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Original Paper

Can Mobile Phone Apps Influence People's Health Behavior Change? An Evidence Review

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Abstract

Background: Globally, mobile phones have achieved wide reach at an unprecedented rate, and mobile phone apps have become increasingly prevalent among users. The number of health-related apps that were published on the two leading platforms (iOS and Android) reached more than 100,000 in 2014. However, there is a lack of synthesized evidence regarding the effectiveness of mobile phone apps in changing people's health-related behaviors.

Objective: The aim was to examine the effectiveness of mobile phone apps in achieving health-related behavior change in a broader range of interventions and the quality of the reported studies.

Methods: We conducted a comprehensive bibliographic search of articles on health behavior change using mobile phone apps in peer-reviewed journals published between January 1, 2010 and June 1, 2015. Databases searched included Medline, PreMedline, PsycINFO, Embase, Health Technology Assessment, Education Resource Information Center (ERIC), and Cumulative Index to Nursing and Allied Health Literature (CINAHL). Articles published in the *Journal of Medical Internet Research* during that same period were hand-searched on the journal's website. Behavior change mechanisms were coded and analyzed. The quality of each included study was assessed by the Cochrane Risk of Bias Assessment Tool.

Results: A total of 23 articles met the inclusion criteria, arranged under 11 themes according to their target behaviors. All studies were conducted in high-income countries. Of these, 17 studies reported statistically significant effects in the direction of targeted behavior change; 19 studies included in this analysis had a 65% or greater retention rate in the intervention group (range 60%-100%); 6 studies reported using behavior change theories with the theory of planned behavior being the most commonly used (in 3 studies). Self-monitoring was the most common behavior change technique applied (in 12 studies). The studies suggest that some features improve the effectiveness of apps, such as less time consumption, user-friendly design, real-time feedback, individualized elements, detailed information, and health professional involvement. All studies were assessed as having some risk of bias.

Conclusions: Our results provide a snapshot of the current evidence of effectiveness for a range of health-related apps. Large sample, high-quality, adequately powered, randomized controlled trials are required. In light of the bias evident in the included studies, better reporting of health-related app interventions is also required. The widespread adoption of mobile phones highlights a significant opportunity to impact health behaviors globally, particularly in low- and middle-income countries.

(J Med Internet Res 2016;18(11):e287) doi:10.2196/jmir.5692

KEYWORDS

review; mobile phone apps; apps; behavior change; intervention; mHealth

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Introduction

Globally, mobile phone apps have become increasingly prevalent among users. By July 2015, Google Play, the largest app store, had 1.6 million apps accessible for users. remains the second-largest app store, with 1.5 million apps available for download [1]. There has been a surge of health-related mobile phone apps in recent years. The number of health-related apps released on the two leading platforms, iPhone operating system (iOS) and Android, had reached more than 100,000 in 2014 [2]. Traditionally, health care has been delivered through face-to-face interaction with clinicians. With this new technology at patients' and health care professionals' (HCPs) fingertips, people are changing the way they interact. Apps used in health care settings have a number of functions, such as information and time management, communications and consulting, patient management and monitoring, health record maintenance and access, reference and information gathering, and clinical decision making [3]. Although several issues challenge the integration of apps into health care settings (eg, app design is primarily driven by commercial developers), their use has been widely expanded into clinical practice [4,5].

In 2014, the World Health Organization reported that noncommunicable diseases (NCDs) are the leading cause of death globally, responsible for 38 million (68%) of the world's 56 million deaths in 2012. More than 40% of these deaths (16 million) were premature and avoidable [6]. Simple interventions that decrease NCD risk factors could reduce premature deaths by one-half to two-thirds [7]. Many of these risk factors, such as tobacco use, unhealthy diet, physical inactivity, stress, depression, harmful use of alcohol, overweight, and obesity, can be modified by behavioral change interventions [6]. Apps appear to be an ideal platform to deliver both simple and effective interventions.

In addition to NCDs, health-related apps have the added potential to aid a wide range of target audiences in a whole range of health issues [8]. For example, they can improve contraceptive knowledge of women [9] or help users to prevent nonspecific low back pain [10]. There are also apps designed as intervention tools to encourage healthy habits, such as a sun protection app that provides real-time sun safety advice [11]. Due to the possible positive implications for public health, there is an increasing interest from commercial companies, government agencies, public health organizations, and the general public to utilize apps as a tool for health behavioral change [12-14].

Several reviews have examined the evidence of effectiveness of health-related apps when targeting one specific behavior, such as physical activity, or a specific condition, such as chronic pain [15-19]. Another study reviewed behavioral functionality of apps in health interventions without assessing the quality of the included studies [20]. The aims of this review are to examine the effectiveness of mobile phone apps in achieving health-related behavior change across a broader range of health issues and to examine the quality of the reported studies.

Methods

Search Strategy

We searched titles, abstracts, and keywords of peer-reviewed articles published from January 1, 2010 to June 1, 2015. A comprehensive bibliographic search was conducted through Medline, PreMedline, PsycINFO, Embase, Health Technology Assessment, Education Resource Information Center (ERIC), and Cumulative Index to Nursing and Allied Health Literature (CINAHL) by using key search terms, such as mobile application, mobile app, smartphone, and information technology, and using the qualifier "behavior change" (see Multimedia Appendix 1 for the full search strategy). In addition, the *Journal of Medical Internet Research* (*JMIR*) was hand-searched for the same period on the journal's website.

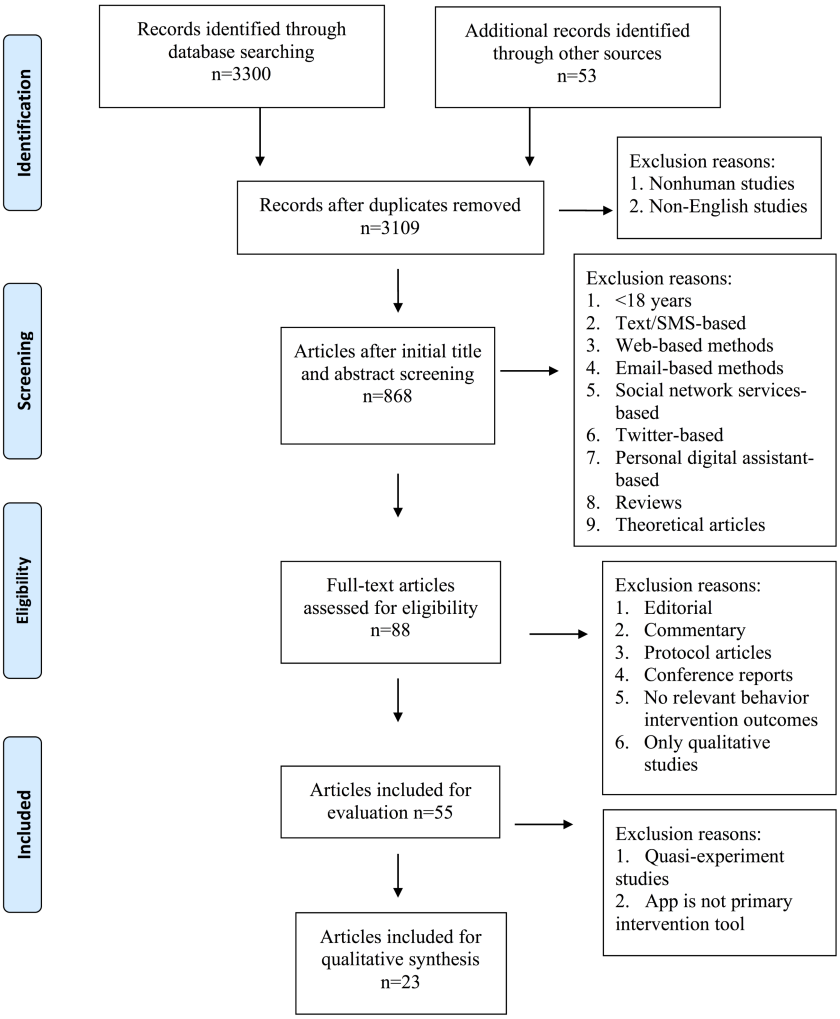
Study Selection

We included articles if they were published in English, in a peer-reviewed journal, after 2010, targeted at an adult population, and presented results from the analysis of primary or secondary outcomes. We only included randomized controlled trials (RCTs), case-control studies, and cohort studies that were designed for app-based interventions to improve any health-related behaviors. The exclusion criteria were quasi-experimental studies or qualitative studies; text message, Web, email, Twitter, social network services, or personal digital assistant-based health interventions; absence of behavior change indicators or outcomes; an app was not the primary intervention tool; and articles focused mostly on app design and development. Conference abstracts, protocol papers, reviews, editorials, and commentary were also excluded.

The initial search returned 3353 articles: 1405 in Medline, 356 in Embase, 791 in CINAHL, 344 in PsycINFO, 296 in ERIC, 71 in PreMedline, 37 in Health Technology Assessment, and 53 in *JMIR*. Following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Figure 1), we eliminated duplicates and screened the titles and abstracts, which narrowed the results to 868 articles. A full-text review reduced the sample to 88 articles; after applying the exclusion criteria, we further narrowed that to 55 articles, of which 32 were quasi-experiment studies or an app was not the primary intervention tool and they were subsequently excluded. This left a final sample of 23 articles to be included for the review. Studies excluded during the full-text review stage and their reasons for exclusion are listed in Multimedia Appendix 2. Data extraction from identified articles was completed by authors JZ and ML with disagreements resolved through discussion with author BF.

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Figure 1. PRISMA 2009 flow diagram.



Data Collection and Analysis

The following information was extracted and analyzed from each of the 23 articles: authors, research location and year of publication, study type, sample size, intervention duration, intervention tools with behavior change mechanisms, target behavior change, control group variables, measurement of behavior change indicators, and reported outcomes and significance levels. The search was kept wide with no specific target health behaviors in the search strategy. Based on the health behaviors identified, the articles were organized into 11 themes: mental health improvement or alcohol addiction, physical activity, weight control and diet control, medication management, lifestyle improvement, diabetes management, sun protection, hypertension management, cardiac rehabilitation, smoking cessation, family planning, and pain management. Apps were deemed effective if they reported quantitative measures of successful behavior change [21]. The characteristics of the studies meeting inclusion criteria are summarized in Multimedia Appendix 3. For trial sample size, large samples usually meant at least 100 participants in each randomized group, moderate sample size was between 60 and 100 participants in each group, and small sample size was less than 60 participants in each group [22,23]. According to the *Cochrane Handbook for Systematic Reviews of Interventions* [22], studies with retention over 80% are classified as having low attrition and studies with retention between 60% and 79% are classified as having moderate attrition. Influencing factors of completing app trials were evaluated to understand determinants of retention rates; features of effective apps were also examined.

Behavior change mechanisms, including the use of theory, techniques, and therapies, were extracted from each study. Behavior change theories applied by the included studies were noted [24]. Behavior change techniques used in the interventions were coded according to Abraham and Michie's taxonomy of behavior change techniques (BCTs) [25]. Mental health or alcohol addiction apps were most likely to be based on a specific behavior therapy (see Multimedia Appendix 3).

Study Quality Assessment

All included studies were appraised using the Cochrane Risk of Bias Assessment Tool [22]. This requires assessing each study against a set of seven criteria: random sequence generation, allocation concealment, blinding of participants, blinding of outcome assessment, incomplete outcome data, selective reporting, and other bias. Low risk of bias for completeness of follow-up was defined by a cut-off of 80% complete follow-up [22] (see Multimedia Appendix 4).

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Results

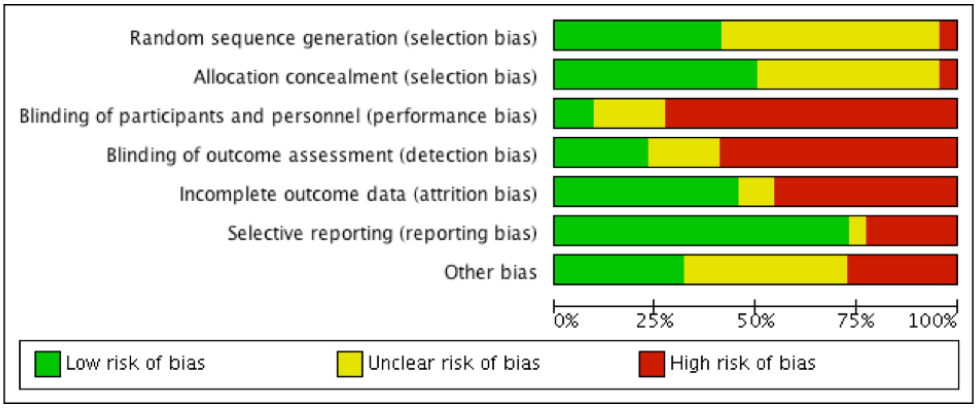
Characteristics of Included Studies

The 23 articles analyzed in this review were organized under 11 themes according to target behaviors. Of these, 7 targeted mental health or alcohol addiction; 4 targeted increasing physical activity, weight control, and diet control; 3 aimed to improve medication management; 2 involved an intervention for lifestyle improvement; and 1 study was identified in each of the following themes: diabetes management, sun protection, hypertension management, cardiac rehabilitation, smoking cessation, family planning, and pain management. All studies were conducted in high-income countries, 10 in the United States, 3 in Australia, 2 in the United Kingdom and Sweden, respectively, and 1 each in South Korea, Italy, New Zealand, Spain, Switzerland, and the Netherlands. As defined by the inclusion criteria, all included studies used RCT design, except one case-control study [26]. There were 6 large sample studies [10,11,27-30]. A three-arm RCT study had the largest sample size (N=1932) [28], whereas 14 studies had a small sample size (ie, <60 participants per group) [9,26,31-42]. Others had moderate sample sizes. The intervention duration ranged between 3 weeks [36] and 8 months [27]. Of all the apps, only 6 studies evaluated commercially available apps [10,11,29,30,40,41] and 1 study tested a publicly downloadable app developed by the Swedish government [28]; other apps were not publicly available. Only one app, from Switzerland, was designed for people older than age 65 years [40]. All apps were designed in the English language, with the exception of one Spanish app [38]. In total,19 included in this analysis had more than 65% retention in the intervention group with a high of 100% [31,35,36] and a low of 60% [32]. Three studies did not report retention rate [26,34,37] (see Multimedia Appendix 3).

Mechanisms of Behavior Change

Across the 23 studies, 3 mechanisms were employed to promote behavior change: behavior change theories, BCTs, and specific behavioral therapies. In total, 6 studies reported using behavior change theories to underpin their app interventions [9,10,27-29,36]. The most commonly used theory was the theory of planned behavior [9,10,28], followed by social cognitive theory [29,36]. The top 3 most commonly used BCTs were self-monitoring (12 interventions) [10,27-29,38- 45], feedback provided on performance (8 interventions) [11,28,29,36,37,41-43], and tailoring messages (8 interventions) [10,26,30,36,38,41-43]. Apps related to mental health or alcohol addiction were usually based on a specific behavioral therapy, such as motivational enhancement therapy [35], behavioral activation therapy [33], and cognitive behavior therapy [34] (see Multimedia Appendix 3).

Figure 2. Cochrane risk of bias summary for health behavior change trials.



Quality of Selected Studies

The quality of reviewed studies is summarized in Multimedia Appendix 4. All 23 studies had some kind of risk of bias according to the Cochrane Risk of Bias Assessment Tool. Only 9 articles adequately reported random sequence generation. A computer random number generator was used in 2 studies [9,27]. The process of minimization, used to make small groups similar, was described in 3 studies [30,43,45]. A total of 11 studies explicitly stated that allocation was concealed (eg, using sequentially numbered opaque, sealed envelopes, central allocation) [9,27-29,31-33,41-44]. Participants were blinded in 1 study, but the assessors had full knowledge of the assignments [36]. Only 1 RCT study of a smoking concession app was double-blinded to the 196 participants and assessors [45]. Assessors were blinded in another 4 studies [9,28,35,38]. Due to the nature of using apps, subject blinding was often not possible across the interventions. The remaining studies were either not blinded or information was not explicitly provided in the reporting. We used a cut-off of 80% completion for low risk of bias for completeness of follow-up [22]. A total of 10 studies were at low risk of attrition bias [9-11,31,35,36,38,42,43,45]. Only 3 studies did not outline the statistical analyses or dropout rate [26,34,37]. With regard to bias of selective outcome reporting, insufficient information was present in 1 study [36] and a high risk of bias was present in 5 studies [30,37,38,40,44]. The quality assessment of the reviewed studies is presented in Multimedia Appendix 4. The Cochrane risk of bias summary is reported in Figure 2.

Effectiveness of Apps and Features

Mental Health or Alcohol Addiction

A total of 7 studies reported on app interventions focused on mental health or alcohol addiction outcomes. Of these, 2 studies described 2 different apps [32,33] that targeted at developing coping skills for different degrees of depression. Watts et al

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[32] tested the effectiveness of an app delivering a cognitive behavior therapy-based program. There was a statistically significantly improvement on a depression test scale in both the app and computer intervention groups at posttest, and no difference between the 2 groups over time in follow-up. In the other RCT study of a behavioral activation app addressing mild-to-moderate and major depression conducted by Ly et al [33], it was found that the treatment worked significantly better for participants with a more severe form of depression. Ainsworth et al [31] reported that for patients with serious mental illness there was no significant difference in quantitative feedback questionnaire scores, which was developed to assess the acceptability and feasibility between app and text message intervention groups, but there was significant improvement in the app group in 2 other measurements (less time to complete assessment and greater number of data points completed). In a study of a stress management app intervention delivered by oncology nurses, Villani et al [34] found there was a significant decrease in anxiety and significant improvement in affective change in terms of anxiety trait reduction and coping skill acquisition in the intervention group.

In total, 3 RCT studies aimed to lower alcohol consumption among adults. Gonzalez et al [35] demonstrated that an app based on motivational enhancement theory resulted in a significant increase in the percentage of days abstinent among participants with alcohol use disorder over the 6-week study period when compared to controls. In the Gustafson et al [27] study, significantly fewer risky drinking days were achieved in self-determination theory-based app intervention group than the patients in control group. Gajecki et al [28] showed that an app based on theory of planned behavior did not seem to affect alcohol consumption among university students.

Increasing Physical Activity, Weight Control, and Diet Control

In total, 4 studies implemented and described app interventions intended to improve physical activity, weight control, and diet control. Rabbi et al [36] found that participants who used an app based on contemporary behavioral science theories walked significantly more than the control group after 3 weeks; further, the users rated the app's personalized suggestions more positively than the nonpersonalized, generic suggestions created by professionals. Laing et al [29] demonstrated that one of the most popular commercially available weight loss apps, MyFitnessPal, which is based on social cognitive theory, was not effective in helping overweight patients lose weight in a clinical setting over a 6-month period. One case-control study [26] identified significantly decreased weight, fat mass, and body mass index (BMI) in the intervention group compared to controls. Carter et al [43] compared an app intervention group (created on an evidence-based behavioral approach) to two other control groups, one using a paper-based food diary and the other using an online food diary. Over the 6-month study period, adherence to the trial was statistically significantly higher in the mobile phone app group compared with the online website group and the paper diary group. Further, the mean weight change, BMI change, and body fat change were highest in the app intervention group.

Medication Management

In total, 3 RCT studies evaluated the effectiveness of apps to improve medication adherence. In an antiretroviral therapy study, Perera et al [37] compared 2 randomized groups using different versions of the same app (an augmented version and standard version) in a 3-month study. There was a significantly higher level of self-reported adherence and decreased viral load among the augmented app group compared to the standard version group. An RCT evaluating an app designed to help elderly Spanish patients reduce nonadherence and medication errors when taking multiple medications reported that app users had significantly better adherence, fewer missed doses, and a significant reduction in medication errors in patients with initial higher rates of errors [38]. In a study of adherence to antidepressant medications among college students, Hammond et al [39] found that there was a strong trend suggesting that the use of a medication reminder app was beneficial in increasing antidepressant medication adherence.

Lifestyle Improvement

Only 2 studies measured lifestyle changes in users of 2 commercially available apps. One trial [30] measured changes in health-related behaviors, sleep problems, and fatigue in airline pilots. It found that the intervention arm had a significant improvement in reducing the level of fatigue, improving sleep quality, increasing strenuous physical activity, and changing snacking behavior measures. The other lifestyle study was a three-arm trial to promote walking [40] that included 2 app groups, one using social motivation strategies and the other employing an individual motivation strategy, and a brochure-based control group. The 2 intervention groups both showed significant improvements in total walking time.

Other Themes

As shown in Multimedia Appendix 3, only a small number of studies were found under the themes of diabetes management, sun protection, hypertension management, cardiac rehabilitation smoking cessation, family planning, and pain management. Kirwan et al [41] found a freely available app supplemented with text message feedback could significantly improve glycemic control between baseline and 9-month follow-up for patients with type 1 diabetes compared to the control group. One of the first evaluation studies of a commercially available sun protection app [11] showed that only 1/7 sun protection behaviors, wearing wide-brimmed hats, was practiced more by intervention than control participants. In a study comparing an app designed for hypertension management with traditional care [42], the intervention group participants achieved a significant decrease in systolic blood pressure at 12 weeks compared to control participants. Varnfield et al [44] found that the intervention group had significantly higher uptake, adherence, and completion of a cardiac rehabilitation program than the control group. A study of an innovative app addressing heavy smoking showed promising quit rates compared to an app that followed standard US Clinical Practice Guidelines [45]. Gilliam et al [9] noted that young women had a significantly higher knowledge of family planning and increased interest in longer-term contraception methods after using an app-based on the theory of planned behavior. In a three-arm RCT for back

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pain management [10], users of the app showed significant improvement compared to the control group in every comparison of the critical physical, behavioral, and worksite outcome measures at 4-month follow-up.

Suggested Features of Effective App Interventions

Identifying features that enhance intervention effectiveness can inform the development of app-based intervention to produce greater health behavior change and support evaluation of complex interventions. The reviewed studies revealed some important features that could be useful in informing future app intervention design. For example, the MyFitnessPal app incorporates self-monitoring, goal setting, feedback, and social networking features, all deemed critical functions in physical activity and dietary interventions, and it has received the highest possible rating (5/5 stars) from app store reviewers [29]. However, participants in the MyFitnessPal app trial only had minimal change in body weight with no difference between groups. This may be because participants found calorie counting took too much time [29]. This finding is consistent with a previous systematic review suggesting that the amount of participant time required is an important consideration for physical activity and health eating interventions [46].

Another example is that despite receiving no training on how to use the app, the usage of the diabetes management app was high among participants, and there was significantly improved glycemic control in the intervention group between baseline and follow-up at 9 months compared to the control group. This may be attributed to a number of important features of this study, such as the user-friendly design, usefulness of the information, usability of the app, and additional weekly personalized text-message feedback from a health care professional [41]. One important feature of the trial improving airline pilots' health-related behavior and sleep was the tailored advice, supplemented by additional background information available on the website [30].

Discussion

In total, 17 studies reviewed reported statistically significant effects in the targeted behavior change, and only one app seemed to have had a negative effect among men with an alcohol use disorder [28]. In one study, behavior change to increase meditation adherence did not reach statistical significance [39]. In total, 10 studies used active comparators that were shown to be also effective; although the intervention groups did not outperform their comparator, the effectiveness of these apps should be considered. For example, in a study to improve patients' coping skills with depression, mobile phone apps and computer groups were both associated with statistically significant benefits at posttest assessment [32]. Interventions including an active comparator could ensure that all patients who agree to participate in the trial will not be knowingly disadvantaged [47]. Further, this could provide some insight to the app developers for the preferred mode of delivery between apps and existing alternatives, like Web-based or text message-based interventions.

In total, 14 studies had quite small sample sizes, and their findings must be interpreted with caution. Additionally, the long-term sustainability of effects is largely unknown. Trials of larger sample size and longer intervention duration or follow-up time are warranted to assess effectiveness of mobile phone app interventions. The quality of the included studies in terms of high risk of bias in selection, performance, detection, or attrition, and the quality of reporting of the interventions in some of the articles also calls for more rigorous study design and reporting.

With respect to the mechanisms of behavior change, it is important to use theory to inform intervention design as well as specifying BCTs [48,49]. It is apparent that interventions based on behavior change theory are more effective than those lacking a theoretical basis [48-50]. In our review, only 6 studies explicitly reported using behavior change theories to underpin their app interventions [9,10,27-29,36]. In total, 21 studies explicitly reported BCTs were incorporated; the other 2 studies [33,35] did not mention any BCT used in the intervention. However, it seemed that the number of BCTs used did not predict effectiveness. For example, the smoking cessation app study reported that applied five BCTs—self-monitoring, goal setting, self-tracking, social support, and being motivated—did not significantly improve outcomes in smoking cessation compared to the control group [45], whereas the pain management app with three BCTs showed significant improvement compared to the control group in every comparison [10]. In our review, the most commonly adopted BCT (in 12 studies) was self-monitoring, but results were mixed in terms of how effective this technique was in changing behavior. This finding may be a consequence of different BCTs targeting different aspects of the behavior change process.

Retention rate is defined as the proportion of participants who remained in the study to completion. Despite the potential convenience and benefits to app users, only 10 studies in our review achieved a high retention rate (>80%) in intervention group [9-11,31,35,36,38,42,43,45]. The My Meal Mate app [43] is a weight loss intervention with a high retention rate; 40 of 43 (93%) participants returned for follow-up at 6 months. Compared with other similar apps, the key features of the My Meal Mate app are expert-designed, tailored content and weekly supportive text messages. Similarly, the FitBack app had a high retention rate of 92% (183/199) and also tailored content to users' preferences and interests; participants achieved greater improvement in all physical, behavioral, and worksite outcome measures than the control group [10]. Varnfield et al [44] had a 77% (46/60) completion rate in the home care cardiac rehabilitation app intervention group, which was approximately 30% more than the control group. The involvement of experts who provided weekly scheduled telephone consultations with informed, personalized feedback on progress according to participants' goals likely contributed to this relatively higher level of participant retention. In a poststudy survey, users rated MyBehavior's personalized suggestions more positively than the nonpersonalized and generic suggestions [36]. Personalization and adaptation in real time appear to be key elements in engaging a diverse group of participants [51]. This is reinforced by Tang et al [52], who found that young adults

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highly valued the personalized features of a weight loss app. These studies support that tailored information, real-time feedback, and expert consultation are the app functions that might be most acceptable and useful to participants. In turn, it is likely that these features could result in maintaining higher retention rates and enhancing intervention effectiveness. Further, our findings also indicate that apps with a simple interface and that make better use of app design and technology may reduce the time required for users to participate in the intervention and improve retention. Identifying features that may enhance intervention effectiveness could inform the development of health behavior change apps and support the evaluation of complex interventions.

Implications for Future Research and Practice

Mobile phone apps are seen as a potential low-cost way to deliver health interventions to both general and at-risk populations. Many such apps exist; however, rigorous research to test their effectiveness and acceptability is lacking. There were 7 publicly available apps that were used in the reviewed studies [10,11,28-30,40,41]. Despite their apparent popularity, public and commercial apps have not been comprehensively evaluated to date; they are currently being used without a thorough understanding of their associated risks and benefits [53]. There is a gap between app concept, delivery, and translation into health behavior change.

The Cochrane Risk of Bias Assessment is a good tool to assess the quality of intervention trials. However, in our findings, the "blinding of participants and personnel" was poor; only one study [45] was double-blinded due to the unique nature of app interventions. The quality of mHealth evidence reporting could be improved through the use of recently published guidelines to aid better understanding and synthesizing findings. The Consolidated Standards for Reporting Trials (CONSORT) provides a 22-item checklist for reporting Web-based and mHealth RCTs [54]. The mHealth Evidence Reporting and Assessment (mERA) checklist could also aid quality improvement of mHealth intervention reporting [55]. Additionally, the Transparent Reporting of Evaluations with Nonrandomized Designs (TREND) statement could assist to improve the reporting quality of nonrandomized evaluations of public health interventions [56]. In this review, only 4 studies described "blinding of outcome assessment" [9,28,35,38]. It might be possible to blind outcome assessors, those doing data analysis, or those administering co-interventions, which is one of the 22 essential items recommended in the CONSORT checklist [54]. It is important for researchers to adopt these guidelines vigilantly for better reporting and communication of research results.

One of the primary benefits of apps is their potential for incredibly high reach. With mobile phone use reaching near saturation among some populations, particularly young adults, and the high rates of consumer acceptability, app effectiveness research must also consider total app reach. This aspect of health behavior change apps has not been assessed, with most studies being exceptionally small in scale. Apps that offer even a small health benefit could still be a valuable public health intervention if the population-level reach is high enough. But, encouragingly, we identified some registered large-scale clinical trial protocols of app-based interventions, suggesting that the current limited scientific evidence may be eased in coming years [57-60].

All identified studies were conducted in high-income countries, which could be partly due to our search criteria limiting publications in English only. However, it is also possible that a significant demand for app research on health behavior change in lower- and middle-income countries is being neglected. The burden of NCDs, such as heart disease, diabetes, cancer, and mental disorders, is high in low- and middle-income countries and is predicted to grow [4]. Mobile phones have great potential to reach populations that previously had restricted access to interventions or health care information [61]. Apps have also created new opportunities and possibilities to reach populations who were largely unreachable via traditional health care channels [62]. mHealth interventions have a positive impact on some chronic diseases in developing countries [63] and text messaging has been recognized as a successful tool to improve behavior change outcomes [13,15]. In comparison with text messaging only, mobile phone apps offer more active engagement in health care and improved convenience at substantially lower cost. However, the current evidence base for the use of app-based interventions in developing countries remains small [64]. The widespread adoption of mobile phones highlights a significant opportunity to impact health behaviors globally, particularly in low- and middle-income countries.

Limitations

Limitations of this review are worth noting. The search terms are restricted to health behavior change, and we focused mostly on medicine- and health science-related databases, which may have excluded publications in other areas. Although iPhone and Android app stores debuted in June 2007 [65], they have experienced exponential growth in popularity since 2010; some relevant articles published before January 2010 could have been missed. The included studies were all conducted in high-income countries where the health care systems are different from many low- and middle-income countries, which limits the ability to draw generalizable conclusions [66]. The inclusion of studies targeted at the adult population could also confine interpretations about whether app-based interventions can influence behavior change among younger users.

Conclusions

To our knowledge, no previous study has completed a comprehensive thematic literature review of mobile phone apps for health behavior change. Although a majority of the studies reviewed reported statistically significant effects in targeted behavior change, adequately powered and relatively longer duration RCTs are still required to determine the effectiveness of app-based interventions. Further research should focus on conducting evaluation research in low- and middle-income countries. Moreover, these results highlight the need for better reporting of health-related app interventions. Collaborations between researchers, HCPs, app developers, and policy makers could enhance the process of delivering and testing evidence-based apps to improve health outcomes.

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Acknowledgments

We thank Angela Webber for providing critical comments.

Authors' Contributions

JZ, ML, and BF contributed to the design of the review protocol. Authors ML and JZ completed data extraction of relevant articles with disagreements resolved through discussion with author BF. JZ drafted the paper; ML and BF reviewed the manuscript and contributed to subsequent drafts. All authors read and approved the final review.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy.

[PDF File (Adobe PDF File), 45KB - jmir_v18i11e287_app1.pdf]

Multimedia Appendix 2

Studies excluded during full text review.

[PDF File (Adobe PDF File), 54KB - jmir_v18i11e287_app2.pdf]

Multimedia Appendix 3

Characteristics of selected studies.

[PDF File (Adobe PDF File), 155KB - jmir_v18i11e287_app3.pdf]

Multimedia Appendix 4

Study Quality Assessment.

[PDF File (Adobe PDF File), 44KB - jmir_v18i11e287_app4.pdf]

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Abbreviations

BCT: behavior change technique
BMI: body mass Index
CONSORT: Consolidated Standards for Reporting Trials
HCP: health care professional
iOS: iPhone operating system
JMIR: Journal of Medical Internet Research
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT: randomized control trial
NCD: noncommunicable disease
TREND: Transparent Reporting of Evaluations with Nonrandomized Designs

Edited by G Eysenbach; submitted 24.02.16; peer-reviewed by MY Chih, M Varnfield, S Duffy, A Birney; comments to author 24.05.16; revised version received 07.07.16; accepted 12.10.16; published 02.11.16.

Please cite as:
Zhao J, Freeman B, Li M
Can Mobile Phone Apps Influence People's Health Behavior Change? An Evidence Review
J Med Internet Res 2016;18(11):e287
URL: http://www.jmir.org/2016/11/e287/
doi:10.2196/jmir.5692
PMID:27806926

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Original Paper

Self-Monitoring Utilization Patterns Among Individuals in an Incentivized Program for Healthy Behaviors

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Abstract

Background: The advent of digital technology has enabled individuals to track meaningful biometric data about themselves. This novel capability has spurred nontraditional health care organizations to develop systems that aid users in managing their health. One of the most prolific systems is Walgreens Balance Rewards for healthy choices (BRhc) program, an incentivized, Web-based self-monitoring program.

Objective: This study was performed to evaluate health data self-tracking characteristics of individuals enrolled in the Walgreens' BRhc program, including the impact of manual versus automatic data entries through a supported device or apps.

Methods: We obtained activity tracking data from a total of 455,341 BRhc users during 2014. Upon identifying users with sufficient follow-up data, we explored temporal trends in user participation.

Results: Thirty-four percent of users quit participating after a single entry of an activity. Among users who tracked at least two activities on different dates, the median length of participating was 8 weeks, with an average of 5.8 activities entered per week. Furthermore, users who participated for at least twenty weeks (28.3% of users; 33,078/116,621) consistently entered 8 to 9 activities per week. The majority of users (77%; 243,774/315,744) recorded activities through manual data entry alone. However, individuals who entered activities automatically through supported devices or apps participated roughly four times longer than their manual activity-entering counterparts (average 20 and 5 weeks, respectively; $P<.001$).

Conclusions: This study provides insights into the utilization patterns of individuals participating in an incentivized, Web-based self-monitoring program. Our results suggest automated health tracking could significantly improve long-term health engagement.

(J Med Internet Res 2016;18(11):e292) doi:10.2196/jmir.6371

KEYWORDS

health behavior; mobile health; mobile apps; reward; self blood pressure monitoring; blood glucose self-monitoring

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Introduction

The majority of Americans (69%) regularly track at least one indicator of health, including their weight, diet, exercise routine, or symptoms related to chronic disease, with a growing minority (21%) taking advantage of mobile health (mHealth) devices to help them [1]. With an increasing repertoire of mHealth devices, there is a growing trend among many individuals to measure, track, change health behavior, and make health decisions based on quantifiable data collected on oneself. Projections show that the number of everyday wearables, devices, and sensors will increase 5-fold by 2019 [2].

Though the effectiveness of self-monitoring using mHealth technology has been highly variable across studies [3], it is well established that effective self-monitoring can have profound health benefits. For example, among diabetics, blood glucose monitoring is a major component of disease management and provides individuals the ability to assess glycemic targets and evaluate response to therapy [4-6]. Additionally, blood pressure monitoring has been associated with improved short-term blood pressure control and medication adherence [7,8], and self-monitoring has also been shown to improve weight loss and short-term activity levels [9,10]. Importantly, monitoring programs, wearable devices, and other nontraditional health care resources can potentially facilitate healthy behavior changes [11].

As nontraditional health care channels such as retail clinics and virtual care are becoming increasingly popular and beneficial, the traditional health care system is beginning to shift from episode-based fee-for-service to value-based reimbursements [12]. Together, these factors have led to an interest in integrating novel self-monitoring systems into wellness programs, chronic condition management, and the diagnosis of acute episodes. This makes understanding health self-monitoring in these systems an important first step in incorporating these technologies into routine patient care.

In September 2012, Walgreens, one of the largest drugstore chains in the United States, launched its Web-based Balance Rewards for healthy choices (BRhc) program (details in Methods). Members enrolled in the program may track activities and biometric measures to earn points which may be redeemed for purchases at Walgreens. The BRhc Web-based portal and mobile app allows users to set goals and track activities over time. Members can track exercise (including walking, running, and cycling), body weight, and sleep. In April 2014, the program expanded to offer members reward points for connecting biometric devices and inputting blood glucose and blood pressure readings. As a large, nationwide, novel health self-monitoring system, the BRhc offers a unique opportunity to evaluate utilization patterns of individuals enrolled in this incentivized program.

The aim of this study is to evaluate characteristics and activity-tracking patterns for individuals enrolled in the Walgreens BRhc program. Our specific objectives are to (1) present overall participation trends, (2) examine participation across different activities, and (3) explore how automatic activity tracking contributes to utilization patterns.

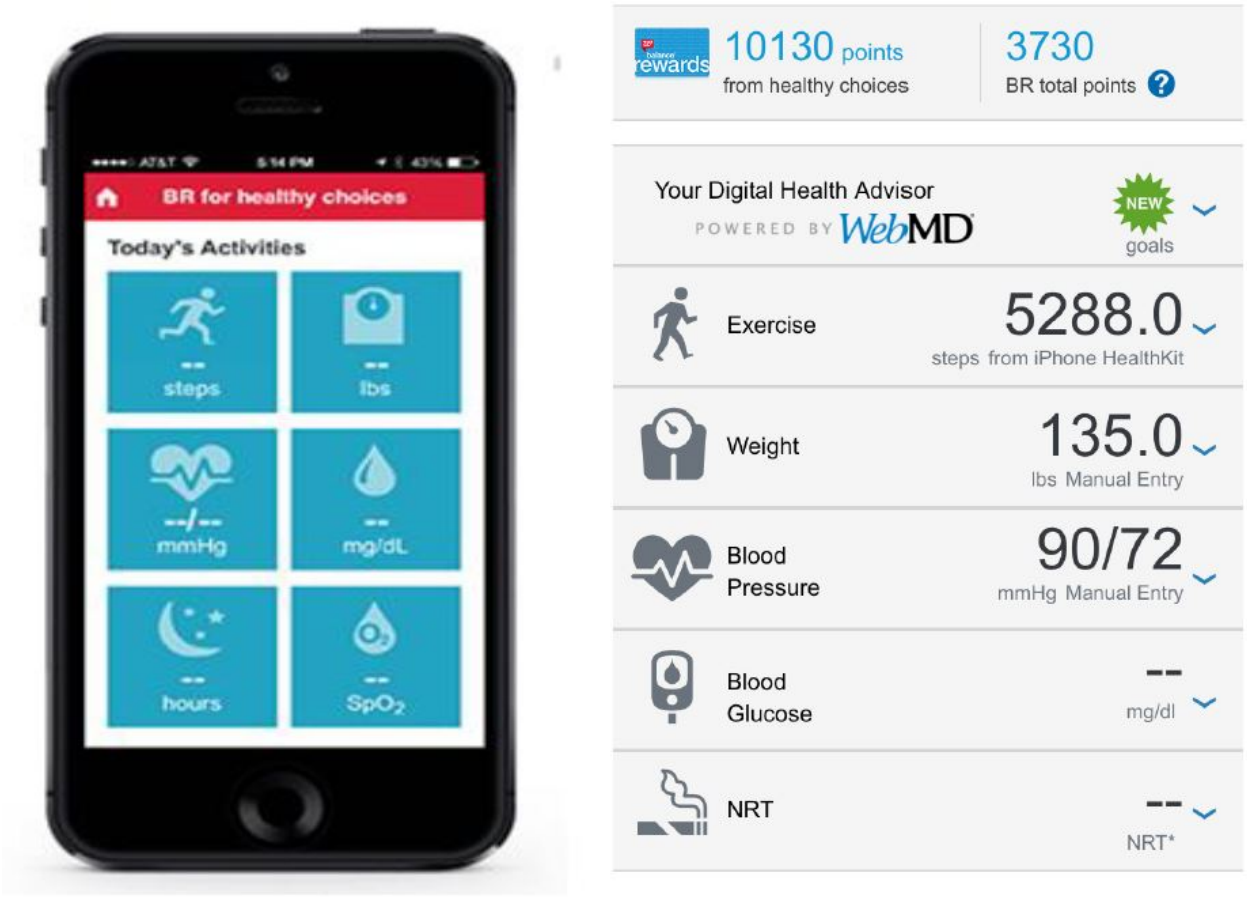
Methods

Program Description

The Walgreens' BRhc program Web-based user portal can be accessed on its website and via a mobile app as depicted in Figure 1. This program allows members to set goals and track health activities over time. One of the main features of the program is the use of incentives to motivate voluntary participation. Through participation, members receive points that can be redeemed for discounts on purchases.

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Figure 1. Screenshot of Walgreens Balance Rewards for healthy choices (BRhc) program.



Earning Points in BRhc Program

Members receive points through engaging in a range of activities, including setting initial health goals (250 points), quitting smoking (250 points), filling prescriptions (100 points), and receiving immunizations (100 points). Members also receive points for logging health activities: 20 points per mile walked, ran, or cycled (maximum 1000 points per month); 20 points per day for logging body weight; 20 points per blood glucose test (maximum 40 points per day), and 20 points for logging blood pressure per day.

Devices or Apps Linked With BRhc Program

Members have the option of logging these activities manually on the Web-based portal or app, or linking a supported mHealth device or app to their BRhc account for automated data upload (linking a supported technology rewards 250 points). Available apps and devices are presented on Walgreens website, where 22 apps cover fitness trackers, weight loss, medication reminders, blood pressure monitors, blood glucose monitors, or telemedicine, and of the 36 devices, some include fitness and sleep trackers, blood pressure monitors, blood glucose monitors, or pulse oximeter [13].

Redemption of Points in Balance Rewards Program

Walgreens Balance Rewards is a loyalty program offered by the Walgreen Company to its customers through earning Balance Rewards points on certain purchases or behaviors through the BRhc program. Integrated Balance Rewards points can be redeemed on most purchases at participating Duane Reade or Walgreens Pharmacy locations. Earned points are converted into redemption dollars at the following tiers: 1000 points = US $1, 2000 points = US $2, 3000 points = US $3, 5000 points = US $5, 10,000 points = US $10, 18,000 points = US $20, 30,000 points = US $35, and 40,000 points = US $ 50. The minimum redeemable is 5000 points for a US $5 reward on a single purchase, and the maximum redeemable per purchase is 40,000 points for US $50. Points expire 3 years after they are earned or if an account has been inactive for 6 months.

Study Data

Walgreens BRhc utilization data for the entirety of 2014 (January 1 to December 31) was available for this study. This includes data on 7 activity-tracking categories: exercise, weight, sleep, blood pressure, blood glucose, tobacco use, and oxygen saturation. For the purposes of this study, we omitted tobacco use and oxygen saturation as they are less common self-tracking activities [1]. All activity records were either entered manually by users via the Web-based portal, or uploaded automatically using a supported device or app. For each activity recorded, the date and mode of entry (ie, manual or automatic) was available. In total, prior to exclusions, this included 30,420,457 activities recorded from 455,341 unique users. We also collected the age and gender of the users when available.

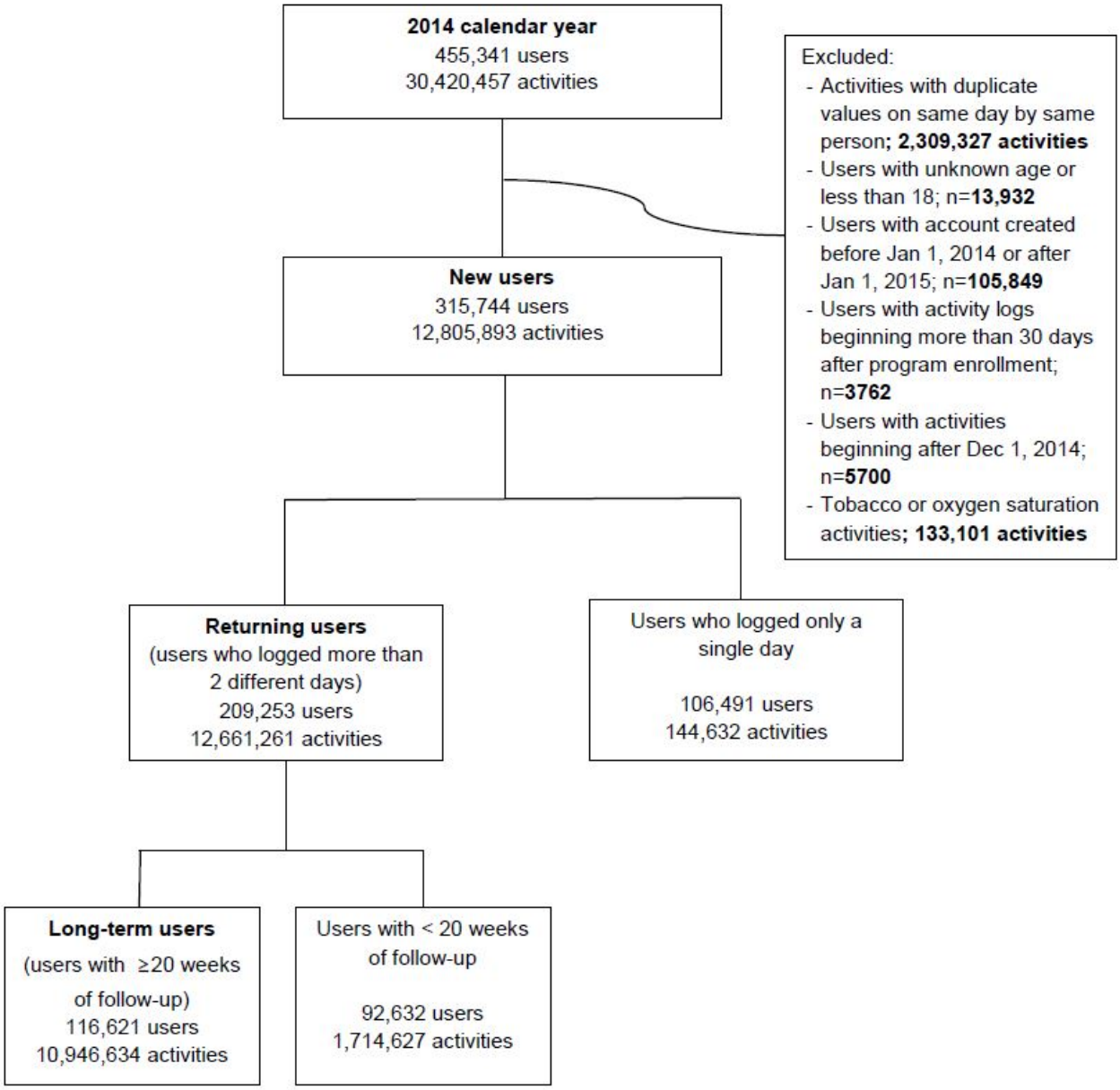
Exclusion criteria were (1) activities recorded with duplicate values entered on the same day by the same person (2,309,327 activities), (2) users with unknown age or less than 18 years old

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(n=13,932), (3) users with accounts created before or after 2014 (n=105,849), (4) users who logged their first activity more than 30 days after enrolling in the program (n=3,762), (5) users whose first recorded activity occurred after December 1, 2014 (ie, less than 1 month of follow-up, n=15,700), and (6) tobacco use and oxygen saturation activities (133,101 activities). This resulted in a study population of 315,744 unique users and 12,805,893 activities recorded.

We also focused on 2 subsets of users: (1) returning users who recorded an activity on 2 or more different dates (209,253 users, 12,661,261 activities recorded), and (2) users who had at least twenty weeks of potential follow-up (ie, first activity occurred before August 2014; 116,621 users, 10,946,634 activities recorded). A study flowchart is presented in Figure 2. Finally, we differentiated users according to their primary mode of activity entry (ie, manual or automatic).

Figure 2. Flowchart of study participants.



Ethical Consideration

Data used in this study comprised gender, age, activity type, date of activity entered either manually or automatically, and amount of activities. These were deidentified datasets and this study was carried out with approval of waiver of informed consent from the Quorum Review Independent Review Board (Review file # 30291/1) for the following reasons: The research involved no more than minimal risk to subjects, the waiver would not adversely affect the rights and welfare of the subjects, and the research could not be carried out without the waiver.

Utilization Metrics

To assess utilization patterns within the BRhc program, we examined metrics related to the duration users participated in the program and the frequency of activities recorded. We identified the participation length for each user; that is the time between the first and last activity recorded. We also noted gaps between consecutive activities recorded—specifically those

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exceeding 1 month and 3 months—and defined the length of active participation as the number of weeks users recorded at least one activity. We also computed the frequency of activities recorded for each user over each week of participation, including the type of activity entered (e.g. exercise) and the mode of entry. In addition to presenting the results across and within each type of activity, we also focused on users tracking blood pressure and blood glucose (n=19,143) as they were likely to have hypertension, or diabetes, or be at high risk for these diseases.

Statistical Analysis

Results are presented as counts, mean (SD), and median (interquartile range) as appropriate. Of the users who recorded an activity on at least two different dates and had at least five months of follow-up, we identified users who recorded activities solely via manual entry and those users who used a supported device or app to upload activities. We compared participation lengths between these groups using *t*-test and Kaplan-Meier analysis. Analyses were performed using SAS version 9.4 (SAS Institute Inc) and figures were created using the *ggplot2* library in R version 2.15.2 [14]. All statistical tests were evaluated at a 2-sided significance level of 0.05.

Results

Findings

In 2014, 455,341 unique users participated in the Walgreens' BRhc program. These users either entered manually or linked a supported device or app that automatically entered 1 of 7 activities tracked in the BRhc program: exercise, weight, sleep, blood pressure, blood glucose data recorded, tobacco use, and oxygen saturation. In total, 30,420,457 activities were entered between January 1 and December 31 (average 66.81 per user). Of the 455,341 users, 315,744 (69.34%) were new users who had at least one month of follow-up activity data. The mean age was 38.65 years (SD 10.95), median was 38.91 (interquartile range [IQR] 31.53 to 42.88) and of the 65.66% (207,330/315,744) of users with nonmissing gender information, 81.71% (169,402/207,330) were women.

Basic demographics and usage characteristics of these 315,744 new members are presented in Table 1.

A large proportion of users (33.73%; 106,491/315,744) who created an account logged in just for a day during the study period. Of the remaining 66.27% of users entering activities for more than 2 days, 77.62% (162,426/209,253) logged activities a month or more after their first entry.

The majority of users (57.00%) of the total study population tracked only 1 type of activity, with exercise being the most common metric tracked (85.52%). However, a sizable number of individuals (21.34%) tracked 3 or more activities – the most common combination being exercise, weight, and sleep. Finally, most users (77.21%) manually logged their activities exclusively through the BRhc Web-based portal, whereas 14.65% of users only logged activities automatically through a supported device or app (8.14% used both means).

Returning Users

Of the 315,744 new members who enrolled in the BRhc program during the study period, 66.27% (209,253/315,744) of users logged activities on multiple occasions. Usage features of these returning users participating in the program are presented in Table 2.

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Table 1. Basic usage characteristics among new Balance Rewards for healthy choices (BRhc) members (N=315,744).

Demographic characteristics	n (%)
Age in years	
18-34	105,070 (33.28)
35-49	164,345 (52.05)
50-64	39,073 (12.37)
≥65	7256 (2.30)
Gender	
Female	169,402 (53.65)
Male	37,928 (12.01)
Unidentified	108,414 (34.34)
Participation length	
1 day	106,491 (33.73)
<4 weeks	46,467 (14.72)
4≤weeks<20	115,598 (36.73)
≥20	46,828 (14.83)
Activity logged	
Exercise	270,036 (85.52)
Weight	129,566 (41.03)
Sleep	105,582 (33.44)
Blood pressure	34,013 (10.77)
Blood glucose	18,705 (5.92)
Number of activities	
1	179,988 (57.00)
2	68,371 (21.65)
≥3	67,385 (21.34)
Source of logging	
Web-based portal	243,774 (77.21)
Device or app	46,262 (14.65)
Both	25,708 (8.14)

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Table 2. Weekly usage characteristics among returning users across activities logged.

Demographic characteristics	Any	Exercise	Sleep	Weight	Blood pressure	Blood glucose
N	209,253	186,037	62,040	56,533	16,318	9737
Age in years, mean (SD)	38.84 (10.84)	38.98 (10.61)	38.97 (12.35)	38.36 (12.48)	41.26 (13.63)	40.66 (13.71)
Female, n (%)	109,826 (52.48)	91,565 (49.22)	46,493 (74.94)	43,311 (76.61)	12,182 (74.65)	7093 (72.85)
Male, n (%)	26,047 (12.45)	22,972 (12. 35)	10,869 (17.52)	9291 (16.43)	2950 (18.08)	1915 (19.67)
Participation length, median (IQR)	8 (4-18)	8 (4-18)	10 (3-21)	7 (2-16)	6 (2-15)	6 (2-14)
Activities logged/week, mean (SD)	5.66 (7.73)	3.62 (4.90)	4.44 (4.73)	2.84 (3.44)	3.53 (4.23)	5.57 (6.27)
Days of activity logged/week, mean (SD)	2.24 (2.12)	2.27 (2.19)	1.87 (1.63)	1.48 (1.40)	1.79 (1.59)	2.19 (1.74)
Gap > 1 month (%)	49,641 (23.72)	45,232 (24.31)	18,502 (29.82)	15,063 (26.64)	4063 (24.90)	2126 (21.83)
Gap > 3 months (%)	11,385 (5.44)	9159 (4.92)	5902 (9.51)	6060 (10.72)	1332 (8.16)	661 (6.8)
Device or app (%)	69,506 (33.22)	66,489 (35.74)	32,424 (52.26)	9020 (15.96)	414 (2.5)	127 (1.3)

The median length of participation for these users was 8 weeks (IQR 4-18). There was a tendency among users who logged exercise and sleep activities to participate in the program the longest (median 8 and 10 weeks, respectively), whereas users who logged blood pressure and blood glucose had the shortest participation duration (median 6 weeks; all $P<.001$). A proportion (23.72%) of users had a moderate (at least one month) gap between consecutive logged entries over their participation period, and a small number of users (5.44%) had a substantial gap (at least three months) between entries. Overall, half of the returning users participated for at least eight weeks, but periods of inactivity were not uncommon.

Meanwhile, returning users logged 5.66 activities per week (SD 7.73) when all different types of activities were included, but median value of logged activities was 2.87 (IQR 0.52-7.67), indicating a small percentage of highly-active users contributed to the increase in the mean frequency. Among specific activities, blood glucose had the highest weekly entry (mean 5.57 entries per week) and body weight had the least (mean 2.84 entries).

Finally, we note that a higher proportion of these returning users used a supported device or app compared to all new users (33.22% vs 22.79%, respectively). The most commonly used device was Fitbit (59.89% of returning users with supported device or app; 41,608/69,472), followed by Jawbone (2.39%; 1666/69,472) and Misfit (1.60%; 1112/69,472), which are activity trackers, wireless-enabled wearable technology devices that measure data such as steps walked, heart rate, or sleep time. The commonly used apps were Runkeeper (20.03%; 13,917/69,472), Lose It! (10.75%; 7472/69,472), MyFitnessPal (7.29%; 5062/69,472) and MapMyFitness (6.41%; 4456/69,472), which also tracked caloric intake, calories burned, and weight. Furthermore, the vast majority (96.57%; 69,506/71,970) of new users who linked a device or app returned to logged activities on subsequent days. However, in part due to the availability of supported tools only for specific activities, we observed vast variability across activities. There is potential that this variability in linked device or app use accounts for the utilization differences between activities observed above. We further examine this hypothesis in more detail in the following sections.

Long-Term Utilization

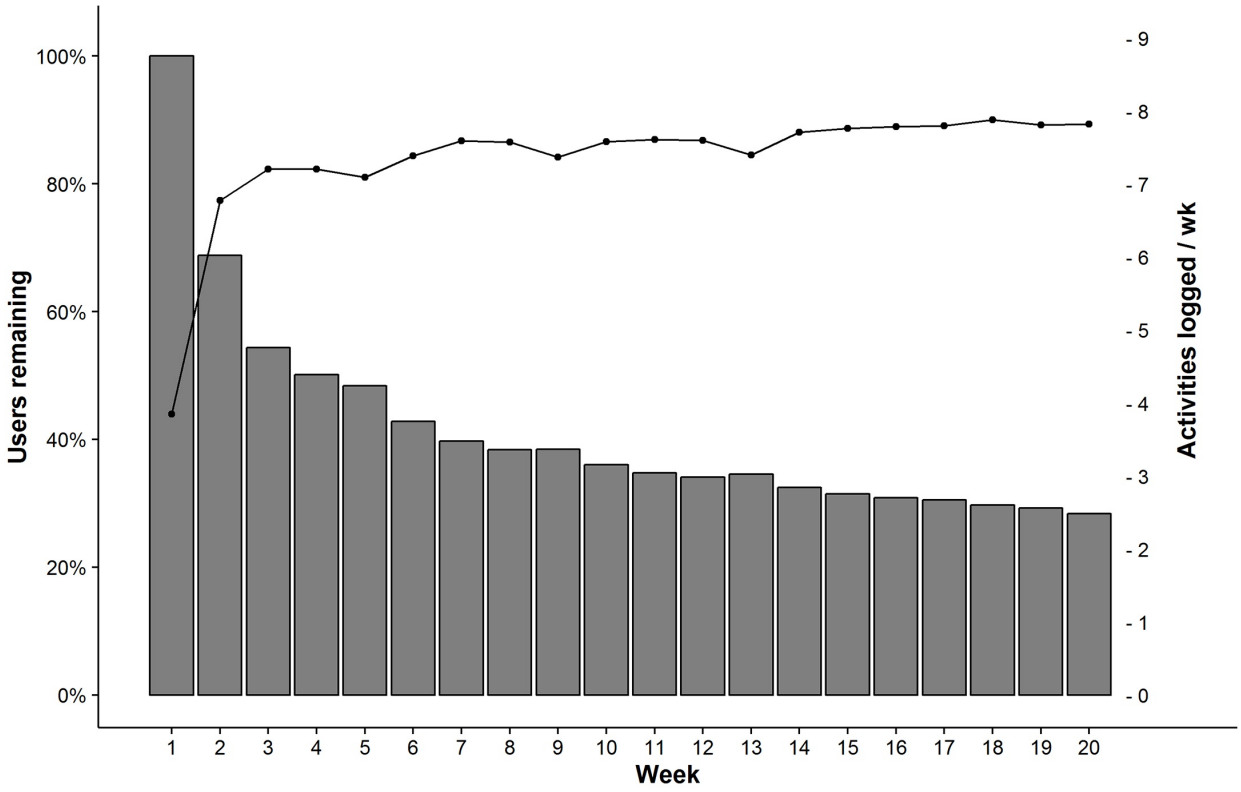
To explore long-term usage, we identified a subset of members (116,621 users with 10,946,634 recorded activities) who joined the program before August 2014 and who had 2 or more log-on dates. This allowed us to examine utilization over the first 20 weeks after program enrollment. Of these users, 31.20% (36,390/116,621) stopped participating after 1 week, and 49.88% (58,177/116,621) stopped within 1 month. However, after this initial dropout, the number of users in the program remains fairly consistent over many weeks (Figure 3).

After 20 weeks, 28.36% (33,078/116,621) of registered users were still actively engaged in the program. Meanwhile, combined with the duration of program participation, the frequency of program participation over the first 20 weeks demonstrated some interesting trends. First, the average number of activities logged by users was 4.28 during the first week in the program. However, after excluding the roughly one-third of users who ceased recording activities after 1 week, the average number of activities logged by participating users increased to 7.53 by the second week. After 4 weeks, this number was 8.01 and remained relatively steady throughout the 20-week period examined (Figure 3).

Overall, this demonstrates that while a large proportion of users stopped participating in the BRhc program early on (roughly half by 4 weeks), those that did continue to log activities did so at a fairly consistent level throughout their participation period. We observed that users log activities roughly three days a week, on average, the most common activity being exercise.

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Figure 3. Percentage of users still logging activities after certain number of weeks, and the average number of activities logged during that week. Bar: users remaining, line: activities logged per week.



The Role of Supported Devices and Apps That Automatically Log Activities

Around one-third of returning users and 23% of all users used a supported device or app which, when linked to the account, was able to record and automatically upload activities directly to the BRhc portal. There was also marked variability in the proportion of users who used such tools across different activities. For example, 35.74% of users (66,489/186,037) logging exercise activities used an automatically uploading device or app while 52.26% (32,424/62,040) of users logging sleep did too.

Among users who joined the program before August 2014, automatic activity logging was strongly associated with longer participation length (Figure 4).

Users logging activities automatically using a linked device or app participated on average (mean) 24.01 weeks versus 10.54 weeks among those logging activities manually (P<.001). Furthermore, users automatically logging activities were active participants (number of weeks recording at least one activity) for 20.15 weeks on average compared with 5.23 weeks (P<.001). This trend was consistent across all the tracking activities where automatic upload was common: exercise (20.41 weeks vs 5.71), sleep (13.61 vs 3.25), and weight (10.76 vs 5.18; all P<.001) but not for blood pressure (6.26 vs 6.18; P=.88) or blood glucose (8.37 vs 6.71; P=.11) where automatic tracking was rare (Table 3).

Although most of the users were female, male participants were more likely to be the active users in this program, especially in weight tracking (mean active weeks of male vs female in manual, 6.09 vs 5.02; P<.001, values in automatic upload, 14.44 vs 9.52; P<.001).

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Table 3. Mean (SD) of participation length (weeks) between users logging activities using the Web-based portal (manual) or through a supported device or app (automatic).

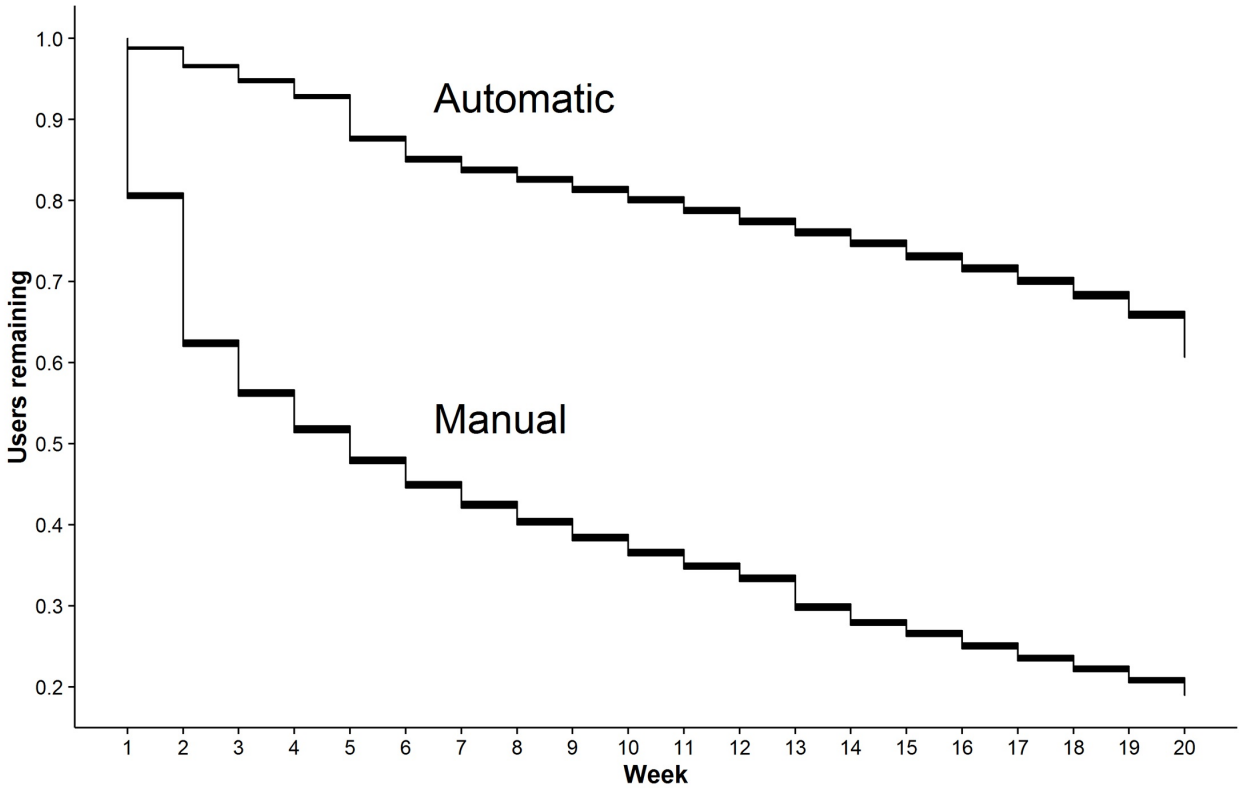
Type of activity		Manual, mean (SD)			Automatic, mean (SD)			*P* value
		Total	Female	Male	Total	Female	Male	
Any	Participation	10.54 (11.64)	10.28 (11.67)	11.72 (12.15)[a]	24.01 (13.47)	24.81 (13.14)	25.30 (13.74)[a]	<.001
	Active participation	5.23 (6.78)	5.14 (6.67)	5.91 (7.73)[a]	20.15 (13.18)	20.71 (12.96)	21.80 (13.61)[a]	<.001
Exercise	Participation	11.34 (11.80)	11.06 (11.90)	12.62 (12.16)[a]	24.03 (13.64)	24.89 (13.22)	25.20 (13.75)	<.001
	Active participation	5.71 (6.96)	5.67 (6.93)	6.22 (7.59)[a]	20.41 (13.22)	21.07 (13.00)	21.85 (13.60)[a]	<.001
Sleep	Participation	8.65 (9.00)	8.67 (8.96)	8.68 (9.40)	21.69 (10.98)	21.58 (10.87)	22.21 (11.35)	<.001
	Active participation	3.25 (3.28)	3.20 (3.14)	3.57 (4.09)[a]	13.61 (10.08)	13.43 (9.97)	14.21 (10.48)[a]	<.001
Weight	Participation	11.66 (11.54)	11.63 (11.43)	11.96 (12.16)	16.41 (11.99)	15.23 (11.31)	20.04 (13.32)[a]	<.001
	Active participation	5.18 (6.57)	5.02 (6.24)	6.09 (8.16)[a]	10.76 (9.53)	9.52 (8.48)	14.44 (11.41)[a]	<.001
Blood pressure	Participation	11.81 (10.61)	11.64 (10.44)	12.68 (11.31)[a]	10.76 (8.96)	10.39 (7.89)	11.19 (9.89)	.19
	Active participation	6.18 (7.39)	5.87 (6.95)	7.59 (8.98)[a]	6.26 (5.67)	6.04 (5.13)	6.46 (6.13)	.88
Blood glucose	Participation	11.58 (10.68)	11.31 (10.49)	12.66 (11.30)	11.74 (8.25)	9.94 (6.91)	14.00 (9.33)	.91
	Active participation	6.71 (8.00)	6.28 (7.54)	8.33 (9.37)[a]	8.37 (7.02)	7.62 (6.44)	9.33 (7.71)	.11

[a]Variable with significant difference between female and male.

Although the majority of all users (77.21%; 243,774/315,744) exclusively logged activities manually through the BRhc Web-based portal, interestingly, automatically-entered data accounted for the majority of all recorded activities. Of the nearly 13 million total activities recorded by returning users, only 23.46% (2,969,761/12,661,261) were manually entered, while the remaining 76.54% (9,691,500/12,661,261) were entered automatically using a linked device or app. Again, we observed that sleep (92.02%; 2,430,157/2,640,769) and exercise (83.00%; 6,966,901/8,393,429) had the highest frequency of activities logged automatically while weight, blood pressure, and blood glucose were lowest (all $P<.001$) among users enrolled prior to August 2014.

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Figure 4. Kaplan Meier survival curve with 95% confidence intervals for the duration of participation among users logging activities manually through the online portal or automatically using a linked device or app.



Users Tracking Blood Pressure and Blood Glucose

BRhc members logging blood pressure and blood glucose recordings may represent a slightly different population than the other BRhc members as they would be more likely to have hypertension, diabetes, be at increased risk, or have the perception to be at risk for these conditions. Furthermore, automated data upload to the BRhc platform using a device or app was rarely used for tracking blood pressure or blood glucose in 2014. However, these users could benefit from the program, as monitoring of blood pressure and blood glucose is critical to the control of hypertension and diabetes.

A total of 19,143 returning users in the BRhc logged blood pressure or blood glucose measurements. Similar to the entire BRhc member population, their average age was 41.62 (SD 13.61) years and 80.25% (14,290/17,806) were female. On average, users logging blood pressure or blood glucose activities tracked a wider range of activities than other users (median 4 vs 2). Most of these users also tracked weight (92.73%; 17,751/19,143), exercise (91.36%; 17,489/19,143), or sleep (86.34%; 16,529/19,143). There were 12,401 new users tracking blood pressure or blood glucose that enrolled in the BRhc program prior to August 2014. Similar to the entire population, 27.02% (3351/12,401) of these users quit logging activities by the first week and 21.84% (2709/12,401) were still recording activities after 20 weeks.

Discussion

Principal Findings

Monitoring of physiologic parameters, health activities, and health behaviors outside of the medical setting has the potential to enable alternative systems of health management that can be both more individualized and convenient for health consumers. An understanding of the patterns of home-based self-tracking can provide insights into optimizing such programs in future health care models.

The Walgreens' BRhc program is one such alternative health management system that, in 2014, enrolled 455,341 members. Walgreens incentivizes users to log health-related activities that can be tracked using the BRhc portal. Recently, a study was performed to increase physical activities using wearable devices and gamification from incentivized consumers [15]. This study analyzed the descriptive data from GOODcoins, a self-guided, consumer engagement and rewards platform incentivizing physical activities. The results suggested that challenges and incentives might work for connected and active participants in achieving healthy physical activities. Our study showed consistent, extended results to the previous finding of how incentivized consumers track health behaviors and health data in real-world setting with large population.

In this study we examined the utilization characteristics of these individuals.

First, BRhc users who provided their gender information were mostly women (81.7%; 169,402/207,330) in their thirties

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(median age 38.9 with IQR 31.5 to 42.9). This finding is consistent with previous studies of Web-based weight loss programs [16,17]. A recent survey from the National Cancer Institute found that being younger and female were associated with increased use of Web-based and other nontraditional health resources [18]. Considering the size of participants and impact of availability of Walgreens drug stores, this phenomenon could be representative of real-world setting, not artificially chosen nor controlled population.

We note that BRhc members were self-selected without any mediation of, for example, health care professionals. Thus, strategies to better engage men [19] and the elderly [20] need to be more fully explored in order for home-based health management to become a more common occurrence in everyday lives across all demographics. Also, in our analysis of a long-term observation group showed that men, although being a small portion of the total users, who voluntarily selected the program tended to be more active users in tracking health behaviors than women. This trend seemed prominent in weight tracking where intentional efforts are needed more than any other activity, even when linked with apps or devices. So engagement methods need to be studied differently according to gender.

We presented frequency and duration utilization metrics of the BRhc program. Approximately one-third of users created an account, logged a single activity, and then never returned. These users reflect an audience with initial interest, but are either immediately turned off or fail to see (or care for) any benefit of continuing to log activities in the program. This result follows a trend seen in other studies, for example: one study of a weight loss app found that it was downloaded by nearly 190,000 users but only 2.6% used the app for at least one week [21]; and another showed high attrition rate and rapid decrease in usage in mobile and Internet programs for maintaining physical activity after cardiac rehabilitation [22]. Especially in the era of consumer-centric mobile or Web-based intervention studies, phenomenon of dropout attrition and nonusage attrition where substantial proportion of users not using the intervention as guided or dropping out before completion, the so called “law of attrition” [23] still remains the challenging issue. Our attrition curve also suggested early “curiosity plateau,” followed by a more steady group of users who remained in the program. In this regard, we believe that identification and understanding of the characteristics of these individuals, and factors that promote interest or motivate behavior change is critically important in this rapidly evolving field.

Factors Associated With Adherence in Healthy Behavior Program

According to a review regarding Web-based recruitment methods for mobile health study, virtual aspect of intervention might lead to comfort in enrolling the trial, less investment in ongoing usage, and possibility of fraudulent enrolling in the trial [24]. Other proposed factors that can influence patient retention and engagements are usability of the program, interactive feedback, tangible and intangible observable advantage in using the program, effort and time required, networking effects or peer pressure, and user factors (demographic education, previous experiences) [23]. To increase a consumer’s motivation and active participation, various incentive-driven mobile health technologies such as education, reminder, feedback, social, financial, or gamification can be simultaneously used and provide its efficacy [25].

In order to test or implement a mobile health program with actively-engaged users, attrition must be actively reported in metrics such as usage half-life, dropout attrition curve, or Kaplan-Meier analysis [23] and analyzed according to user factors (sociodemographic, health condition etc), usability, and components of the program itself for solving the attrition problem.

Also for the behavior change, it is not clear whether a previous active tracker is viewed as a superuser in the BRhc program or a person who does not participate in health behavior tracking has become an active tracker initiated by the program. Further exploration around behavior changes is needed to clarify the impact of behavior changes on users at different stages.

Michie et al developed and refined the behavioral change technique taxonomy for behavioral change intervention [26], and this system can be effectively adopted for implementing and evaluating a mobile health intervention program. In the BRhc program, incentives such as rewards points, goal setting, and self-monitoring of behavior were used as behavior change techniques motivated by Fogg’s behavioral change methods [27,28]. This program definitely proved its positive impact on pervasiveness recognized by 800,000 users, 250,000 connected devices, and 73 miles logged as of April 2015 [29], but further issues with continuous engagement or participation of various ages with gender seemed to be solved.

Long-Term Adherence to Healthy Behavior Program and Automated Self-Monitoring Tool

Our results of long-term utilization demonstrated that roughly one-third of returning users quit within 1 week, half quit within a month, and two-thirds quit by 5 months. However, the attrition rate declined rapidly after this, particularly so in users logging activities using a linked device or app. Over half (57%) of all users that were still participating after 1 month continued to participate for at least twenty weeks. Since motivating behavior change to improve health management requires continuous and often complex processes, engaging consumers both initially and for prolonged lengths of time will be important components of success. There is still much to learn about motivating long-term participation, but at a minimum, tools should be simple enough for users and incorporate proven behavior change theories through the use of rewards or incentives [30].

One such tool to improve long-term health self-monitoring is mobile and wireless health-tracking technologies. These technologies can collect, transmit, and aggregate health data – automated, thus removing this burden from the user. We discovered that users tracking data using devices participated in the program, on average, 24 weeks compared with 11 weeks among users not using any device. Furthermore, these users were active 20 weeks on average compared with 5 weeks. Another study looking for adherence to the protocol through mobile phone apps which compared website or paper diaries

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for weight loss also proved the advantage of mobile phone apps even when it was not a fully automated process [31].

More advanced and user-friendly self-monitoring tools are continually being developed, and their capacity to interact with and be interpreted within traditional (eg, electronic health records) and nontraditional health care systems will be critical in their implementation. It is becoming a common feature of many new mobile health devices to enable automated collection, downloading, and sharing of measured biometrics. Yet, while our study showcased the benefit of automated systems, we feel the next frontier in this field needs to address the interpretation of data collected from these devices beyond displaying the data to users in attractive pictures [32]. Many studies have shown the benefit of remote monitoring in improving outcomes with patients not only in chronic condition such as chronic obstructive pulmonary disease, heart failure, diabetes, or hypertension [33,34] but also meaningful interpretation of data at the point of need can be valuable in acute infectious disease such as Ebola outbreak [35].

Individuals With Chronic Condition and Automated Self-Monitoring Tool

Individuals with chronic conditions could potentially benefit most from automated tracking tools. Health complications from hypertension and diabetes, for example, are largely preventable with proper management. However, these conditions (and others) are often poorly controlled. In a number of cases, automated interventions have shown health benefits: a prior study showed that a fully automated behavioral intervention leveraging Web, mobile, and automated mobile phone calls significantly improved glycemic control, body weight, and diabetes risk among prediabetics [36]; another showed that a physical activity intervention consisting of automated weekly exercise scheduling reminders, a message board to share their experience with others, and feedback on their level of physical activity increased and maintained levels of physical activity in healthy adults [37]; and another showed that a fully automated smoking cessation program using email, Web, interactive voice response, and short messaging service was associated with abstinence rates without the use of nicotine replacement therapy [38]. However, even with access to the latest technologies to monitor any biometric or condition, engagement, which leads to behavior change, is key. Technology in and of itself is unlikely to drive change toward positive health outcomes. Additional factors, like incentives used in the BRhc program and how they interact with technologies to engage participants have shown positive health behavior changes [39] and potential to drive the future of health self-monitoring.

Limitations

This study focused on characteristics of users of an incentivized, Web-based self-monitoring program. Although users of the BRhc program can be representative of real-world setting, when we look at long-term utilization, the composition of users—self-selected, young, and most likely female—as well as high attrition rate affect the validity and generalizability of our findings. Further exploration of the relationship between utilization patterns and their impact on perceived value, especially among users tracking blood pressure or blood glucose, are needed to better understand the potential impact on behavior change and chronic conditions management.

Since this program used incentive for behavior change and engagement, relationship between Balance Reward points and usage activities should have been investigated. Balance Rewards points are calculated both from purchasing certain products and earning behavioral points from the BRhc program to be used as redemption. However, since the variables of total reward points or redemption contents were not available in our database, and hypothetical BRhc program can be calculated from usage activities itself, it was difficult to prove the role of “incentive” leading to behavior changes. Also incentive itself was relatively small. If a first-time user creates an account, sets up a goal, and logs in 9 different activities for 1 month, not skipping even one, he or she will get maximum 6050 points, which can be redeemed at 6 dollars a month.

Conclusions

Web-based and mobile health self-monitoring is popular in the general population, and could play a critical role in the future of health management and wellness. Self-monitoring has been shown to improve health and management of chronic conditions. However, there are considerable challenges in initiating and sustaining engagement for long periods of time. This study provides insights into utilization patterns of incentivized users participating in a large, nationwide, Web-based self-monitoring program and supports the benefit of automated health tracking to help maintain long-term engagement.

Acknowledgments

This research was supported in part by the National Institutes of Health (NIH)/National Center for Advancing Translational Sciences through a grant UL1TR001114, and a grant from the Qualcomm Foundation.

Conflicts of Interest

Authors Michael Taitel, Greg Orr, Osayi Akinbosoye, and Jenny Jiang are members of Health Analytics, Research & Reporting department in the Walgreens Company.

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Abbreviations

BRhc: Balance Rewards for healthy choices
mHealth: mobile health

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Edited by G Eysenbach; submitted 20.07.16; peer-reviewed by T van Mierlo, S Wangberg, I Korhonen, A Paglialonga; comments to author 11.08.16; revised version received 23.09.16; accepted 12.10.16; published 17.11.16.

Please cite as:
Kim JY, Wineinger NE, Taitel M, Radin JM, Akinbosoye O, Jiang J, Nikzad N, Orr G, Topol E, Steinhubl S
Self-Monitoring Utilization Patterns Among Individuals in an Incentivized Program for Healthy Behaviors
J Med Internet Res 2016;18(11):e292
URL: http://www.jmir.org/2016/11/e292/
doi:10.2196/jmir.6371
PMID:27856407

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Original Paper

Text to Move: A Randomized Controlled Trial of a Text-Messaging Program to Improve Physical Activity Behaviors in Patients With Type 2 Diabetes Mellitus

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Abstract

Background: Text messages are increasingly being used because of the low cost and the ubiquitous nature of mobile phones to engage patients in self-care behaviors. Self-care is particularly important in achieving treatment outcomes in type 2 diabetes mellitus (T2DM).

Objective: This study examined the effect of personalized text messages on physical activity, as measured by a pedometer, and clinical outcomes in a diverse population of patients with T2DM.

Methods: Text to Move (TTM) incorporates physical activity monitoring and coaching to provide automated and personalized text messages to help patients with T2DM achieve their physical activity goals. A total of 126 English- or Spanish-speaking patients with glycated hemoglobin A_{1c} (HbA_{1c}) >7 were enrolled in-person to participate in the study for 6 months and were randomized into either the intervention arm that received the full complement of the intervention or a control arm that received only pedometers. The primary outcome was change in physical activity. We also assessed the effect of the intervention on HbA_{1c}, weight, and participant engagement.

Results: All participants (intervention: n=64; control: n=62) were included in the analyses. The intervention group had significantly higher monthly step counts in the third (risk ratio [RR] 4.89, 95% CI 1.20 to 19.92, *P*=.03) and fourth (RR 6.88, 95% CI 1.21 to 39.00, *P*=.03) months of the study compared to the control group. However, over the 6-month follow-up period, monthly step counts did not differ statistically by group (intervention group: 9092 steps; control group: 3722 steps; RR 2.44, 95% CI 0.68 to 8.74, *P*=.17). HbA_{1c} decreased by 0.07% (95% CI –0.47 to 0.34, *P*=.75) in the TTM group compared to the control group. Within groups, HbA_{1c} decreased significantly from baseline in the TTM group by –0.43% (95% CI –0.75 to –0.12, *P*=.01), but nonsignificantly in the control group by –0.21% (95% CI –0.49 to 0.06, *P*=.13). Similar changes were observed for other secondary outcomes.

Conclusion: Personalized text messaging can be used to improve outcomes in patients with T2DM by employing optimal patient engagement measures.

(J Med Internet Res 2016;18(11):e307) doi:10.2196/jmir.6439

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KEYWORDS

type 2 diabetes; text messaging; mobile phones; physical activity; engagement; pedometers

Introduction

Background

The prevalence of type 2 diabetes mellitus (T2DM) in adults in the United States has more than quadrupled from 5.5 million in 1980 to 21.3 million in 2012 with an estimated total cost of US $245 billion [1]. To achieve the treatment goal of preventing or delaying complications of chronic disease, diabetes requires extensive multiple behavioral adjustments and self-care behaviors [1-3]. Today, diabetes education programs are offered in a variety of settings to equip patients with the knowledge and skills needed to modify their behavior and successfully self-manage the disease. However, physical activity (PA) and nutritional changes are more difficult for patients because of barriers such as socioeconomic factors, inadequate knowledge, lack of insight and motivation to change, or frustrations about inability to maintain consistent change [2,4].

It is well established that regular PA is effective in facilitating the attainment of treatment goals in the management of T2DM [4-6]. PA is associated with reductions in low-density lipoprotein cholesterol, systolic blood pressure, weight, symptoms of depression, and risk of cardiovascular all-cause mortality, and is associated with improvement in health-related quality of life [5,6]. Unfortunately, patients with T2DM are less likely to engage in regular PA, with recent estimates demonstrating a lower participation rate compared to the national average [7]. Given the growing number of patients with T2DM who are obese or have low levels of PA, improvements in this single behavior could have significant impact on overall outcomes in diabetes management.

The American Diabetes Association recommends encouraging patients to partake in mild to moderate PA, and coaching may be most beneficial in helping patients adopt and maintain regular engagement in PA [5]. There is increasing evidence of the effectiveness of coaching to support and better engage patients in managing their health [8]. However, to achieve coaching objectives, the process requires frequent contact or communication between the coach and the patient, which may not be feasible in an already overburdened health care system. In this project, we leveraged two key connected health cornerstones—objective data collection and targeted feedback—to develop a PA coaching program. Studies have shown that compared with non-behavior change theory-based interventions, theory-based interventions tend to be more effective in changing behaviors because they can allow for tailoring of the intervention to the individual due to enhanced bidirectional engagement [9-11]. Therefore, we collected PA data by digital pedometers and delivered targeted feedback via text messages based on the individual's PA data and the stage of change on the transtheoretical model of behavior change. We conducted a randomized clinical trial to test the hypothesis that T2DM patients assigned to a PA monitoring and text-messaging program will be more active and attain better clinical outcomes compared to a control group of patients not receiving text messages.

Objectives

The primary objective of this trial was to evaluate the effectiveness of sending daily PA-focused text messages versus no text messages on PA, measured by pedometers, in patients with T2DM receiving care at 4 health care centers affiliated with a large academic medical center. Secondarily, we evaluated the effects of the intervention on glycated hemoglobin A_{1c} (HbA_{1c}) levels, weight changes, PA behavior change, level of engagement in the program, and the patient's perception of usability and satisfaction with the text-messaging program.

Methods

Study Oversight

The study was approved by the Partners HealthCare Human Research Committees, the Institutional Review Board (IRB) for the Massachusetts General Hospital. All participants provided written informed consent.

Participants

Participants were recruited from 4 health centers affiliated with a large academic medical center that serves a highly diverse population with high proportions of low-income and ethnic minorities. Eligible participants were English- or Spanish-speaking patients, aged 18 years and older, with a diagnosis of T2DM and most recent HbA_{1c} >7.0%. They had to have a computer with Internet access at home or at work, be willing to attend 2 in-person study visits, and also be willing to receive a minimum of 60 text messages per month for 6 months on their personal mobile phone. We excluded patients with significant cognitive deficits, physical disabilities, and medical or other surgical conditions precluding participation in moderate PA.

Trial Design

The Text to Move (TTM) study was a 2 parallel group randomized controlled trial conducted from July 2012 to October 2013. The trial consisted of 2 study visits timed to coincide with a scheduled clinic appointment with their primary care providers (PCPs): screening/enrollment at the beginning of the study and a 6-month follow-up visit at the end of the study. All study materials, including the consent form, were translated into Spanish by an IRB-approved, certified Spanish translator. Participants received a check for US $50 at the end of each study visit.

Screening and Enrollment

Primary care providers and diabetes self-management educators at the study sites were informed about the study and asked to refer potentially eligible patients for participation. A study staff member also reviewed TopCare, Partners HealthCare's Web-based population registry for the management of patients with diabetes, to identify potential candidates. The list of

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potential participants identified from TopCare was sent to the managing PCPs for approval. All patients with T2DM, approved by their PCPs, were sent a recruitment letter with a 1-week opt-out option to inform the study team of their availability or nonavailability to participate in the study. Interested patients were prescreened by telephone for eligibility by research assistants using standardized scripts; eligible patients were invited for the in-person enrollment visit.

The enrollment visit lasted approximately 30 to 45 minutes and was conducted by research assistants in semiprivate rooms at each of the practices. Standardized enrollment procedures included rescreening to ascertain eligibility, informed consent procedures, on-the-spot HbA_{1c} self-check (Bayer HbA_{1c} Now), and completion of 3 study questionnaires:

1. Enrollment questionnaire: to collect baseline demographic information);

2. Physical activity Stages of Change Questionnaire: based on the transtheoretical model of change and assesses the motivational readiness of PA behavior change [12]; and

3. Patient Health Questionnaire (PHQ-8): a screener for depression [13].

Screening for third grade-level reading ability was done by testing the participant's comprehension of sample study text messages. Also at this visit, participants received the study devices consisting of a study pedometer (ActiPed+) and accompanying Bluetooth wireless technology-enabled Universal Serial Bus (USB) connection device (ActiLink USB wireless stick) and device user guides. The study pedometer served only to capture or track activity data; it did not deliver any form of personalized feedback to participants.

The pedometer used in this study was the FitLinxx activity-tracking device, called the ActiPed+, which is available for consumer use. The ActiPed+ is a small, wireless activity sensor that clips onto any shoe and accurately tracks steps, distance traveled, calories burned, and activity time. The pedometer data were uploaded via the ActiLink USB wireless stick to the device Web portal [14] where participants could view their PA data on their personal account and modify their PA goals. Images of the devices and portal are included in Multimedia Appendices 1 and 2. The ActiPed+ has capacity to store up to 3 weeks' worth of data. To view or download activity data from the pedometer, an ActiLink USB wireless stick needs to be installed on a computer with Internet access. The data automatically uploads any time the participant gets within a few feet of the ActiLink USB stick. Participants were instructed to upload their step data as regularly as possible, but no longer than 3 days so that they could view their data online and receive timely feedback on their activity levels through the study text messages. The study staff showed participants how to use the device and the website and also instructed them to set PA goals that they could modify on a monthly basis. However, the recommended PA goal of 30 minutes per day for at least 5 days in a week was preset for all participants [15].

Randomization

After eligible patients signed the consent form, they were randomly assigned to receive the TTM intervention or to the control group with a 1:1 allocation ratio. A computer-generated permutated block randomization schedule, with block sizes ranging from 2 to 10, was established with STATA 12′s ralloc procedure. A third party, not involved with the study, randomly picked blocks and treatment assignments then concealed them in numbered opaque envelopes. Thus, study staff were not aware of treatment assignment before the participant opened the opaque randomization envelope at the enrollment visit. Similar to many technology-based studies, study participants and research assistants were not blinded to treatment assignments, but the investigators were not aware of treatment assignments.

The intervention (TTM) group participants received the study text messages with activity feedback, a study pedometer (plus connection device) to monitor their daily activity, reminder telephone calls to those participants who do not upload their activity data after 5 consecutive days, and usual care. Participants assigned to the control group received a study pedometer (plus connection device), reminder telephone calls for those participants who did not upload their activity data after 5 consecutive days, and usual care, but did not receive the study text messages with activity feedback.

Follow-Up

Follow-up visits were conducted in-person by research assistants at the end of the 6-month study period. At this visit, participants completed the study surveys, had their follow-up HbA_{1c} test, and returned all study equipment. The follow-up questionnaires consisted of the Physical Activity Stages of Change Questionnaire and study-specific usability and satisfaction questionnaires.

The Intervention

The intervention consisted of at least 2 automated text messages per day—one in the morning (weekdays: 9 am EST; weekends: 11 am EST) and a second message in the evenings at 6 pm EST. The messages were designed to provide bite-sized (160-character length) coaching based on daily step counts, captured by the pedometers, and preset PA goals which were agreed on at the initial visit. Additionally, at the initial visit, we collected baseline demographic and behavioral information that was entered into the text-messaging system to tailor the messages to participants. In all, a bank of more than 1000 text messages was designed by an interdisciplinary team of physicians, nurses, behavioral psychologists, health educators, health coaches, and social workers. The text messages were designed using health literacy concepts so they could be understood at a third grade reading level and were also available in Spanish. The Spanish translations went through a rigorous process to ensure simplicity and accuracy and were translated by IRB-approved Spanish translators and reviewed by a bilingual physician and health educators. All study data, including outgoing and incoming text messages, PA, goals, and stage of change, were displayed on the study dashboard, which was monitored weekly by study staff.

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Morning messages provided feedback based on the previous day's activity. For a participant with activity data in the previous 24 hours, an example of activity feedback message was "TTM study: as of 8:27 am, you were active for 45 mins yesterday which is 75% of your daily goal." For participants without activity data in the past 24 hours, they received a reminder to upload their activity data. A sample reminder message was "TTM study: A quick reminder to upload your pedometer data. Need help? Call xxx-xxx-xxx." Afternoon and evening messages focused more on coaching themes, such as support, health education, motivation, and reminders to engage in healthy behaviors.

The text messages were designed to be targeted to an individual's stage of behavior change as determined by the transtheoretical model of behavior change. A behavioral psychologist used grounded theory techniques to group the messages into different stages of behavior change and themes. Major themes included health education, motivation/self-efficacy, support, health assessment, and basic pedometer messages. The PA stage of behavior change questionnaire [12] was used to determine baseline stage of behavior change at the enrollment visit. For example, patients identified as being in the contemplation stage received a different combination of educational, motivational, and activity-related messages than patients in the action stage. For example, a participant in the contemplation stage might receive the message "TTM Study: Take a minute to consider these questions, 'What are some benefits of becoming more physically active? What are the benefits of staying the same?'" Another participant in the action stage would receive a different kind of message, such as "TTM study: How can you add steps to your regular activity? Can you take the stairs instead of an elevator?" In general, the text messages suggested additional ways to engage in PA, such as dancing, gardening, walking to lunch, walking the dog, parking farther from the worksite or mall entrance, etc.

Participants' transition to another stage of the behavior change model was assessed monthly and was determined by attainment of activity goals captured by pedometers (participant had to meet PA goal for at least 20 days in a month to transition to another stage) and also by responses to items from the physical activity stage of change questionnaire that was delivered via text message. A study staff monitored and made the change on the study dashboard.

To optimize engagement, some of the messages were designed to be interactive, 2-way messages with short structured responses that were sent out twice a week (Tuesdays and Thursdays). Some of the interactive messages focused on satisfaction with the program, health status, knowledge of PA, food intake, and medication adherence. Sample 2-way messages included: "How would you rate your stress level over the last few weeks? 1=no stress 2=some stress 3=moderate stress 4=a lot of stress." A response from the participant generated an automatic follow-up response from the system that completed the series of that interaction. For example, a participant who responded "3″ to the preceding question received the message: "Sounds like a lot to handle, how about talking with your doctor about stress management tools?"

Outcome Assessments

The primary outcome for this study was mean step counts (collected by the wireless pedometers) per month for the entire 6-month study duration. Secondary outcomes included comparison of HbA_{1c} test results collected at enrollment and closeout visits. We also evaluated changes in weight (lb) measured at the clinic visit and collected from the medical records and PA stage of behavior change via the physical activity stage of change questionnaire [12]. In the intervention group, we also assessed usability and satisfaction by study-specific questionnaires and engagement with the intervention by the number of days that participants wore their pedometers in the study and the response rate to the 2-way interactive text messages. We further assessed engagement as a dichotomous outcome by classifying participants who responded to at least 1 text message per week for the entire 6-month duration as "engaged," whereas those who did not respond to at least 1 message per week were regarded as "unengaged."

Sample Size

We calculated a sample size of 120 (60 participants per group) would be sufficient to detect a true difference of 1500 in mean step count between the control and intervention arms with 80% power and a 2-sided .05 significance level. This was based on the assumption that the standard deviation of the response variable was 2600 in both groups and was adjusted for a dropout rate of 20% [16]. Power calculations were performed in Stata 12 (StataCorp LP, College Station, TX, USA).

Statistical Analysis

Only participants who completed closeout procedures were included in the final analyses. From initial testing, we observed that the pedometer registered some minimal steps (usually <100 steps) even when unused. Therefore, to differentiate real activity data (step counts) from "noise" data, we removed all step counts that were less than 100 steps. The intention-to-treat principle was used and participants were analyzed in the treatment group to which they were allocated. The last observation carried forward method was used for missing data from dropouts and loss to follow-up. Descriptive statistics, means (continuous data), and percentages (categorical variables) were used to summarize baseline characteristics by treatment group. Characteristics were compared between the 2 groups using independent *t* tests or chi-square tests as appropriate. The primary outcome, monthly step counts, was log transformed for normalization. Thereafter, we performed a repeated-measure procedure in SAS (PROC MIXED) for overall effect comparison between the 2 treatment groups, the monthly variation of step counts, and the interaction of group and time for the 6-month study duration. Least-square means of the log-transformed monthly step counts were back-log transformed to generate final estimates of least-square means. To control for baseline differences in HbA_{1c}, an analysis of covariance, with follow-up HbA_{1c} at the end of the 6-month study period as the dependent variable and baseline HbA_{1c} and treatment group as independent variables, was performed [17]. Furthermore, we evaluated the response rate to the 2-way text messages among the intervention

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participants. We dichotomized the response rate to create 2 subgroups among the TTM group, engaged and unengaged participants, and examined the impact of text message response rate on daily activity and HbA_{1c} values. Data analyses were done with SAS version 9.3 (SAS Institute, Cary, NC, USA). All tests were 2-tailed and *P* values less than .05 were considered statistically significant.

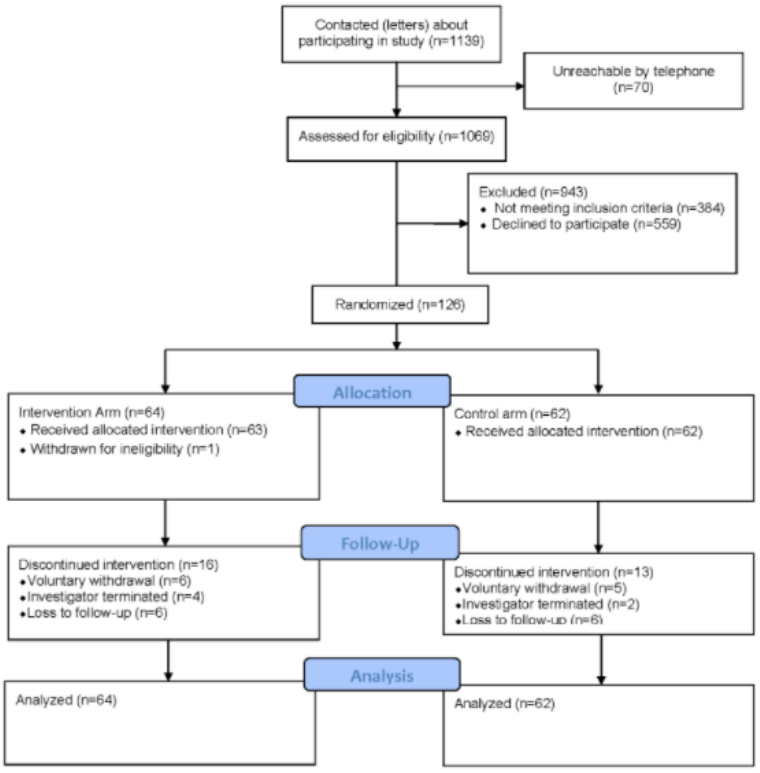
Results

Participant Flow, Baseline Data, and Numbers Analyzed

Figure 1 is a flowchart describing the participant recruitment process. Between July 2012 and March 2013, a total of 1139 patients from the participating health centers that were approved by their PCPs were contacted about participating in the study. Of these, 70 patients were unreachable by telephone after recruitment letters were sent out to them, 559 patients were not interested in participating, 364 were ineligible at telephone prescreening with reasons ranging from no cell phone to physical limitation that precluded participation in moderate activity, and an additional 20 patients were found to be ineligible at the enrollment visit (primarily HbA_{1c} <7% and low health literacy).

A total of 126 participants were enrolled in the study and randomized to the control or intervention arm of the study. Of the total that enrolled, 12 participants withdrew voluntarily from the study. In the TTM group, reasons for withdrawal included hospitalization (n=1), loss of interest in continuing participation (n=2), pedometer-related problems (n=2), and loss of computer (n=2). In the control group, reasons for withdrawal included hospitalization (n=1), disappointment for not being assigned to the TTM group (n=1), memory loss (n=1), pedometer-related problem (n=1), and loss of interest (n=2). A participant who signed the consent form and was randomized to the TTM group was withdrawn from the study because she did not meet the HbA_{1c} eligibility criterion of >7%. This was discovered before the participant was enrolled in the text-messaging program. Six participants met prespecified drop criteria. Reasons for termination included inability to receive text messages on phone (n=1), inability to download the pedometer software (n=2), no longer had a computer (n=2), and no longer had Internet connection (n=1) and therefore had no means of uploading step counts. Participants who failed to attend the final study visit despite multiple contact attempts by study staff (n=12) were regarded as lost to follow-up. A total of 95 participants completed closeout procedures between February 2013 and October 2013. We analyzed data for all enrolled participants; their baseline characteristics are summarized by treatment arms in Table 1. The 2 groups were not statistically different at baseline.

Figure 1. Participant flowchart.



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Table 1. Baseline participant characteristics (N=126).

Characteristics	Intervention (n=64)	Control (n=62)	*P* value
Age (years), mean (SD)	50.3 (10.5)	52.6 (12.6)	.26
Gender, n (%)			.11
Female	28 (44)	37 (60)	
Male	36 (56)	25 (40)	
Race, n (%)			.56
Asian/Pacific Islander	3 (5)	0 (0)	
African-American	5 (8)	7 (11)	
Hispanic	15 (23)	16 (26)	
White	39 (61)	38 (61)	
Other	2 (3)	1 (2)	
Language, n (%)			.23
English	54 (84)	46 (74)	
Spanish	10 (16)	16 (26)	
Marital status, n (%)			.88
Divorced/Separated	12 (19)	10 (16)	
Living with partner	7 (11)	5 (8)	
Married	31 (48)	36 (58)	
Single (never married)	11 (17)	9 (15)	
Widowed	3 (5)	2 (3)	
Education,[a] n (%)			.06
Grade 1-8	4 (6)	6 (10)	
Grade 9-11	6 (9)	5 (8)	
Grade 12 or GED	28 (44)	13 (22)	
1-3 years of college	18 (28)	19 (32)	
≥4 years of college	8 (13)	17 (28)	
Employment, n (%)			.24
Employed full time	33 (52)	32 (52)	
Employed part time	8 (13)	6 (10)	
Unemployed	9 (14)	12 (19)	
Homemaker	4 (6)	3 (5)	
Retired	3 (5)	7 (11)	
Disabled	4 (6)	0 (0)	
Student	1 (2)	0 (0)	
Other	2 (3)	2 (3)	
Health center, n (%)			.67
Charlestown	8 (13)	10 (16)	
Chelsea	21 (33)	25 (40)	
Everett	14 (22)	10 (16)	
Revere	21 (33)	17 (27)	
PHQ-8 score,[a] n (%)			.74
0-4	46 (73)	41 (67)	

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Characteristics	Intervention (n=64)	Control (n=62)	*P* value
5-9	13 (21)	15 (25)	
10-14	1 (2)	3 (5)	
15-19	2 (3)	2 (3)	
20-24	1 (2)	0 (0)	
Weight (lb), mean (SD)	215.0 (56.8)	208.2 (46.9)	.53
Enrollment season, n (%)			>.99
Winter	21 (33)	21 (34)	
Spring	1 (2)	0 (0)	
Summer	11 (17)	11 (18)	
Fall	31 (48)	30 (48)	

[a] Two participants in the control group had missing data.

Outcomes and Estimation

Results showed that majority of the study population (67%, 84/126) had basal activity with mean daily step counts less than 2500 steps in the first week of the study. Over the 6-month follow-up period, the intervention group (9092 steps) had more overall monthly step counts than the control group (3722 steps), but this was not statistically significant (risk ratio [RR] 2.44, 95% CI 0.68 to 8.74, *P*=.17). Table 2 presents between-group differences of least-square means of the monthly step counts and Table 3 presents median monthly step counts. Within each group, monthly step counts decreased significantly from baseline to the end of the study: from 35,786 steps to 1041 steps in the intervention group and from 31,002 steps to 342 steps in the control group. Over the study period, monthly step counts varied between groups. In particular, we observed significant differences in the third and fourth month of the study. The intervention group had significantly higher monthly step counts in the third (RR 4.89, 95% CI 1.20 to 19.92, *P*=.03) and fourth (RR 6.88, 95% CI 1.21 to 39.00; *P*=.03) months compared to the control group.

Table 2. Total monthly least squares means of step counts.

Month	Intervention, least squares means	Control, least squares means	Effect estimate, RR (95% CI)	*P* value
1	35,786	31,002	1.15 (0.36 to 3.73)	.81
2	31,138	13,493	2.31 (0.59 to 9.08)	.23
3	37,436	7653	4.89 (1.20 to 19.92)	.03
4	14,254	2072	6.88 (1.21 to 39.00)	.03
5	913	1170	0.78 (0.10 to 6.37)	.82
6	1041	342	3.04 (0.36 to 25.93)	.31

Table 3. Median monthly step counts.

Month	Intervention, median (IQR)	Control, median (IQR)
1	85,509 (40,384-121,720)	60,967 (34,327-120,384)
2	59,467 (34,852-121,160)	52,117 (23,041-101,889)
3	73,927 (22,670-134,866)	36,610 (11,000-86,940)
4	46,003 (11,228-76,386)	22,738 (0-96,011)
5	8485 (0-66,550)	17,665 (0-75,823)
6	14,180 (0-74,302)	8220 (0-56,150)

Between groups, baseline mean HbA_{1c} (Table 4) was significantly higher in the TTM group (mean 9.02%, SD 1.63 vs mean 8.38%, SD 1.37; mean difference 0.64%, 95% CI –0.11 to 1.17, *P*=.02), but follow-up HbA_{1c} was not statistically different between groups (8.59%, SD 1.60 vs 8.17%, SD 1.60; difference: mean 0.42%, 95% CI –0.14 to 0.99, *P*=.14). After adjusting for baseline differences, HbA_{1c} decreased by 0.07% (95% CI –0.47 to 0.34, *P*=.75) in the TTM group compared with the control group. Within-group differences showed that HbA_{1c} decreased significantly from baseline in the TTM group by –0.43% (95% CI –0.75 to –0.12, *P*=.01) and nonsignificantly in the control group by –0.21% (95% CI –0.49 to 0.06, *P*=.13), but these pre-post changes were statistically different by group (mean difference 0.22%, 95% CI –0.19 to 0.64, *P*=.29).

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Follow-up weight was not significantly different by group (TTM: mean 211.99, SD 53.93 lb; control: mean 208.89, SD 48.59 lb; mean difference 3.10 lb, 95% CI –24.50 to 18.30, *P*=.77).

Table 4. Glycated hemoglobin A_{1c} (HbA_{1c}).

Follow-up period	TTM (%), mean (SD)	Control (%), mean (SD)	Mean difference (95% CI)	*P* value
Baseline	9.02 (1.63)	8.38 (1.37)	0.64 (–0.11 to 1.17)	.02
Closeout	8.59 (1.60)	8.17 (1.60)	0.42 (–0.14, 0.99)	.14
Change scores	–0.43	–0.21	0.22 (–0.19 to 0.64)	.29
ANCOVA			–0.07 (–0.47 to 0.34)	.75

Table 5 shows the participants' perception of their stage of behavior change. None of the participants identified as being in the precontemplation stage. At baseline, there were no significant differences by group. However, in the follow-up period, we observed that there was a greater proportion of TTM group participants in the contemplation stage compared with controls in that stage (25% vs 9.7%, *P*=.03).

Table 5. Stages of change on the transtheoretical model of behavior change.

Stages of change	Baseline			Follow-up		
	TTM, n (%)	Control, n (%)	*P*	TTM, n (%)	Control, n (%)	*P* value
Precontemplation	0 (0)	0 (0)		0 (0)	0 (0)	
Contemplation	23 (36)	21 (34)	.85	16 (25)	6 (10)	.03
Preparation	3 (5)	7 (11)	.20	8 (13)	10 (16)	.62
Action	4 (6)	2 (3)	.68	4 (6)	7 (11)	.36
Maintenance	34 (53)	32 (52)	>.99	36 (56)	39 (63)	.47

Engagement, as measured by number of days with pedometer data, did not differ by group. Overall, the TTM group wore their pedometers for a mean 109 (SD 40) days compared to a mean 97 (SD 56) days in the control group (mean difference 12, 95% CI 9.77-29.91, *P*=.32). Adherence to activity tracking measured by the proportion of participants with pedometer data (ie, participants wearing their pedometers) also varied by month (Table 6). It decreased from 93% (43/46) in the first month to 67% (31/46) at the end of the study in the TTM group; in the control group, this proportion decreased from 94% (46/49) in the first month to 55% (27/49) by the end of the study.

Table 6. Adherence to activity tracking: participants with activity data.

Month	Intervention (n=46), n (%)	Control (n=49), n (%)	*P* value
1	43 (93)	46 (94)	>.99
2	43 (93)	43 (88)	.49
3	44 (96)	41 (84)	.09
4	42 (91)	35 (71)	.02
5	30 (65)	33 (67)	.83
6	31 (67)	27 (55)	.22

Ancillary Analyses

We found that 78% (36/46) of participants in the TTM group responded to at least 1 of the 2-way messages that were sent over the course of the study period. In all, 16 of the participants (35%) from the TTM group engaged with the intervention by responding to at least 1 text message per week for the entire 6-month duration, whereas 30 participants did not engage with the intervention by responding to at least 1 message per week. Adjusting for baseline characteristics, we found that engaged participants, on average, had 1122 more daily step counts (95% CI 84 to 2160, *P*=.04) and also had greater reductions in HbA_{1c} levels (mean difference –0.78%, 95% CI –1.64 to 0.09, *P*=.08) compared with the unengaged participants.

On a scale of 1 to 10, the overall mean participant rating of the usefulness of TTM was 8.62 (SD 1.79, range 4-10). A great majority of participants (94%, 43/46) would recommend TTM to their friends, 72% (33/46) reported that they would like to keep using the program, and 78% (36/46) would buy it for themselves or for another if it were for sale. The majority of participants who used the intervention found it helpful in improving their PA behaviors as shown in Figure 2.

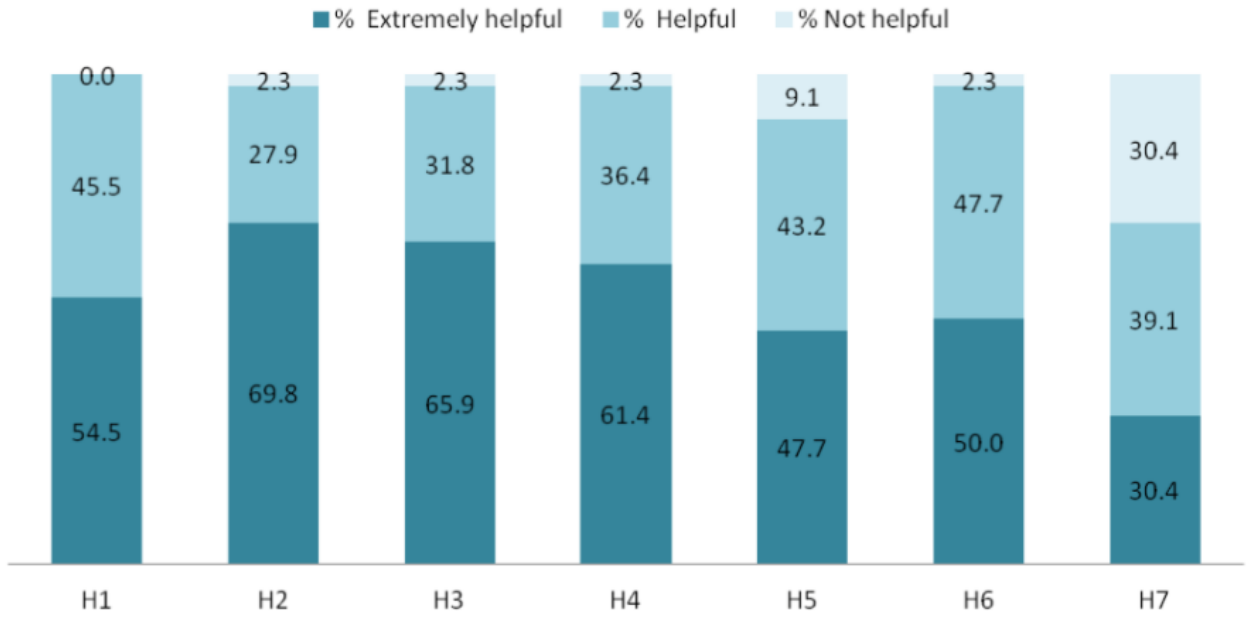
Of the TTM users, 72% (33/46) of participants discussed their use of TTM with friends and family. They were generally

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well-supported by their social networks to use the intervention, with most participants receiving encouragement from friends and family (72%) and weekly reminders from them to engage in more PA (67%). Also, 63% (29/46) of participants discussed TTM with their PCPs.

More than half of participants (57%, 26/36) did not report any problems using TTM. Some of the problems experienced included problems with the USB connection device (n=7), difficulty uploading step counts (n=7), viewing step counts online (n=4), receiving text messages (n=2), and responding to text messages (n=4). For overall improvement of the text-messaging program, 26% (12/46) of participants enjoyed the program as it was and would not recommend any modifications. However, 17% (8/46) of participants wanted to see improvements in the text-messaging intervention. Specifically, they want the messages to be less repetitive and wanted to see more messages at different times of the day, such as additional messages at lunchtime. Additional recommendations included more opportunities to speak with a live person (9%, 4/46) and improved step count functionality (9%, 4/46). The remaining 33% (15/46) either did not respond or had no suggestions to improve the program.

Figure 2. Participant perceptions of Text to Move. H1: providing educational information about PA; H2: giving feedback about number of step counts; H3: encouragement to increase level of PA; H4: reminders to be physically active; H5: asking questions that one could respond to; H6: helping one meet PA goals; H7: starting conversations about PA goals with doctor.



Discussion

Several industries are now able to leverage large amounts of data to provide intelligent and personalized information to consumers. This study attempted to use similar principles to personalize feedback to patients to improve their level of PA. Compared with similar studies [18-20], this study is innovative and stands out for several reasons. First, participants received at least two automated text messages per day for the entire 6 months: morning messages reported on the previous day's activity goal attainment and the afternoon/evening message served to educate, motivate, or assess the participant's health. Second, the texts included bidirectional interactive messages sent twice per week to foster participant engagement. Third, the monthly PA stage of change assessments increased the dynamism and relevance of the text messages. Fourth, we were able to demonstrate monthly variations in PA behaviors and engagement in this mobile-based study, which could inform future intervention design and implementation.

This study did not find significant overall effects of targeted text messaging on improving PA over the 6-month period. However, the TTM group did have significantly higher monthly step counts than the control group in the third and fourth months of the study, perhaps suggesting an optimal intervention period or an untoward effect resulting from the differential use of pedometer, by group, in the fourth month of the study. One of the reasons for not detecting changes between the groups might be linked to the design of the study. Giving pedometers to the control group may have blunted the effect of the intervention. There is some evidence that shows that simply providing people with activity trackers is correlated with improvements in PA levels by up to 13% [21]. This is consistent with the well-known Hawthorne effect in which individuals change their usual behavior in response to their awareness of being observed [22]. We provided pedometers to our control group to be able to objectively measure PA rather than self-reported data. For our other important secondary outcomes, we found that participation in the TTM program helped participants significantly lower their HbA_{1c} as well as weight from baseline. However, when compared to the change within the control group, the difference was not significant. This could possibly be explained by the increase in PA in the control group resulting from the use of a pedometer.

Other technology-based studies evaluating the effect of PA in the management of T2DM have demonstrated that such interventions are indeed effective [23]. Only 3 of 15 studies

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included in a review of such interventions were mobile phone-based and all demonstrated nonsignificant increases in PA [24-26]. Similarly, all 3 studies demonstrated significant decreases in HbA_{1c} from baseline. Similar to this study, all 3 studies were randomized trials, but the TTM approach is different because none of these included interactive 2-way messaging, automated daily PA-focused messages, or a theoretical framework in their design. Another PA monitoring and text-messaging study by Newton et al [27] conducted with type 1 diabetic patients did not increase PA. Unlike the TTM study, this study sent messages once a week, did not include 2-way messages, and did not personalize the messages. Connelly et al [23] concluded that applying methods/features to promote adherence to the intervention is associated with greater benefits. This is in consonance with our findings that engaged TTM participants responding to interactive study messages had significantly higher daily step counts and lower HbA_{1c} levels compared to those who did not.

Adherence to wearing pedometers was high and similar in both groups at the beginning of the study but decreased over the course of the study period. This suggests that pedometers alone may not sustain engagement in activity behaviors. By the fourth month of the study, the TTM group was significantly more adherent in the use of their activity trackers compared to the control group suggesting that this might be an optimal intervention period for the TTM intervention. The importance of adherence to the intervention cannot be overemphasized. Engaging in the program resulted in significantly improved outcomes compared to participants who did not engage. Even after adjusting for potential confounders (eg, age, race, gender, baseline activity), we found that the difference in outcomes was significant. Our intervention only offered motivation through targeted education and coaching messages. This seems to have worked for a subset of the cohort, helping them stay engaged with the program. Future efforts could incorporate other motivational techniques (eg, incentives, social support) to engage a higher number of participants and improve the overall outcomes in the intervention group.

Some of the decrease in engagement could be related to technical difficulties. By the end of our study, approximately 67% of intervention participants had pedometer data compared with 55% in controls. This drop in adherence over time is a common occurrence in technology-based studies. Faridi et al [24] reported that only 25% of intervention participants used their pedometers for at least 75% of study duration, whereas Newton et al [27] reported that 37% of intervention participants stopped wearing pedometers by the end of study period. Technical difficulties and forgetting to wear study pedometers were identified as major barriers to optimal adherence in other studies, and was true for our study participants as well.

Today, activity-tracking sensors have been greatly improved. They are now available in a variety of user-friendly forms that can be easily worn for most of the day: bracelets, wristbands, belt hooks, in mobile phones, smartwatches, and so on. Improvements in our big data analytic capabilities can now help us deliver dynamic and highly personalized interventions to patients in more sophisticated ways [28]. For instance, instead of just providing coaching, advanced analytic methodologies could help us determine the appropriate motivational technique to use with patients and help deliver completely different interventions to different patients. Some could get an intervention focused on enhancing social support in their day-to-day diabetes care, whereas others could be incentivized for positive behaviors. These advanced techniques hold great promise and can increase the proportion of patients who will engage with such programs long term. Other factors that may influence adherence include the frequency and timing of messages. Although more frequent messages could serve as a useful reminder, it could also potentially have a nagging or irritating effect. Also, sending messages at a "good" time when participants can practice or "catch up" on activity could be potentially helpful to participants.

Limitations

This study has a number of limitations. Firstly, the requirement of a computer with Internet access to upload activity data coupled with problems installing the pedometer software introduced a number of operational challenges that increased the attrition rate in this study—approximately 24%. High attrition rates are common in these types of studies; therefore, we anticipated this a priori and augmented our sample size. More so, there is no difference in participants who dropped out of the study compared with those who completed follow-up, which rules out selection bias. Secondly, the differential rate of adherence to activity tracker use in the fourth month of the study, whereby the control group was less adherent to using the activity tracker, could have led to a misclassification of outcome data in the control group if they were indeed active but just did not use the activity tracker. Thirdly, we observed group differences in baseline HbA_{1c} that could potentially bias comparisons of follow-up changes, but we used a statistical approach to control for this baseline difference. Fourthly, we did not collect height to account for body mass. We believe that the TTM intervention, which encourages mild-moderate activity, can be used by anyone regardless of body mass index. Fifthly, we did not evaluate the effectiveness of the different types/themes of messages. As a result, we are not able to tell from this study which of the daily feedback, reminders, or educational-motivational messages was directly responsible for study effects, but we do know that participants that responded to the 2-way messages achieved better outcomes compared to those who did not respond regularly to study messages. Finally, due to the self-report nature of the stage of change questionnaire, participants may have overestimated their stage of change at baseline and some participants might have received messages that were not appropriate for their actual stage of behavior change at the beginning of the study.

Generalizability

Participants were recruited from 4 health care centers affiliated with a large academic medical center that serves a highly diverse population of ethnic minorities and immigrants. The areas served by these health centers also have some of the highest poverty levels in the state of Massachusetts. Apart from referring their patients to participate in the study, the care providers had no other formal role to play in the study. As such, the program can

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be implemented in various clinical settings as well as nonclinical settings. The pedometer technology was a limiting factor that introduced a number of operational challenges in implementing the study. However, the TTM program is not tied to any particular activity tracker and can easily integrate with any activity-tracking technology that is appropriate for the population under consideration.

Conclusion

Text-messaging interventions that deliver targeted coaching, can be deployed on any type of phone (mobile phone or ordinary feature phones), and are feasible to develop and deploy can be used to engage patients with T2DM. Patients find such programs acceptable and a majority of patients were very satisfied with the intervention. Significant improvements in clinical outcomes can be obtained if such programs are able to achieve meaningful engagement in participants. The relatively low cost and ease of use makes it possible for such programs to be easily scaled and sustained for a longer duration across a diverse patient population regardless of age, educational, economic, or ethnic background. Future studies evaluating the effect of other personalization strategies, such as timing, optimal intervention period, frequency, and content of messages, will further help to improve adherence to such interventions. Also, strategies to use other motivational techniques could be explored to engage a larger subset of patients. Finally, efforts to integrate such care models into the workflow and usual care delivery of providers could be evaluated to help scale such programs in the future.

Acknowledgments

The investigators would like to gratefully acknowledge the following for their invaluable support: the Text to Move Study team (Misbah Mohammed, Meaghan Doherty, Clare Flanagan, Suzanne Rossov, Ellen Murachver, Shiyi Zan, Julie Kvedar, Caitlin Masters, Kurleigh Henry, Rob Havasy,Alyssa Woulfe, Bianca Porneala, and Sara Golas), the McKesson Foundation for funding this project, and Dr López thanks the RWJ Foundation Harold Amos Faculty Development Program and NIDDK 1K23DK098280-01 for their support.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Pedometer image.

[PNG File, 741KB - jmir_v18i11e307_app1.png]

Multimedia Appendix 2

Actihealth portal.

[PNG File, 317KB - jmir_v18i11e307_app2.png]

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Abbreviations

IRB: Institutional Review Board
PA: physical activity
PCP: primary care provider
PHQ-8: Patient Health Questionnaire
RR: risk ratio

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T2DM: type 2 diabetes mellitus
TTM: Text to Move
USB: Universal Serial Bus

Edited by CL Parra-Calderón, G Eysenbach; submitted 03.08.16; peer-reviewed by L Fernandez-Luque, S Li; comments to author 22.08.16; revised version received 16.09.16; accepted 28.10.16; published 18.11.16.

Please cite as:
Agboola S, Jethwani K, Lopez L, Searl M, O'Keefe S, Kvedar J
Text to Move: A Randomized Controlled Trial of a Text-Messaging Program to Improve Physical Activity Behaviors in Patients With Type 2 Diabetes Mellitus
J Med Internet Res 2016;18(11):e307
URL: http://www.jmir.org/2016/11/e307/
doi:10.2196/jmir.6439
PMID:27864165

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Original Paper

Mobile Apps in Oncology: A Survey on Health Care Professionals' Attitude Toward Telemedicine, mHealth, and Oncological Apps

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Abstract

Background: Mobile apps are an evolving trend in the medical field. To date, few apps in an oncological context exist.

Objective: The aim was to analyze the attitude of health care professionals (HCPs) toward telemedicine, mHealth, and mobile apps in the field of oncology.

Methods: We developed and conducted an online survey with 24 questions evaluating HCPs' general attitude toward telemedicine and patients using medical mobile apps. Specific questions on the possible functionality for patients and the resulting advantages and disadvantages for both the patients' and HCPs' daily clinical routine were evaluated.

Results: A total of 108 HCPs completed the survey. In all, 88.9% (96/108) considered telemedicine useful and 84.3% (91/108) supported the idea of an oncological app complementing classical treatment. Automatic reminders, timetables, and assessment of side effects and quality of life during therapy were rated as the most important functions. In contrast, uncertainty regarding medical responsibility and data privacy were reasons mostly named by critics. Most (64.8%, 70/108) were in favor of an alert function due to data input needing further clarification, and 94% (66/70) were willing to contact the patient after a critical alert. In all, 93.5% (101/108) supported the idea of using the collected data for scientific research. Moreover, 75.0% (81/108) believed establishing a mobile app could be beneficial for the providing hospital.

Conclusions: A majority of HCPs are in favor of telemedicine and the use of oncological apps by patients. Assessing side effects can lead to quicker response and thus lower inconvenience for patients. Clinical data, such as life quality and treatment satisfaction, could be used to evaluate and improve the therapy workflow. Eventually, a mobile app would enhance the patients' relationship to their treating department because they are in permanent contact.

(J Med Internet Res 2016;18(11):e312) doi:10.2196/jmir.6399

KEYWORDS

mHealth; eHealth; telemedicine; mobile application; app; smartphone; oncology; patient-reported outcome

Introduction

For younger generations, it is impossible to imagine an everyday life without mobile phones. The estimated number of those devices will exceed 2.16 billion in 2016 [1]. In the last decade, apps for mobile phones and tablets have changed our life immensely. Currently, more than 2.2 million apps [2] are available in the Google Play store and approximately 1.8 million

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apps [3] are available in the Apple App Store. Both distribute nearly 70,000 apps each in the category Health and Fitness, and approximately 33,000 and 46,000 each, respectively, as medical apps [2,3]. Apps for chronic diseases, mental health, or fitness are forthcoming [4-6]. Gadgets to track blood sugar, heart rate, or body weight are used more commonly. For the medical field, the World Health Organization (WHO) defines these tools as mHealth or "medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants, and other wireless devices" [7].

It is apparent the willingness to use mHealth apps or devices is high and the need is growing [8]. mHealth is always closely associated with telemedicine, which the WHO defines as: "The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communication technologies for the exchange of valid information for diagnosis, treatment, and prevention of disease and injuries, research and evaluation..." [9].

Practicing mHealth as a patient-assisting approach only is not expedient. Rather, mHealth with professionally advised telemedical services as a holistic concept of diagnostics and treatment is the objective of further development.

Recently, Denis et al [10] showed a significant improvement in overall survival in patients with high-risk lung cancer using a mobile-friendly Web app. In a randomized controlled trial, they compared patients using an app for self-scoring symptoms to those in a nonintervention arm. Median overall survival was 19 months versus 12 months, respectively. It was discussed that due to the regular patient self-reported outcome, earlier medical care could be achieved. Prior publications by Denis et al [11] showed higher compliance, and even 5 weeks' earlier detection of relapse, by using an Internet-based app.

To date, few native apps for mobile phones or tablets in an oncological context exist that support cancer management or cancer patients themselves during therapy as well as follow-up and allow for data analysis and/or direct feedback about therapy parameters [12,13]. A recent review by Brouard et al [13] identified 117 apps for patients, mostly for oncological information and treatment monitoring. The scientific validation (mentioned in the store description) of those apps was poor (27.4%, 32/117). Collado-Borrell et al [14] evaluated 166 apps (Android: n=75; Apple: n=59; both: n=32) for cancer patients. The purposes of the apps were mainly informative (39.8%, 66/166), diagnostic (38.6%, 64/166), and preventive (28.3%, 47/166). Moreover, the study showed a lack of involvement by qualified professionals, as only 48.8% (81/166) were developed by health care organizations. There is an ongoing discussion whether apps are really valuable and whether health care professionals (HCPs) will accept the use of them by patients in clinical day-to-day life. Therefore, we initiated a survey to evaluate the opinions of HCPs on oncological apps within our Oncology Center (Onkologisches Zentrum am RHCCC am MRI Technical University Munich, Munich, Germany). This paper analyzes the general attitude of HCPs toward mHealth, oncological apps, and their use by patients.

Methods

A team of experienced oncologists and medical computer scientists developed a questionnaire containing 24 questions evaluating opinions on the use of mHealth and mobile apps in an oncological context at the Technical University Munich, Klinikum rechts der Isar. Focus was on HCPs' general attitude toward telemedicine and patients using medical mobile apps using specific questions on functionality and the possible advantages and disadvantages of an app, as well as questions relating to emergency notifications regarding severely ill patients' entries. In addition, we evaluated opinions on data transfer options, data use for scientific purposes, and possible simplification and standardization of follow-up check-ups (see Multimedia Appendix 1: original questionnaire [German]).

One question per page was displayed. Questions were either designed in multiple-choice format with a single answer (forced entry; questions 1, 2, 5, 11, 12, 14, 16-18, 20-23) or multiple answers (forced entry with free-text response option; questions 8-10, 13, 15), as a matrix/rating scale (forced entry; question 6) or free-text mode (optional entry; questions 3, 4, 7, 19, 24). In addition, certain questions were polar questions (questions 2, 5, 12, 14) with branching logic because some queries were related to previous responses. To avoid a central tendency bias, questions in a rating scale mode consisted of an even number of answers. If necessary, technical terms were explained in a footnote. Because all questions were designed with forced entries or optional free text, only completed questionnaires could be submitted by the user and were analyzed. The participant was able to revise answers using a back button.

A sample of 18 experienced professionals in the field of oncology pretested and crosschecked the survey to determine whether the questions were clear and understandable. Consequently, minor changes were made to provide a better understanding and a more user-friendly interface. A link to the survey was sent to HCPs at our hospital via an in-house email distributor representing a convenience sample. The participation was anonymous and voluntary. Approval by the ethics committee and informed consent were not necessary because it was a survey not involving patients.

We conducted the survey for 6 weeks on an online platform (Survio sro, Czech Republic) in March and April 2016 in accordance to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines [15]. The platform ensured data protection and security (2048-bit SSL security, ISO/IEC 270001 standards, daily backups). Unique survey visitors were determined by cookies, which were valid depending on particular browser settings. Because the survey was conducted anonymously, we could not prevent users accessing and submitting the survey multiple times.

Statistical calculations were performed using SPSS version 23 (IBM Corp, Armonk, NY, USA) in a primarily descriptive way.

Results

A total of 108 HCPs (female: n=48; male: n=60) completed the online questionnaire (completion time: median 7.4, range

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2.3-322.3 minutes). The survey software counted 290 unique survey visitors, 118 of which only visited the start page and never started the survey and 64 started the survey but did not submit the answers. Hence, the participation rate was 59.1% (172/290) and the completion rate was 37.2% (108/290). Participants' characteristics are shown in Table 1.

Table 1. Participants' characteristics (N=108).

Characteristic	n (%)
Gender	
Female	48 (44.4)
Male	60 (55.6)
Age (years)	
20-39	58 (53.7)
40-59	42 (38.9)
≥60	8 (7.4)
Position	
Resident	24 (22.2)
Attending physician	17 (15.7)
Senior physician	27 (25.0)
Head of department	8 (7.5)
Nurse	15 (13.9)
Other	17 (15.7)
Medical specialty	
Internal medicine	46 (42.6)
Surgery	42 (38.9)
Other	20 (18.5)
Treatment of oncological patients	
Yes	83 (76.9)
No	25 (23.1)
Scientific background	
Yes	88 (81.5)
No	20 (18.5)

The majority of respondents (88.9%, 96/108) considered telemedicine useful. When asked for advantages of telemedicine, participants named location independence, better documentation of data and test results, improved and continual care for patients in rural areas, enhancement in communication between HCPs and patients, improved patient compliance, the possible use of data for scientific evaluations, and the potential of patient-independent information. In turn, primary disadvantages were concerns about data privacy, loss of the personal visual impression of patients, less time for clinical routine, a possible lack of financial compensation for the service, and the pressure to answer patient requests promptly.

In total, 84.3% (91/108) supported the idea of an oncological app complementing classical treatment, whereas 15.7% (17/108) did not regard it as reasonable. If respondents were in favor of oncological apps (n=91), we asked for their opinion on certain functions (Figure 1). Timetables during therapy (eg, dates for chemotherapy or radiotherapy), a reminder for those dates, and a reminder for medication intake and dosage were rated very useful by 74% (67/91), 77% (70/91), and 67% (61/91), respectively, and as useful by 26% (24/91), 22% (20/91), and 30% (27/91), respectively. Assessing quality of life (very useful: 54%, 49/91; useful: 44%, 40/91), current side effects (very useful: 48%, 44/91; useful: 43%, 39/91), and laboratory test results (very useful: 44%, 40/91; useful: 45%, 41/91) were classified as valuable. Further, registering parameters for possible clinical trials (very useful: 42%, 38/91; useful: 45%, 41/91), monitoring treatment satisfaction (very useful: 40%, 36/91; useful: 44%, 40/91), and collecting results of medical imaging (very useful: 35%, 32/91; useful: 43%, 39/91) were also seen as feasible functions. Guidelines and information about current therapy (very useful 28%, 25/91; useful 52%, 47/91) and visuals of patient inputs such as blood results and side effects (very useful: 22%, 20/91; useful: 55%, 50/91) were other functions of high relevance.

All critics not in favor of oncological apps (n=17) specified their motives (Figure 2). As expected, legal uncertainty regarding medical responsibility (77%, 13/17), data privacy

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issues (77%, 13/17), and possible problems with insecure data transfer and storage (65%, 11/17) were named arguments against establishing an app. The wish for personal contact between HCP and patient (41%, 7/17), missing technical skills (24%, 4/17), and doubt in improvements of data documentation (24%, 4/17) were additional reasons.

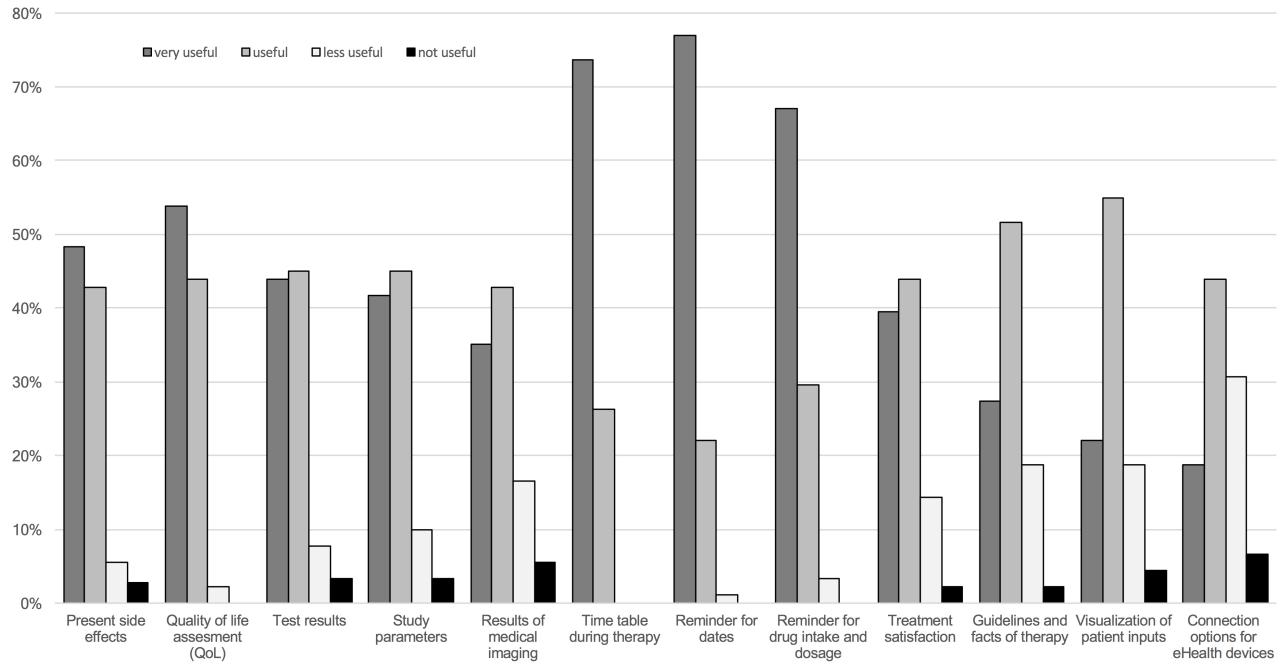
Further, we asked the HCPs who considered apps useful (n=91) for their preferred way of data transfer. In all, 75% (68/91) named an encrypted upload to the servers of the clinic as the best possible way, whereas 35% (32/91) preferred a local submission (eg, via offline tablets at the clinic). Cloud storage was favored by 23% (21/91), data transfer via email attachment by 12% (11/91), and 11% (10/91) had no preference. Furthermore, we asked for preferences concerning data export. Direct integration in the hospital information system (74%, 67/91), export for inspection and analysis via PC (59%, 54/91), or mobile device (52%, 47/91) were highly recommended. Paper-based data provision (24%, 22/91) or email (14%, 13/91) were further answers.

Of all respondents, 77.8% (84/108) believed in a clear time savings if the collected data by an app were available for follow-up appointments, whereas 22.2% (24/108) were not convinced of the benefit of app-based patient documentation.

Moreover, we asked questions about an alert function for data inputted by patients requiring an immediate action (eg, severe side effects). Of all, 64.8% (70/108) preferred to be alerted if their patient entered data that needed further clarification, whereas 35.2% (38/108) did not want to be contacted. HCPs in favor of this feature (n=70) were asked for their favorite time interval for making contact. Of these, 49% (34/70) preferred an alarm mechanism for the treating physician within 24 to 48 hours, whereas 40% (28/70) were in favor of an immediate notification of severe cases to the physician on duty, 14% (10/70) preferred an independent query in an implemented alert system, and 27% (19/70) of HCPs chose “no answer.” In addition, most preferred a graded notification from mild to severe. If HCPs were alarmed, 94% (66/70) were willing to contact the patient, whereas 6% (4/70) would refuse to. Reasons were lack of time (3/4), legal insecurity (2/4), and the wish to delegate this task to other staff (1/4).

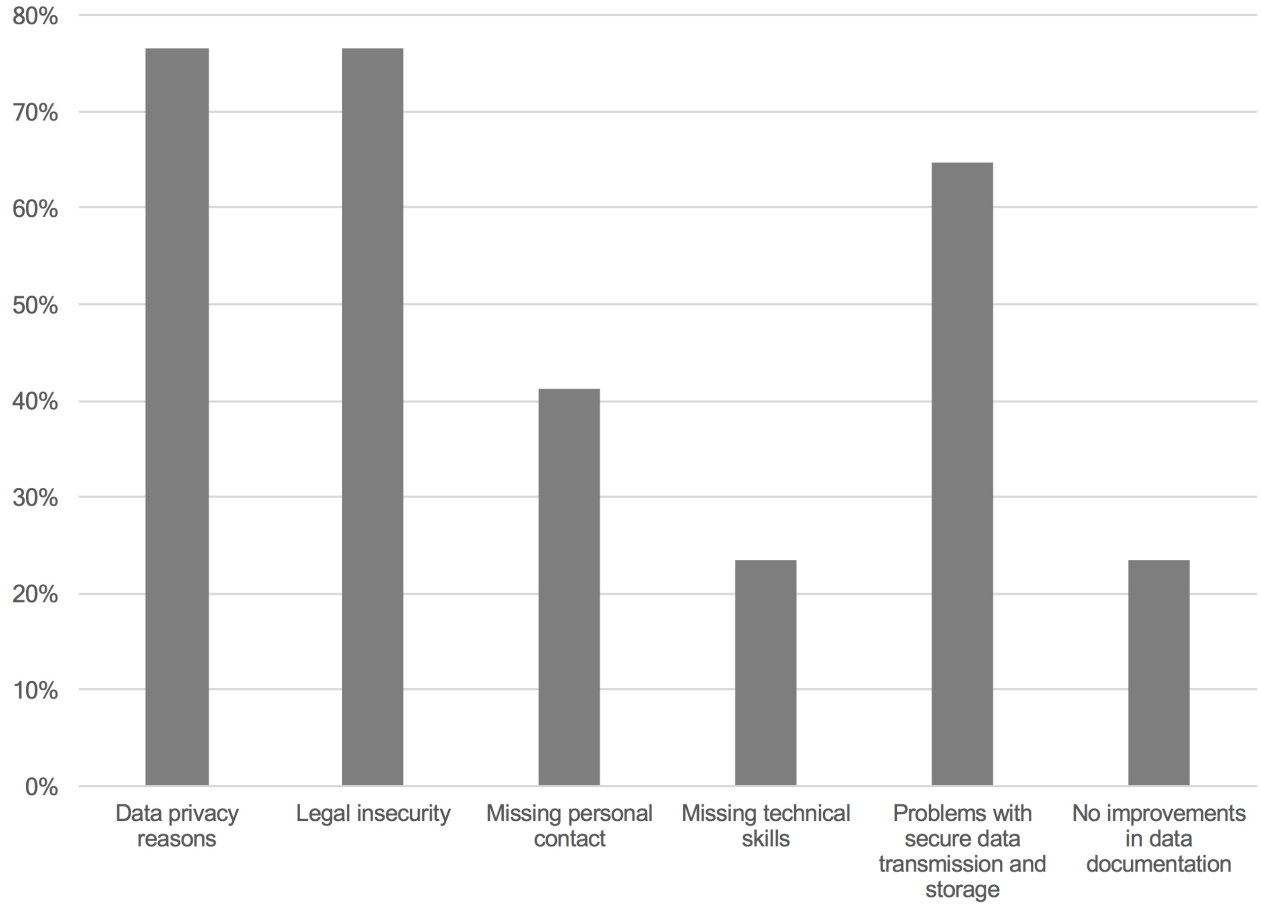
All respondents were asked about their opinion on using the collected data for scientific evaluations. Of all, 93.5% (101/108) supported it, whereas 6.5% (7/108) did not. Furthermore, we asked all HCPs if they believed an app could be a competitive advantage for the providing hospital. Three-quarters agreed strongly (75.0%, 81/108), whereas 25.0% (27/108) disagreed.

Figure 1. Diagram showing health care providers’ opinion on possible functions for oncological apps (n=91).



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Figure 2. Diagram showing health care providers' reasons to reject the use of oncological apps (n=17).



Discussion

This survey analyzed the attitude of HCPs toward telemedicine, mHealth, and mobile apps in the field of oncology. Using an online questionnaire, we conducted the survey within our oncological center.

Telemedicine is widely accepted in our cohort of HCPs (88.9%, 96/108). Most frequently, participants stated the advantage of being in an independent location and improving the care for patients in rural areas. Especially in Germany, where the health sector faces a shortage of general physicians [16] and a nursing crisis [17] in rural areas, telemedicine could improve the situation. Oncological patients in particular need a close and continual connection to their treating department, as their disease needs accurate observation and, if necessary, a quick response to progression. However, not every town or small city in rural areas offers the same standards of care, and traveling to more developed regions needs time, financial backing, and physical strength. Telemedicine could ease the situation and lower the pressure on highly frequented HCPs in rural areas without decreasing the standard of care. A systematic review of eHealth apps by Banbury et al [18] showed increased access to health care in remote areas, an enhancement in the professional development of HCPs, and lower travel costs. Jhaveri et al [19] evaluated a remote chemotherapy supervision model in a rural area in Queensland, Australia, that enabled rural physicians and nurses to treat patients with telemedical advice from big centers. It showed a better continuity of patient care, reduction of travel costs, shorter waiting times, and importantly no reported adverse events. As telemedicine is based on electronic storage, data can be saved long term and more efficiently and with smaller space compared to paper-based documentation [20].

An improvement of patients' communication and the possibility to inform themselves about their disease are further important advantages for telemedicine. A higher patient compliance is obtained by a closer link to the treating department and the offered functionality of the app for reminding the patient of things such as follow-up dates, drug intake, or physical exercises. Wang et al [21] designed a randomized controlled trial and showed a higher compliance for patients with esophageal cancer using Internet follow-up after radiotherapy compared to a control group. A 15-year experience with telemedicine in Korea published by Kim et al [22] compared telemedical services for patients versus face-to-face medical service and showed a significant improvement of compliance in drug administration and lifestyle changes. However, HCPs also named certain disadvantages regarding telemedicine. The most mentioned is a possible lack of data protection and violation of privacy. Nowadays, it is possible to encrypt data and transfer it via a highly secure line to a server or cloud [23,24]. Further, the right of medical confidentiality and the right to informational self-determination are not violated by the use of telemedicine. The missed time for clinical routine work and the resulting pressure to answer patient requests promptly

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concerns many HCPs. As telemedicine offers a wide field of possible features, some of them could even spare time in everyday clinical routine. Nilsson et al [25] sent a nurse to patients who measured their blood pressure and, if necessary, contacted a doctor by video conference. Levy et al [26] asked patients to monitor their blood sugar levels themselves and send the data via text message to a nurse who reviewed them and, if necessary, adjusted the insulin dose. Both evaluations showed at least similar effectiveness as face-to-face contact with doctors. Hence, time-consuming tasks (eg, follow-up appointments) could be replaced and complemented by telemedical services. Further, the pressure for immediate answer via telemedical services can be eased by implementing standardized response times (eg, 24-48 hours in nonsevere cases).

The financial compensation for telemedicine is limited by country laws and local health plan regulations. The current development in Germany points toward increased financial compensation; since 2016, telemedical services in cardiology are billable [27]. A limit of telemedicine is the lack of visual impression of the patient by HCPs. Clinical diagnosis is often based on a long-standing experience and holistic care of the patient. This dimension is missing in telemedical approaches. Hence, initial diagnosis should never be made over such a medium.

In our survey, we investigated mobile apps as a telemedical or mHealth tool for patient-reported symptoms and disease parameters in an oncological setting. Of all participants, 84.3% (91/108) support the idea of an oncological app complementing classical treatment. Assessing side effects present during therapy is one of the most important functions. Giving the patient the opportunity to grade their side effects on a regular basis (eg, weekly) enables the HCP to contact patients in severe cases. Further, the development of side effects over time can be important information, if available at follow-up appointments. Transferring imaging and test findings completes the documentation of the course of the disease and allows for prompt reaction in case of progression. Assessing study parameters (eg, blood pressure, blood sugar, weight) and quality of life is important for scientific evaluations. Gathering treatment satisfaction data improves department workflows and allows for patient-friendly treatment processes.

A timetable and notification system were highly recommended. Reminding patients of chemotherapy or radiotherapy dates could reduce the inconvenience on both sides and improve patient compliance. A reminder of drug intake and dosage could support drug adherence, reduce medication errors, and save time in emergency situations [28,29]. Guidelines and facts during/after therapy (eg, care instructions, diet tips, exercises) could help to improve the treatment process and inform patients about their disease.

Visualization of patients' input is a feature mostly to improve patients' compliance because presenting blood results or side effects in graphs gives a better understanding of the course of disease. Further, connection possibilities to other eHealth devices (eg, fitness bands, blood pressure monitor, blood glucose meter) would provide even more detailed information about the patient's clinical constitution. A possible future functionality could be automated algorithms, which calculate the personal risk profile for disease progression using all the previously named patient inputs. This would be a further step toward holistic, personalized medicine.

Those HCPs not in favor of using an oncological app were mostly afraid of legal uncertainties regarding medical responsibility (77%, 13/17). Each country regulates medical apps and legal responsibility differently. However, the legally required duty of care by HCPs and the right of informed consent by patients should be important values also applied to medical apps.

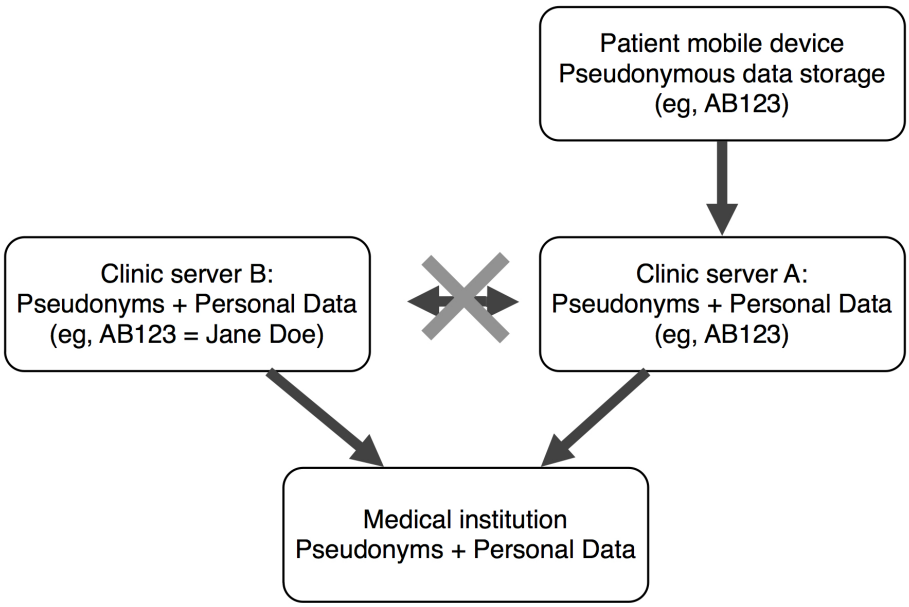
Another problem is the fear of data privacy issues (77%, 13/17) and insecure data transfer and storage (65%, 11/17). An anonymous approach is not possible because the medical institution needs to identify the patient. A pseudonymous approach (Figure 3) could be a compromise. Patients receive a pseudonym (eg, AB123) during registration at the clinic. With this pseudonym, the patient logs in to the app and data are stored locally and pseudonymously on the device. Then, pseudonymous data are sent encrypted to a Server A. Only on Server B are stored the pseudonyms in conjunction with personal data of the patient (eg, AB123=Jane Doe), and it is not linked to Server A. Hence, only the medical institution, which has access to Server A and B, can retrieve both pseudonymous and personal data.

A further point of criticism is the missing personal contact between HCP and patient (41%, 7/17). An app can never replace the personal patient-physician relationship, which is an important factor for treatment success. However, an app can reduce unnecessary patient contacts; moreover, it can complement classical treatment.

Of the asked HCPs, 64.8% (70/108) want to be contacted in case of data input that indicates severe and moderate side effects. A possible scenario could be to report those to the physician on duty (40%, 28/70 agree) and treat those immediately. Moderate side effects can be reported to the treating physician (49%, 34/70 agree) within a certain time interval (eg, 24-48 hours) and lead to further treatment or a wait-and-see strategy. Denis et al [11] evaluated high-risk lung cancer patients who filled out weekly Web-based questionnaires. Relapse was detected, on average, 5 weeks before planned restaging. Hence, needed treatment could be started significantly earlier than with standard follow-up procedures. In the case of severe side effects, 94% (66/70) are willing to contact the patient. This would lead to quicker response and earlier treatment of the condition. However, how to define the perfect cut-off between data inputs that indicate severe and moderate side effects remains subject to further investigation.

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Figure 3. Diagram showing a schematic pseudonymous data transfer to a server at the clinic via a secure line.



Another point of interest for HCPs is the scientific value of the collected data. The HCPs (93.5%, 101/108) are keen to evaluate the data and use it for further assessment in diagnostics and the improvement of therapy. Because they choose to perform the survey in a university hospital, the resulting scientific background of the interviewee (81.5%, 88/108 working on scientific projects) might contribute to the high percentage. Furthermore, an app could also be used in prospective trials. Needed clinical visits during long-term randomized controlled trials are always connected with a high organizational workload and depend on the compliance of patients. Certain study parameters could be easily obtained and transferred via a mobile app and could extend the standard retrieved data. The interdisciplinary character would be complemented with a longitudinal approach. Of course, patient compliance and informed consent are important requirements for the success of scientific evaluations. To that, Chen et al [30] showed a general willingness of the public to share data for health research.

This work shows a great approval for telemedicine, mHealth, and apps in oncology among HCPs. Assessing side effects can lead to quicker response and thus lower inconvenience for patients. Clinical data such as life quality and treatment satisfaction could be used to evaluate and improve the therapy workflow. Registered test and medical imaging results can be used to document the disease progression and the collected data can be used for scientific evaluations. Eventually, mobile apps would enhance the patients' relation to his treating department because they are in permanent contact—a trend also evolving in the medical field.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Original questionnaire (German).

[PDF File (Adobe PDF File), 102KB - jmir_v18i11e312_app1.pdf]

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Abbreviations

CHERRIES: Checklist for Reporting Results of Internet E-Surveys
HCP: health care professional

Edited by CL Parra-Calderón; submitted 25.07.16; peer-reviewed by H Wu, L McCann, S Smith; comments to author 05.10.16; revised version received 19.10.16; accepted 08.11.16; published 24.11.16.

Please cite as:
Kessel KA, Vogel MME, Schmidt-Graf F, Combs SE
Mobile Apps in Oncology: A Survey on Health Care Professionals' Attitude Toward Telemedicine, mHealth, and Oncological Apps
J Med Internet Res 2016;18(11):e312
URL: http://www.jmir.org/2016/11/e312/
doi:10.2196/jmir.6399
PMID:27884810

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Review

The Use of Social Media in Recruitment for Medical Research Studies: A Scoping Review

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Abstract

Background: Recruiting an adequate number of participants into medical research studies is challenging for many researchers. Over the past 10 years, the use of social media websites has increased in the general population. Consequently, social media websites are a new, powerful method for recruiting participants into such studies.

Objective: The objective was to answer the following questions: (1) Is the use of social media more effective at research participant recruitment than traditional methods? (2) Does social media recruit a sample of research participants comparable to that recruited via other methods? (3) Is social media more cost-effective at research participant recruitment than traditional methods?

Methods: Using the MEDLINE, PsycINFO, and EMBASE databases, all medical research studies that used social media and at least one other method for recruitment were identified. These studies were then categorized as either interventional studies or observational studies. For each study, the effectiveness of recruitment, demographic characteristics of the participants, and cost-effectiveness of recruitment using social media were evaluated and compared with that of the other methods used. The social media sites used in recruitment were identified, and if a study stated that the target population was "difficult to reach" as identified by the authors of the study, this was noted.

Results: Out of 30 studies, 12 found social media to be the most effective recruitment method, 15 did not, and 3 found social media to be equally effective as another recruitment method. Of the 12 studies that found social media to be the best recruitment method, 8 were observational studies while 4 were interventional studies. Of the 15 studies that did not find social media to be the best recruitment method, 7 were interventional studies while 8 were observational studies. In total, 8 studies stated that the target population was "hard-to-reach," and 6 of these studies found social media to be the most effective recruitment method. Out of 14 studies that reported demographic data for participants, 2 studies found that social media recruited a sample comparable to that recruited via traditional methods and 12 did not. Out of 13 studies that reported cost-effectiveness, 5 studies found social media to be the most cost-effective recruitment method, 7 did not, and 1 study found social media equally cost-effective as compared with other methods.

Conclusions: Only 12 studies out of 30 found social media to be the most effective recruitment method. There is evidence that social media can be the best recruitment method for hard-to-reach populations and observational studies. With only 30 studies having compared recruitment through social media with other methods, more studies need to be done that report the effectiveness of recruitment for each strategy, demographics of participants recruited, and cost-effectiveness of each method.

(J Med Internet Res 2016;18(11):e286) doi:10.2196/jmir.5698

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KEYWORDS

patient selection; social media; social networking; intervention study; observational study; Internet

Introduction

For any study, recruitment of an adequate number of participants who reflect the targeted population is essential. Failure to achieve this goal can compromise the validity of the results, increase costs, and delay or even cause early termination of the study [1]. This is a major problem today; less than 20% of clinical trials finish on time [2]. Roughly half of these delays are due to difficulties in patient recruitment [2].

Web 2.0, or interactive communication through the Web represents a valuable method of sharing information. In 2015, 90% of Canadian households had access to the Web [3]. At the forefront of Web usage today are social media websites. For the purposes of this paper, social media websites are defined as websites that let users make profiles and use these profiles to connect and interact with other individuals. The use of such websites is constantly growing, reflecting the population as a whole. As of 2015, the majority of Canadians use social media. The most popular social media website is Facebook with 59% of Canadians having an account [4]. While detailed statistics on the increasing use of social media are not available for Canada, in the United States, 65% of US adults used a social media website in 2015, an increase from 7% in 2005 [5]. While use increased from 12% to 90% from 2005 to 2015 for the age group 18-29 years, more recently its use has increased rapidly in older populations—it is now used by 77% of 30- to 49-year-olds, 51% of 50- to 64-year-olds, and 35% of those aged 65+ years, increasing from 8%, 5%, and 2%, respectively, in 2005 [5]. Furthermore, 56% of low-income individuals now report using social media [5].

As a result of these increases in social media usage over the last few years, social media represents a potential source for recruitment of participants. Studies have shown that a high volume of individuals can be successfully recruited for research purposes using social media [6-8]. Researchers have utilized these sites, such as Facebook, for recruitment of individuals into their studies [6,7]. Recruitment through this method has been shown to be cost-effective [6-8]. Additionally, social media has been shown to recruit populations that cannot be easily accessed through traditional methods of recruitment [9,10], a specific example of which is low-income populations [11].

Literature reviews on the role of social media in recruitment have been done by Park and Calamaro [12] and Ryan [13]. These reviews also identified social media as being effective in recruiting both hard-to-reach populations and adolescents and young adults (AYAs), as well as being cost-effective. However, the majority of these studies have only looked at AYAs and not older populations where social media usage has increased. Furthermore, many of these studies have not directly compared recruitment via social media with that via traditional methods. To fill these gaps, a scoping review was conducted to answer the following questions: (1) Is social media more effective at research participant recruitment than traditional methods? (2) Does social media recruit a sample of research participants comparable to that recruited via other methods? (3) Is social media more cost-effective at research participant recruitment than traditional methods?

Methods

Search Strategy

A scoping review was performed using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Articles appearing in a journal and written in English were included. Review articles, abstracts, dissertations, narratives, and letters were excluded.

Types of Participants

Study participants included adults and children participating in any health care–related research study including recruitment via social media.

Types of Interventions

Any type of interventional study or observational study was included.

Types of Controls or Comparators

Studies with recruitment via at least one other method such as newspaper, in person, and telephone were included.

Types of Outcomes

Three outcomes were assessed for this review: (1) *effectiveness* of recruitment, (2) *comparativeness* of recruited participants in relation to the population of interest, and (3) *cost-effectiveness* of recruitment. The *effectiveness* of recruitment was measured as the number of participants recruited via social media over a given time period as compared with the other recruitment methods. *Comparativeness* of the recruitment of participants was assessed by comparing the demographic characteristics of patients recruited via social media with that of other methods. *Cost-effectiveness* of each recruitment method was determined by dividing the total cost of advertisement for a particular recruitment strategy by the total number of participants recruited through that strategy.

Information Sources and Search Strategy

The original literature search was conducted between July 8 and July 11, 2014, using the databases MEDLINE (1946-2014), PsycINFO (1987-2014), and EMBASE (1980-2014 week 27). The search was updated on May 7 and May 8, 2015, as well as on July 26 and July 27, 2016. The search terms for the MEDLINE database were as follows: (“Recruit*” OR “Patient Selection (MeSH) (Medical Subject Headings) or Patient Recruit*” OR “Subject Recruit*” OR “Participant Recruit*” OR “Recruit* Strategies”) AND (“Social Media (MeSH) or Social Media” OR “Social Network” OR “Social Networking (MeSH) or Social Networking” OR “Facebook” OR “Youtube” OR “Qzone” OR “Sina Weibo” OR “WhatsApp” OR “Google+” OR “Tumblr” OR “Twitter” OR “WeChat” OR “Tencent Weibo” OR “LinkedIn” OR “Youku” OR “Instagram” OR “Tudou” OR “RenRen” OR “Pinterest” OR “Badoo” OR

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"Orkut" OR "Foursquare" OR "Vine" OR "Vkontakte" OR "Myspace" OR "Snapchat" OR "Reddit" OR "Bebo" OR "Hi5"). Multimedia Appendix 1 contains the full search strategy. After the articles were found, the reference lists of relevant studies were searched for additional studies. To be as comprehensive as possible, social media sites used primarily outside North America were also included in the search.

Screening Process

The screening process involved 2 stages: (1) title and abstract exclusion and (2) full-text exclusion. Titles were excluded if they were not related to health care or the topic of social media and recruitment. Abstracts were excluded if they were not a primary journal article, unrelated to social media and recruitment, or did not use social media in the recruitment strategy. Full-text studies were excluded if they did not measure the primary outcome (*effectiveness* of recruitment) or did not have an appropriate control group.

Data Extraction

The relevant studies were then screened for data, including the number of people recruited via each method, the demographic characteristics of the study participants (age, sex, ethnicity, economic status, and educational level), characteristics of the study (country of origin, social media sites used, other recruitment methods, the method used to measure primary outcome, and geographic distribution), reported costs of recruitment activities, and incentives.

Results

Study Selection

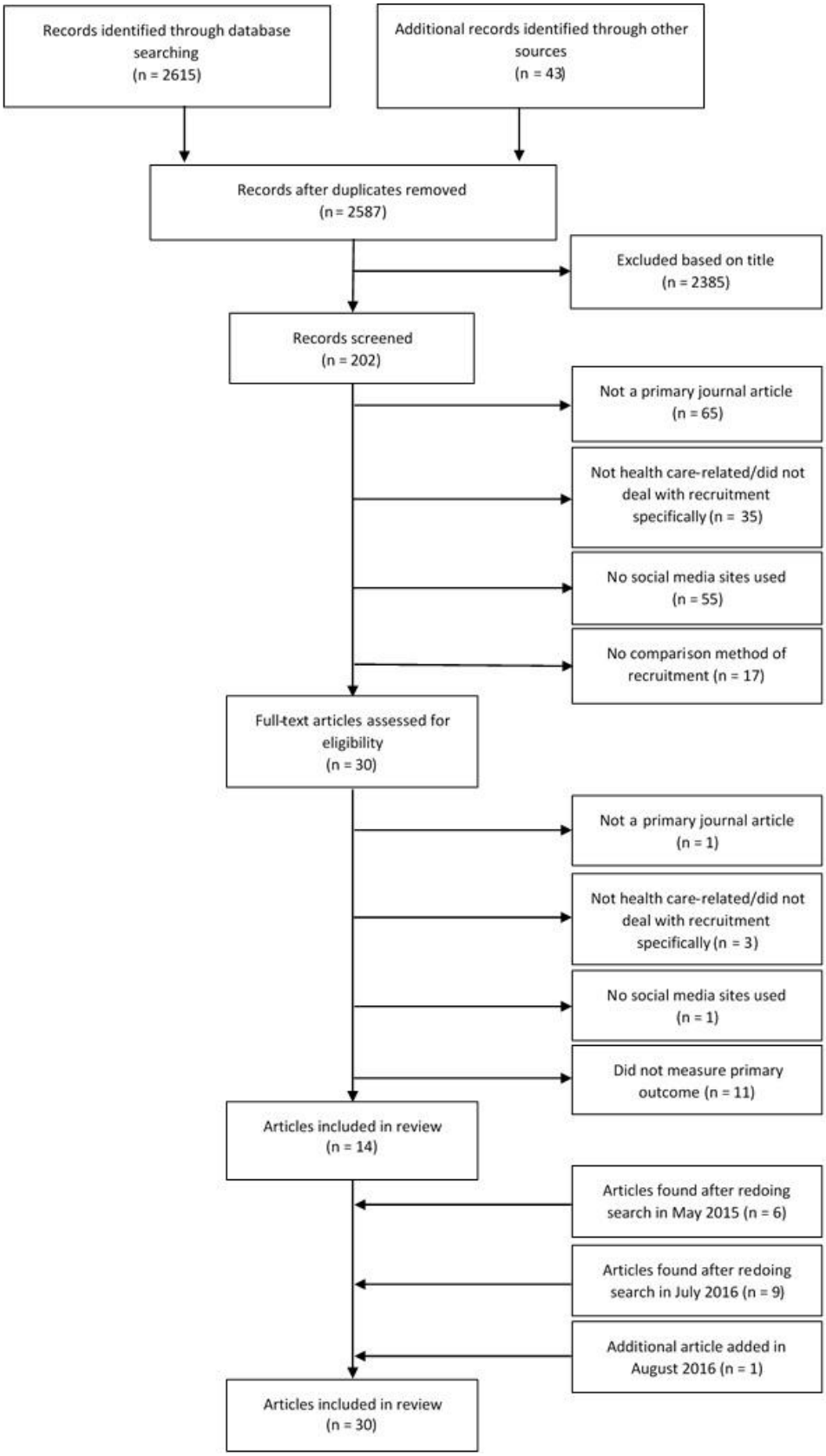
The search produced 2658 results, out of which 71 results were duplicates (Figure 1), leaving 2587 results. From these results, 2385 were excluded because the titles were irrelevant to the topic of social media and recruitment, leaving 202 abstracts to be reviewed. From this, 172 more abstracts were excluded because they were not primary research articles (n=65), were not health care–related or did not deal with recruitment specifically (n=35), did not use social media for recruitment (n=55), or did not have a comparison recruitment method (n=17). This left 30 full-text articles to be assessed for eligibility. Out of this total, 16 more of these studies were excluded because they did not measure the number of people recruited via social media over a given period of time (n=11), were not health care–related (n=3), did not use social media sites (n=1), or were not primary research articles (n=1). A total of 6 additional studies were found after redoing the search in May 2015, 9 additional studies were found in July 2016, and 1 additional study was added in August 2016, for a total of n=30 articles that were included in the review.

Recruitment Effectiveness

The percentage of participants recruited via social media ranged from 0% (0/12) to 98.29% (1610/1638) [14-42] as shown in Table 1, and the median percentage was 32%. The article by Head et al [35] has 2 studies and has been counted as 2 articles for the purpose of Figure 1. In further sections of this paper, the article by Head et al [35] is counted as a single article or 2 articles, according to whether the conclusions from the 2 studies pertinent to the outcomes of this paper are the same or different. Out of 30 studies, 12 studies (40%) reported higher rates of recruitment through social media as compared with any of the other methods used [14-17,26,28,31,32,35, 36,41,42] and 15 studies (50%) reported recruitment via social media to be less effective than at least one other method used [18-21,23-25, 27,33-35,37-40]. Heffner et al [20] and Rabin et al [24] found social media to be the least effective method out of multiple (>2) recruitment methods used. Rabin et al [24] were unable to recruit a single participant via social media.

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Figure 1. Search strategy results.



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Table 1. The percentage of participants recruited through social media by study (the number of participants recruited through social media is also provided in parentheses, when reported).

Primary article	Percentage of participants recruited through social media
Balfe et al [14]	76% (29/38)
Frandsen et al [15]	51.9% (138/266)
Johnson et al [16]	49.6% (402/811)
Yuan et al [17]	81.09% (1544/1904)
Burrell et al [18]	23.8% (24/105)
Graham et al [19]	8.0% (40/500)
Heffner et al [20]	5.0% (11/222)
Layi et al [21]	20.0%
Martinez et al [22]	36% (5/14)
Quach et al [23]	17.0% (81/477)
Rabin et al [24]	0% (0/12)
Shere et al [25]	4% (2/45)
Theriault et al [26]	83.8% (201/240)
Vial et al [27]	12.77% (163/1276)
Carlini et al [28]	41.4% (286/690)
Haines-Saah et al [29]	28% (17/60)
Miyagi et al [30]	52.3% (127/243)
Wilkerson et al [31]	93.3% (320/343)
Ince et al [32]	77% (74/96)
Hernandez-Romieu et al [33]	13.7% (110/803)
Rait et al [34]	22.5% (45/200)
Head et al [35], study 1	98.29% (1610/1638)
Head et al [35], study 2	3.8% (5/131)
Kayrouz et al [36]	86% (70/81)
Gu et al [37]	37.4% (58/155)
Subbaraman et al [38]	7.0%
Khatri et al [39]	18.2% (96/527)
Partridge et al [40]	2.0% (5/250)
Carter-Harris et al [41]	91.7% (331/361)
Frandsen et al [42]	52.6% (92/175)

Of the 12 studies that found social media to be the best method of recruitment, 8 were observational studies [14,16,17,26,28,31,35,41] and the remaining 4 were interventional studies [15,32,36,42], as shown in Multimedia Appendix 2. In addition, 6 of these studies targeted populations deemed hard to reach [16,17,28,31,32,36], and 6 studies targeted specific conditions or disorders [14,16,17,28,31,32]. Furthermore, 1 study targeted only young adults (aged 23-30 years) [14]. Among the 12 studies, 8 studies used only Facebook for recruitment [14-16,28,35,36,41,42]. Of the remaining 4 studies, 2 studies used a combination of Facebook and Twitter [31,32] and 2 studies used a combination of Facebook and other social media websites [17,26].

Of the 15 studies that did not find social media to be the best method, 7 studies were interventional studies [18-21,24,25,40], whereas 8 were observational studies [23,27,33-35,37-39]. Of these studies, 3 studies specifically targeted young and middle-aged adults [24,25,40], 2 studies targeted adolescents [34,37], and 2 studies targeted older adults [35,41]. Martinez et al [22] recruited 35.7% of participants via social media and 35.7% of participants via community-based organizations. Haines-Saah et al [29] recruited 28% of participants via social media and 28% of participants via friend referral. Miyagi et al [30] recruited 52% of participants through Facebook and 48% via a website. The studies by Martinez et al [22] and Haines-Saah et al [29] were both interventional studies, whereas the study by Miyagi et al [30] was an observational study.

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Demographics

A total of 23 studies reported the geographic regions targeted by social media during recruitment, as shown in Multimedia Appendix 2. Among these, 13 studies targeted local regions within a country [15,18,22,23,26,27,30,33-35,37,40,42], 8 studies [14,19,28,31,35,38,39,41] targeted recruitment nationally, and 2 studies targeted recruitment internationally [16,36].

Only 13 studies out of 30 reported at least one demographic characteristic for patients recruited through social media and other methods [15-18,20,25,28,33,35,37,41,42], with 10 studies providing in-depth demographic information [15,16,20,25,33,35,37,41,42]. However, Shere et al [25] and Yuan et al [17] included Craigslist in their definition of social media; therefore, their demographic analysis was not included in this review because Craigslist does not fall under our definition of a social media website.

With respect to ethnicity, it was found that there was no significant difference between recruitment strategies in 5 studies [15,16,20,35,37]. Despite social media recruiting different percentages of white and black participants compared with other avenues, Hernandez-Romieu et al [33] concluded that social media did not have a racial bias in recruitment, as in this case the researchers were deliberately aiming at a 50% white and 50% black sample. However, Burrell et al [18], who used Grindr to recruit, noted a significantly increased white population when compared with traditional methods, which they attributed to the fact that Grindr could only be used by individuals possessing a smartphone. Head et al [35] (studies 1 and 2) and Carter-Harris et al [41] also noted a significantly increased white population recruited through Facebook. Out of the 10 studies that formally measured the age of participants recruited, 3 recruited a comparable sample [16,28,41]. There was a younger median age in 3 studies [15,20,42], and 1 study [18] had a much higher proportion of 18- to 30-year-olds recruited via social media (56% vs 18.8%). Quach et al [23], while not formally reporting demographics, noted that social media recruited younger individuals. Although not included in the demographic analysis, Yuan et al [17] also noted that the proportion of individuals aged 60+ years recruited through Facebook was lower than that for other age groups. Hernandez-Romieu et al [33], on the other hand, noted that participants recruited via Facebook were typically older than those recruited via other avenues, and this difference was significant for black participants recruited. Head et al [35] also noted an older median age in studies 1 and 2, which was attributed to the fact that Craigslist, the main comparative recruitment method used, is more popular with younger individuals. Out of the 8 studies that reported the sex of recruited participants [15,16,20,28,35,37,41,42], 7 studies recruited a comparable sample through social media [15,16,20,28,35,41,42]. The economic status of individuals was reported in 6 studies and no significant differences were found [15,33,35,41,42]. However, Balfe et al [14] noted that social media recruited more middle-class individuals. A total of 7 studies provided information about educational attainment of recruited individuals [15,18,20,33,35,41]. It was found that education levels were higher in the social media group than in the traditional media group in 2 cases [18,20], and Hernandez-Romieu et al [33] found this to be the case for white participants recruited. Head et al [35] (study 1) noted lower education levels for individuals in the social media group, which was attributed to the fact that Craigslist is more popular with better educated individuals. Quach et al [23] also noted that education levels were higher in the social media recruitment group.

Cost-Effectiveness and Incentives

A total of 13 studies directly compared cost-effectiveness across different recruitment strategies [15,16,19,20,28,31,33,34,36,37,39,41,42], and the results are presented in Table 2. The cost of advertisement on social media websites was determined by bidding prices for ads, which varied on a daily basis, or the cost of placing a banner ad on a particular website. Among these studies, 5 studies [16,31,33,36,41] found social media to be the most cost-effective method, whereas 7 studies found it less cost-effective than another method used [15,19,20,28,34,37,42]. Wilkerson et al [31] reported no cost using social media for recruitment, and Khatri et al [39] reported no costs for all methods used. Among the 5 studies that found social media to be the most cost-effective method, 4 were observational studies [16,31,33,41], whereas 1 study was an interventional study [36]. Of the 7 studies that found recruitment through social media less cost-effective than another method, 4 were interventional studies [15,19,20,42] and 3 were observational studies [28,34,37]. Despite not formally measuring cost-effectiveness, Theriault et al [26] noted social media to be “less costly” than traditional methods. This study was also an observational study. A total of 15 studies reported the use of incentives during recruitment, 12 of which were monetary [14,15,22,23,25,29-31,34,35,41] and 1 of which was nonmonetary [17]. The remaining 2 studies used a combination of monetary and nonmonetary incentives [37,40]. Quach et al [23] specifically looked at the effect of incentives on recruitment. Recruitment was split into 2 phases: phase 1, which offered a Can $5 gift card upon survey completion, and phase 2, which had no incentives. It was found that phase 1 attracted significantly more individuals than phase 2 (355 vs 125).

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Table 2. Cost of recruitment for different strategies.

Reference	Cost of recruitment
Frandsen et al [15]	Facebook, AU $42.34/participant; newspaper, AU $21.52/participant.
Johnson et al [16]	First ad campaign: Google, US $13.43/registrant; Facebook, US $3.80/registrant. Second ad campaign: Google, US $18.97/registrant; Facebook, US $7.71/registrant. Mailed campaign, US $154.95/registrant.
Graham et al [19]	Myspace Latino, US $600/registrant; Yahoo en Espanol, US $119.95/registrant; MSN Latino, US $141.15/registrant; MiGente, US $4166.67/registrant.
Heffner et al [20]	Social media, US $172.76/participant; standard media, US $46.98/participant; broadcast emails, US $27.10/participant; word of mouth, US $5.27/participant; medical Internet media, US $26.19/participant; Google AdWords, US $50.26/participant.
Carlini et al [28]	Facebook, US $8.92/respondent. Google, US $16.22/respondent. Email, US $5.95/respondent. Newsletter: Florida, US $13.12/respondent; New Jersey, US $35.60/respondent; California, US $250.00/respondent.
Wilkerson et al [31]	Facebook, US $0/participant; email, US $0/participant; mobile ads, US $375.00/participant; browser ads, US $187.50/participant.
Hernandez-Romieu et al [33]	Facebook, US $68.6/participant; venues, US $91.2/participant.
Rait et al [34]	Facebook, US $149.64/registrant; bus ads, US $255/registrant; referral, US $7/registrant; school talks, US $336/registrant; fliers, US $10/registrant.
Kayrouz et al [36]	Facebook, US $37/participant; traditional, US $40/participant.
Gu et al [37]	Facebook, US $30.29/participant; Twitter, US $22.20/participant; QR Codes, US $6.57/participant.
Khatri et al [39]	US $0 for all methods.
Carter-Harris et al [41]	Facebook, US $1.51/participant; newspaper, US $40.80/participant.
Frandsen et al [42]	Facebook, AU $56.34/participant; traditional media, AU $52.33/participant.

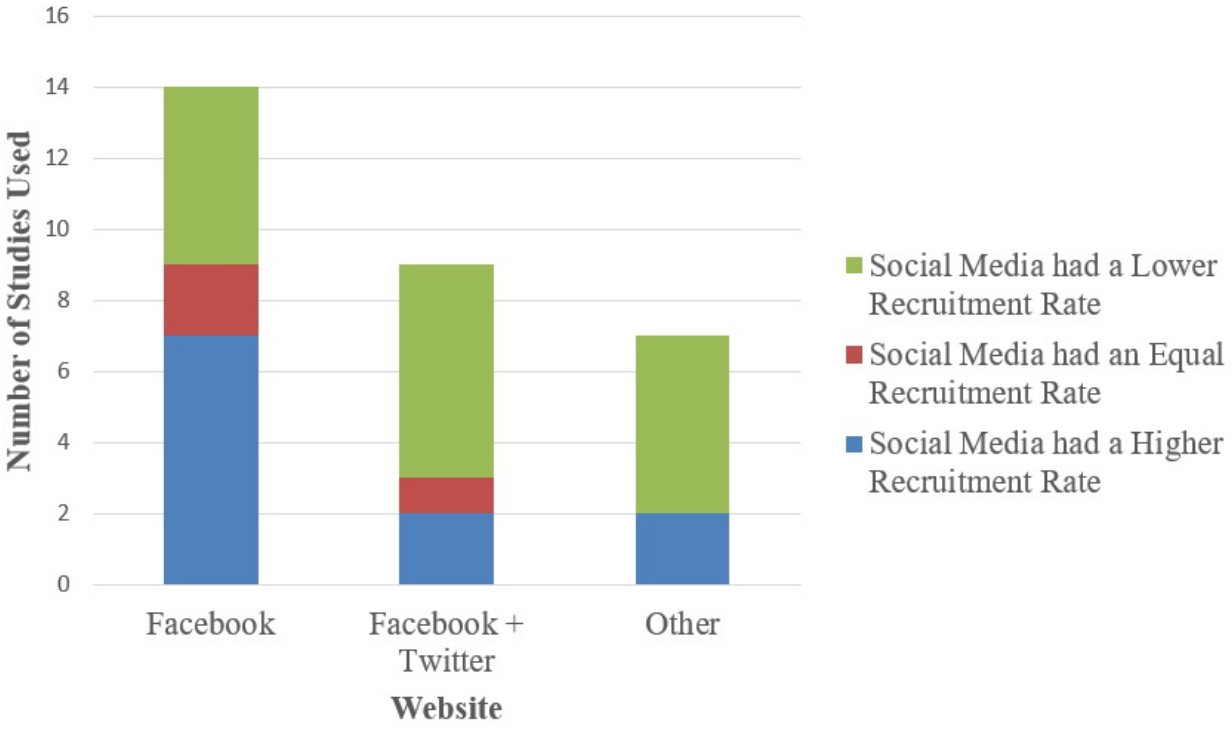
Setting

Out of 30 studies, 18 studies were done in the United States [16-22,24,27,28,31,33-35,37,38,41], 5 studies in Australia [15,26,36,40,42], 3 studies in Canada [23,25,29], 1 study in Ireland [14], 1 study in the Netherlands [32], 1 study in Japan [30], and 1 study in the United Kingdom [39].

It was found that 14 out of 30 studies used Facebook solely [14-16,27,28,30,33-36,40-42]. Although Twitter was never used by itself, 9 studies used a combination of both Facebook and Twitter during the recruitment process [20,21,23,25,29,31,32,37,38]. The overwhelming majority of studies (28/30) used Facebook in some way during recruitment, indicating that this was the most popular website for this purpose. The only times Facebook was not used were when there were social media sites that targeted a specific population of interest, such as MSM (men who have sex with men) [18] and Latinos [19]. Other recruitment methods included visiting various community venues such as clubs and bars, health care centers, and universities. There was also recruitment done via numerous websites that would not be classified as social media based on our definition, such as Craigslist, Kijiji, and Google AdWords. Overall, using a combination of social media websites, or not using Facebook, resulted in lower recruitment through social media (Figure 2).

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Figure 2. Recruitment success based on social media website(s) used. Note: Other = GRINDR, Myspace Latino + MiGente, Facebook + Google AdWords, Facebook + Twitter + Ning, Facebook + Gaydar, Facebook + Twitter + Youtube, Facebook + Twitter + LinkedIn + Tumblr, Facebook + Twitter + Instagram + Grindr + Jack'd + Scruff.



Discussion

Principal Findings

It was found that social media was the most effective method in 12/30 studies and not the most effective method for recruiting patients in 15/30 studies. The effectiveness of social media for recruitment of study participants is highly variable and dependent on specific study characteristics such as age, whether the population is difficult to reach through traditional methods, and the method used to measure the primary outcome. This contrasts with the finding that social media is a highly effective recruitment method presented in studies such as those by Fenner et al [6] and Ramo and Prochaska [7]. One possible reason for this is the fact that these studies did not use other methods of recruitment, and therefore solely focused their efforts on recruitment through social media. Among the studies where the effort put into each recruitment method was discernible, it was generally found that the effort put into recruitment via social media correlated with the number of participants recruited through this method. Effort was defined as the combination of the number of social media websites used, the extensiveness of the social media recruitment strategy as compared with that of traditional methods, the frequency with which recruitment was conducted, and the time spent on recruitment through social media when this information was reported. Studies that put more effort into recruitment via social media than via other methods generally recruited the most number of participants through social media [17,22,32,36,41] and vice versa [18,20,25,27,33,37,38,40].

It was found that in 2 cases [16,28] social media was able to recruit a sample that was comparable to the control group. However, in 12 cases the sample recruited via social media was not comparable to the general population. Participants were found to be younger [15,17,18,20,23,42], older [33,35], more white [18,35,41], had a higher education level [18,20,23,33], had a lower education level [35], more female [37], and had higher socioeconomic status [14]. It was also noted that all studies were from developed countries.

There is evidence that social media is best able to recruit individuals for observational survey-type studies as opposed to interventional studies; however, with a limited number of studies (n=12) to evaluate, more studies are needed. There is also evidence that social media can be a better recruitment method than other Internet sources alone. Of the 7 studies that compared recruitment via social media only with other Internet sources, 5 found social media to be the top method of recruitment [17,28,30,31,35]. Studies that targeted more specific groups, rather than a more general audience, can also potentially be more successful at recruiting via social media. For instance, social media seemed to be successful at recruiting hard-to-reach populations [16,17,28,31,32,36] and individuals with specific conditions or disorders [14,16,17,28,31,32]. This finding was in agreement with the findings of Park and Calamaro [12] and Ryan [13]. This is likely because in such a case it is difficult for any one conventional source to find a sufficient number of individuals, as was noted in the study by Johnson et al [16]. Once again, however, there is limited evidence for this. More studies need to be done looking at the effectiveness of recruitment using social media in these specific groups. Interestingly, the use of multiple social media websites appeared to result in lower recruitment through social media. When multiple social media websites were used, however, the most

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successful website at recruitment was Facebook. Low recruitment through Facebook alone typically indicated low overall recruitment through social media and vice versa. Therefore, we speculate that this finding is not due to the use of multiple social media sites but due to the success of recruitment through other methods in these studies.

A total of 5 studies found social media to be the most cost-effective method [16,31,33,36,41], whereas 7 studies found that it was not the most cost-effective method [15,19,20,28,34,37,42]. Therefore, no significant conclusions on cost-effectiveness can be made. This finding is slightly different from Park and Calamaro's [12] conclusion of social media being cost-effective. One potential explanation for this is that other studies, which focused solely on recruitment using social media, recruited higher numbers of individuals (450 in the study by Ramo and Prochaska and 426 in the study by Fenner et al) [6,7]. However, these studies also did not compare cost-effectiveness of other methods in recruiting the same target population, so it is uncertain whether traditional methods would be even more cost-effective in these cases. Additionally, the sample sizes of both the study by Park and Calamaro [12] (n=3) and our review (n=12) are likely too small to draw highly accurate conclusions. The cost of recruitment is also highly variable and depends on interactions between recruitment sites, study size, and target population. Advertisements are additionally affected by the bid price needed to display the advertisements, as noted by Fenner et al [6] and Ramo and Prochaska [7]. Therefore, a more complex analysis is needed to understand cost-effectiveness when recruiting through social media.

Recruitment through social media is affected by several factors. Quach et al [23] explicitly showed that adding a monetary incentive can increase recruitment through social media. Although 1 study represents limited evidence for the effectiveness of incentives, this finding is in line with the conclusion by Bower et al [43] that monetary incentives can increase recruitment into medical health studies. Another important factor is sex. It has been shown that women are more likely to search the Web for health information than men [44] and are more likely to participate in health studies [45]. Although no differences between male and female recruitment were found in this review, having an adequate representativeness in sex needs to be kept in mind by researchers when designing recruitment mechanisms.

When recruiting a target population, it is also important to consider how that population uses social media. For instance, for young MSM, Holloway et al [46] noted that this population was more likely to use dating sites when meeting new sexual partners and used Facebook when communicating with individuals they already knew. Therefore, researchers interested in targeting this population for a sexual health study should use these dating sites for recruitment and use Facebook for a nonsexual health study. Some social media sites are also more popular among certain demographics—for instance, within MSM, Grindr is more popular among whites, whereas Jack'd is more popular among African Americans [47].

Overall, researchers should consider how the target population uses social media when deciding which recruitment strategies to use, taking into account factors such as age, sex, the likelihood of a comparable sample, and whether the population would be difficult to reach through traditional methods. Even if social media can recruit more individuals than other methods, researchers must still estimate the cost-effectiveness of recruitment via this method, and in the event that cost-effectiveness is low, determine if recruitment is worth the low cost-effectiveness.

Limitations of Using Social Media for Research Recruitment

Ads on social media websites were targeted at specific age groups and locations based only on the information an individual provided on his or her profile. Therefore, there is no guarantee that awareness of the study reached all potential participants, and this could bias the results. Many studies created a separate page to recruit participants. Once again, not all potential participants may have been made aware of this page. For the studies that involved surveys, individuals could have reported false demographic information in the survey or could have given multiple responses, and verification of information on the Web remains more difficult than in person. In addition, individuals may not have correctly reported their source of recruitment, as Johnson et al [16] noted.

Within social media itself different types of recruiting strategies were used across different studies, such as creating a separate page to advertise the study, targeted advertisements, and private messages. Different strategies can alter the number or demographics of participants recruited and thus may not necessarily lead to a fair comparison between social media and other methods.

There is also the possibility that neither social media nor traditional methods were representative of the target population, as Ince et al [32] and Gu et al [37] noted. This can result from self-selection bias, where individuals who agree to participate in a study are more motivated than the general target population, and the demographic characteristics of these individuals differ from the remainder of the target population [48]. Although this may limit the ability to have a representative outcome when recruiting with social media, if researchers can understand the ways in which self-selection bias takes place, then recruitment of a representative outcome, as compared with the target population, is still possible. For example, Fenner et al [6] noted that, at their study site, rural participants were underrepresented because of the increased driving distance to reach the site. Oversampling of rural participants can therefore create a representative outcome [6].

Limitations of This Study

To identify relevant studies, an extensive list of keywords was used in the search strategy, and the reference lists of the identified studies were additionally scanned in order to extract more relevant studies. However, although we have tried to be as thorough as possible in identifying the literature, it is possible that some relevant studies were missed. Also, given the rapidly growing adoption of social media, we anticipate this body of

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literature to expand exponentially; this review is limited to studies published before August 10, 2016. Although we included all popular social media sites in the search strategy, not all existing social media sites were included because of the sheer number of such sites. Additionally, only studies written in English were selected.

This review looked at the recruitment strategies of different studies, rather than the main result of these studies themselves. To the best of our knowledge, there is no checklist for measuring the quality of recruitment strategy. Therefore, the quality of these studies cannot be measured in this regard.

Another limitation of the study is that the definition of a social media website varies across the literature. For instance, according to the definition by Shere et al [25], the sites Craigslist and Kijiji would be classified as social media, and so these authors concluded that social media was the most effective method owing to high recruitment via Craigslist and Kijiji even though recruitment via Facebook and Twitter was low. According to the definition by Theriault et al [26], the site Gaydar would not be classified as social media, but under our definition it would be. In such cases, we tried to fit the results to our definition of a social media site, but others may have a different definition of a social media site. This has an effect on the conclusions that can be drawn about recruitment of participants.

In addition, to measure the comparativeness of the population recruited, demographic characteristics of participants recruited through social media were only compared with characteristics of those recruited through other methods. We cannot rule out the possibility that neither social media nor traditional methods had outcomes that were representative of the target population, as is what occurred in the studies by Ince et al [32] and Gu et al [37]. This can limit the conclusions that can be made regarding representativeness.

Future Directions

Despite several studies pointing to social media as a potential method of recruiting patients in the preliminary search, the fact that only 30 studies were identified that explicitly compare recruitment methods shows that more studies need to be done in this area. Furthermore, several of these studies also did not assess the demographics of the recruited participants—such as age, ethnicity, income, and education level—or the cost-effectiveness of each recruitment strategy. In order to truly assess the viability of social media as a recruitment tool, future studies should measure these factors as well. Studies that found social media to be effective tended to target specific populations and used surveys, but sample sizes were too low to make strong conclusions. More studies need to be done to determine the validity of these statements.

Conclusions

Given the rising cost of conducting health research, and increased competition for such funds in Canada, new and innovative methods to recruit study participants are needed. Leveraging the growing popularity of social media has the potential to enhance research recruitment methods. However, based on our scoping review of the literature, social media was found to be the best recruitment method in only 12 out of 30 (40%) studies assessed in terms of number of individuals recruited. Social media also tended to recruit younger individuals (when this information was reported). However, for hard-to-reach populations, for populations with specific conditions or disorders, and for observational studies, social media can potentially be the most effective recruitment strategy. Although many studies used social media in recruitment, only 30 studies have explicitly compared social media with other recruitment methods. Additionally, many of these studies did not measure demographics of the population recruited. Therefore, more studies need to be done in this area. These studies should not only measure how many participants can be recruited through each strategy, but also clearly report demographics and the cost-effectiveness of each strategy.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Detailed search strategy.

[XLSX File (Microsoft Excel File), 10KB - jmir_v18i11e286_app1.xlsx]

Multimedia Appendix 2

Study characteristics, recruitment effectiveness by method, demographics of participants recruited by method, and geographic areas targeted by method.

[XLSX File (Microsoft Excel File), 26KB - jmir_v18i11e286_app2.xlsx]

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Abbreviations

AYA: adolescent and young adult
MeSH: Medical Subject Headings
MSM: men who have sex with men
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Edited by G Eysenbach; submitted 25.02.16; peer-reviewed by R Haines-Saah, E Hall, J Apolinário-Hagen; comments to author 31.03.16; revised version received 28.06.16; accepted 12.08.16; published 07.11.16.

Please cite as:
Topolovec-Vranic J, Natarajan K
The Use of Social Media in Recruitment for Medical Research Studies: A Scoping Review
J Med Internet Res 2016;18(11):e286
URL: http://www.jmir.org/2016/11/e286/
doi:10.2196/jmir.5698
PMID:27821383

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Original Paper

Knowledge Exchange and Discovery in the Age of Social Media: The Journey From Inception to Establishment of a Parent-Led Web-Based Research Advisory Community for Childhood Disability

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Abstract

Background: Efforts to involve parents and families in all aspects of research, from initiating the question through to dissemination and knowledge exchange, are increasing. While social media as a method for health communication has shown numerous benefits, including increasing accessibility, interactions with others, and access to health care information, little work has been published on the use of social media to enhance research partnerships.

Objective: Our objective was to describe the development and evaluation of a Web-based research advisory community, hosted on Facebook and connecting a diverse group of parents of special needs children with researchers at *CanChild Centre for Childhood Disability Research*. The goal of this community is to work together and exchange knowledge in order to improve research and the lives of children and their families.

Methods: The Web-based Parents Participating in Research (PPR) advisory community was a secret Facebook group launched in June 2014 and run by 2 parent moderators who worked in consultation with *CanChild*. We evaluated its success using Facebook statistics of engagement and activity (eg, number of posts, number of comments) between June 2014 and April 2015, and a Web-based survey of members.

Results: The PPR community had 96 participants (2 parent moderators, 13 researchers, and 81 family members) as of April 1, 2015. Over 9 months, 432 original posts were made: 155 (35.9%) by moderators, 197 (45.6%) by parents, and 80 (18.5%) by researchers. Posts had a median of 3 likes (range 0-24) and 4 comments (range 0-113). Members, rather than moderators, generated 64% (277/432) of posts. The survey had a 51% response rate (49/96 members), with 40 (82%) being parent members and 9 (18%) being researchers. The initial purpose of the group was to be an advisory to *CanChild*, and 76% (28/37) of parents and all the researchers (9/9) identified having an impact on childhood disability research as their reason for participating. A total of 58% (23/40) of parents and 56% (5/9) of researchers indicated they felt safe to share sensitive or personal information. While researchers shared evidence-based resources and consulted with families to get guidance on specific issues, there was an unexpected benefit of gaining an understanding of what issues were important to families in their daily lives. Parents felt a sense of belonging to this community where they could share their stories but also wanted more researcher participation and clarity on the purpose of the group.

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Conclusions: The PPR community grew from inception to an established community with active engagement and knowledge exchange. Both parents and researchers described valuable experiences. Researchers should consider social media as a means of engaging families in all phases of research to ensure that research and its outcomes are meaningful to those who need it most.

(J Med Internet Res 2016;18(11):e293) doi:10.2196/jmir.5994

KEYWORDS

knowledge exchange; research engagement; collaborative research; scientific collaboration; Web-based community; social media; Facebook; childhood disability; patient and public involvement(PPI)

Introduction

Families with children with disabilities and medical complexity constitute approximately 4.6% of Canada's pediatric population under the age of 15 years [1]. The growth in this population over the past 20 years has driven an increase in childhood disability research. Historically, in childhood disability research, applied health researchers seeking to directly influence clinical practice have worked collaboratively with individuals responsible for making relevant clinical, health, and social policy decisions and allocating resources [2]. However, over the past 5 to 10 years, efforts to actively involve families and patients in research have been increasing. Rosenbaum, in a position piece on family-centered research, identified "how much richer our studies have become with the active input of families and parents and thoughtful critics during the development of projects" [3]. Involving families in research is believed to improve service delivery, patient experience, and patient outcomes [4]. Input from families generates research questions that are targeted at family needs, which are not always aligned with the priorities of researchers. Efforts to identify high-priority questions in cerebral palsy research found that, although there was considerable overlap between what clinicians and families considered key research topics, some topics that families identified as important were not considered important by clinicians. The researchers discovered that social issues and effective alternative therapies were not of interest to clinicians but were important to families as they related to daily function and activity [5].

In addition to the growing amount of support for the inclusion of families in the research process [2,3,6], the expectations of funding agencies that patients and families be included are also increasing [7-9]. Although the importance of and need for engagement have been acknowledged, little evidence exists about the best way to actively engage families to provide input that is valuable to clinicians and researchers [6,10,11]. Research conducted into engaging families in research has highlighted several barriers that limit the ability of families to participate in research and be fully engaged. From a researcher's perspective, these barriers may include a desire to maintain control, unwillingness to consider parents as equals in terms of contributions and competence, and time and cost limitations. From a consumer's perspective, these barriers may include time, difficulty accepting and transitioning into a new role, and lacking knowledge or the confidence to contribute [4].

Social media have received increased attention over the past 10 years as a means of connecting and improving health communication. Social media platforms such as Facebook and Twitter are free, and provide quick and accessible methods to access information and engage with other stakeholder groups. While 52% of online adults use multiple social media sites in the United States, 71% use Facebook, which remains the most popular site for those who use only one and overlaps significantly with other platforms [12]. In a systematic review, Moorhead et al identified the benefits of social media (including Wikipedia, YouTube, Facebook, and virtual game and social worlds) for health communication as (1) increased interactions with others, (2) more available, shared, and tailored information, (3) increased accessibility and widening access to health information, (4) peer, social, and emotional support, (5) public health surveillance, and 6) the potential to influence health policy [13]. Limitations were mainly related to concerns about reliability of information, confidentiality, and privacy. Of the 98 research studies included in the review by Moorhead et al, 13 were using Facebook as a means of increasing awareness and communicating about a range of topics (eg, concussion, diabetes, breast cancer, attention-deficit/hyperactivity disorder) [13]. Facebook has also been used as part of a social media campaign intended to raise awareness for Hirschsprung disease and to connect and engage families affected by this rare condition [14]. While reach and responsiveness are considered strengths of social media usage, other studies have reported benefits of creating smaller communities. In particular, a primary care maternity clinic in Finland provided its clients with a Web service containing social media tools similar to those of Facebook, in order to foster a support network for its members [15]. The participating mothers reported that one factor that increased their feelings of belongingness was the fact that membership was strictly limited to clients of the same maternity clinic. This closed network positively affected the mothers' levels of trust and increased their willingness to discuss intimate issues.

While describing management strategies for online health communities, Young proposed a community life cycle that consists of 4 stages: inception, establishment, maturity, and mitosis [16]. Each stage is characterized by various milestones, and monitoring a community's growth can facilitate progression through these stages. The inception stage is the first stage that starts as soon as an organization begins to engage potential members. The primary focus during this stage is to make connections and build a core group of active members. Engagement at this time is limited, with only 0% to 50% of activity initiated by community members. The establishment stage comes next and begins when community members generate more than 50% of the activity and ends when they generate most (90%) of the growth and activity. The primary focus of this stage is establishing a sense of community by

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acknowledging the contributions of members and encouraging further participation and engagement. The maturity stage begins when more than 90% of community activity and growth is generated by its members. During this stage, the size of the community reaches its critical mass and the sense of community is well established. Although communities at this stage are considered self-sustaining, management is still needed. The final stage, known as the mitosis stage, begins when the community becomes largely self-sustaining and ends when activity and growth begin to negatively affect the sense of community. This is a critical stage, as successful communities run the risk of becoming too large and active, subsequently triggering member disengagement. Community monitoring is essential at this stage, as managers may witness the emergence of special interest groups and community subsets. These subgroups have the potential to split off to create splinter groups and begin the community life cycle once more.

We describe the development and evaluation of a Web-based research advisory committee hosted on Facebook and connecting a diverse group of parents of special needs children with researchers at *CanChild* at McMaster University in Hamilton, Ontario, Canada. The goal of establishing this parent-researcher community was to work together and exchange knowledge in order to improve research and the lives of children with special needs and their families. We describe the first year of our online community, during which we have moved from inception to an established community.

Methods

Building the Community

Based on *CanChild* 's knowledge translation strategic plan [17], *CanChild* planned on developing a research advisory group to facilitate active engagement from family members. The purpose of the group would be to exchange knowledge on project planning, research direction, the current state of special needs parenting, supports, and services, as well as how to translate research knowledge to best serve parents and youth living with disability. The original vision for our research advisory group was to bring together youth and young adults with disabilities, family members, and researchers for quarterly meetings (either in person or via teleconference) to facilitate the research direction. In early discussions (October 2012) related to the development of this group , a parent (JS) proposed the idea of a parent advisory community hosted on Facebook (Facebook, Inc, Menlo Park, CA, USA). It was thought that a virtual group would allow greater involvement from families and researchers (both geographically and categorically) and more instantaneous feedback, and would be more convenient. Since this parent (JS) had already developed a network of special needs families across Canada and the world, she partnered with another parent to see whether other parents were interested in supporting this idea. In less than 2 hours, more than 30 parents were interested in participating. While parents were keen to participate, it was also important to convince the researchers that this was a viable venture. Our parent made a presentation to the *CanChild* knowledge translation team, and this was taken to the entire *CanChild* team for approval. While not an overwhelming number of researchers were using Facebook, it was agreed to try it as a pilot project to be evaluated and revisited in 6 months.

Evaluation Method

To evaluate this Web-based community, we collected and analyzed posts, likes, and comments in the group over a period from June 2014 to March 2015. In addition, we gathered data through a survey sent to all members (active or not) of the group.

Facebook Evaluation

We informally evaluated the Facebook group at 6 months, when the *CanChild* director agreed to provide further support and resources for the group with the mandate to provide a more formal evaluation. The formal evaluation took place from June 2014 to April 2015. To determine whether the Parents Participating in Research (PPR) group was successful from both the researchers' and families' perspectives, we evaluated the group using quantitative Facebook statistics of engagement and activity (eg, number of posts, likes, comments, and engaged members). We further analyzed the posts by family members and researchers to determine what broad topics or discussions areas were most frequently discussed.

The PPR Web-Based Survey

We used a voluntary, closed, online survey of PPR Facebook members for further evaluation. The institutional review board committee deemed a separate approval for the survey not to be necessary, as the survey was part of a quality improvement measure. In developing the survey, we used a participatory approach and asked for parent volunteers within the Facebook group to help formulate the questions. There were 5 iterations of the questionnaire. The participation of the other members in designing the survey was mediated through the group moderator, who forwarded the suggestions and requests anonymized to DR and OK. The final version consisted of 13 questions covering the aspects "member's description," "research literacy," "safety of the group," "motivation," "perceived change," and "future directions," along with an open-ended section for respondents to provide comments. The survey was distributed using SurveyMonkey (Palo Alto, CA, USA), and the link was shared with the group members through multiple channels as posts, email, and direct messages. Multimedia Appendix 1 shows a copy of the survey. According to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines, the link provided allowed for only one response per Internet protocol address, no personal information was collected, and participation was voluntary [18]. The intention was to also reach those parents and researchers who joined the Facebook group but did not use it on a regular basis. Over the period of 1 month (March 2015) the moderator launched 3 reminder actions. No incentive was offered for completing the survey.

We analyzed quantitative data using frequency statistics. For the open-ended question "what would you change about the group?" 2 of the authors reviewed and coded responses into categories based on agreement. Quotes selected to include in the paper were chosen by consensus of all authors that were thought to represent an interesting perspective on the Facebook group that wasn't captured in the quantitative portion of the survey.

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Results

Building the Community

In starting this Web-based community, several decisions had to be made based on principles established for community-based research [19]. The first was that the community would be set up and run by the 2 parent moderators. They worked in consultation with *CanChild* and considered everything from choosing the type of group, to finding members, to setting rules of engagement and deciding on areas of discussion. Tutoring was also a factor to help many members of the research team understand how to use Facebook.

Private Versus Public

It was decided that a private (or secret) Facebook group be set up for the purpose of this advisory community, and it was named "Parents Participating in Research" (PPR). The rationale for making the group private was that it allowed moderators to control who was part of the group (members would have to be invited to join by an administrator, and posts would be seen only by other members within the group) and that the group would *not* be searchable (allowing for increased confidentiality of information shared by parents and researchers).

Rules of Engagement

To moderate the space and ensure a clear purpose, rules of engagement were developed (see Multimedia Appendix 2). All members were asked to read and agree to follow the guidelines set out before commenting in the forum. We provided a community document for this purpose, with the idea that we would revisit these rules on a regular basis to ensure that we were providing a safe and comfortable space.

Community Space

The PPR Facebook group launched in June 2014 with its first members (primarily those who expressed an interest in the initial Facebook post) invited into the group on June 10 and 11, 2014. After signing off on the rules of engagement, they were invited to introduce themselves (or their children) in either the community photo album or in the group timeline. This was done to foster a sense of community and to help us remember that there is indeed a person behind every question and response. While not mandatory, introductions were encouraged to promote participation and engagement.

Icebreakers

Icebreakers were topics introduced by the moderator and used to help stimulate conversation and establish rapport. Multimedia Appendix 3 shows an example of an icebreaker.

Facebook Evaluation

As of April 1, 2015, the PPR Facebook page had a total of 96 members (2 parent moderators, 13 researchers/ *CanChild* members, and 81 family members). The majority of the members were female, but there were 11 male members (7 of whom were researchers). We estimated that 4 members left the group during the pilot stage of this project. Members were primarily located in Canada (with representation from Alberta, Saskatchewan, Manitoba, Ontario, and Quebec; 1 from the United Kingdom, and 1 from Australia).

Engagement

During the time period June 2014 to March 2015, a total of 432 posts were made (this figure only includes original posts, not comments generated from the posts). Breaking this figure down further, 155 (35.9%) of these posts were made by a moderator (averaging 77.5 posts per member), and 197 (45.6%) posts were made by parents (averaging 2.4 posts per member). Researchers accounted for 80 (18.5%) of the 432 posts, averaging 6.2 posts per member. There was an initial surge of members in the inception phase (approximately June 2014) when a large proportion of members (n=31, 32%) were added to the group. This influx of members was accompanied by a high level of engagement, with a total of 64 primary posts being made in the month of June (mean posts per month: n=42.9, range 20-64 posts). Another period of increased engagement occurred in November of 2014 (64 primary posts made), as that month featured a Family Engagement Day hosted at McMaster University by *CanChild*, celebrating its 25th anniversary. As indicated above, moderators restricted access to the group to ensure that the group remained manageable and the group was not searchable from the public Facebook domain.

Based on the number of views, as displayed by Facebook, posts were generally seen by all members of the group (indicating that members checked in frequently). Posts had a median of 3 likes (range 0-24) and 4 comments (range 0-113).

Families

While the purpose of the Facebook group was to connect researchers and parents of special needs children, the Web-based community also provided a private environment in which parents could discuss personal issues and interact with other families with similar experiences. Many discussions covering various topics were initiated, and during the 9-month analysis period, 197 (45.6%) were made by parents alone (excluding moderators and researchers). Among these posts, the topics that were most frequently talked about were childcare (eg, topics surrounding behavioral issues, difficulties communicating with professionals), education and school (eg, topics surrounding participation and inclusion at school), and diagnosis-specific posts (eg, obtaining an accurate diagnosis, seeking research or therapy for a specific diagnosis). Furthermore, parents who connected with the group reported many benefits, including feelings of belonging, that this was truly a community they could be proud to call their own. They reported pride in making a difference in research, even if indirectly, and repeatedly said that they felt that their ideas, thoughts, and experiences were validated, that sharing their stories was not futile. As a result of parents recognizing the need for clinicians and researchers to hear their stories, several parent members initiated the development of a book of stories, which they will compile and whose proceeds will go back into furthering research. Additionally, parents indicated that they were able to ask questions and access information and resources that they would not have otherwise found, from people they could trust to give them the right information.

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Researchers

This Web-based community provided researchers with an opportunity to consult families of special needs children to get guidance and hear issues that are important to them. Examples of the type of requests were a call for parents to read and provide input on a parent resource being developed, to provide input on the logistics and content of a Family Engagement Day, and to express their interest in contributing as a partner in a grant proposal to a national funding agency. An additional benefit was that researchers were able to guide parents to credible resources that were relevant to their needs, a limitation that was outlined in previous Web-based communities [13,14]. Of the 80 posts made by researchers, 44 (55%) were posts linking parents to a variety of credible resources, including websites, news stories, videos, info graphics, and articles.

One example of the direct impact and meaningfulness of the group for both parents and researchers was a post from one mother who expressed her disappointment that many family members do not understand the needs and abilities of her child. Family members tend to give well-meant but hurtful advice that can lead to tension within the extended family. Other parents from our group suggested that writing up a short profile about her child may be helpful. The mother took that suggestion to heart, developed a beautiful profile of her child's strengths, likes, and dislikes, and posted the profile for others in our group to review and comment on. Other members praised the idea and the approach of this mother, and it generated an important discussion, regardless of the underlying diagnoses of their children. It was noted that aspects such as attitudes, family supports, and the ability to participate are important aspects of the quality of life of children and their parents. This discussion overlapped with the interest of one of the researchers (OK) in using the International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization [20], to better describe needs of patients with chronic health conditions and disabilities. The profile created by the mother was a good example to illustrate how the needs of the child could be classified in terms of the ICF. After obtaining consent from the mother who posted the profile, we used an anonymous version of it in a grant proposal to illustrate the needs of families in sharing meaningful information about their child using the ICF [21].

PPR Web-Based Survey Results

Members' Description

With 49 of a possible 96 responders to the survey, the response rate was 51%. A total of 82% (n=40) of the responders indicated that they were participating in the Facebook group due to their personal experience with disability (parents) and 18% (n=9) due to their research experience (researchers). Approximately two-thirds of parents and researchers indicated that they read the posts on a daily basis.

Research Literacy

The parents were asked to rate their research knowledge on a scale from 1 (low) to 10 (high) for 2 time points: (1) a retrospective assessment of their knowledge when initially joining the group and (2) their current knowledge. The parents had a median value of 6 (responses ranging from 0 to 10) (n=40) at entry to the group, which had increased to 8 (with responses also ranging from 0 to 10) (n=40) at the time of filling out the survey.

Safety

To evaluate how safe the users felt participating in this group, we asked respondents to indicate to what extent they regulated what they posted. Among the parents, 23 (58%) indicated that they felt safe to post sensitive or personal information, 10 (25%) indicated that they regulated what they posted, and 4 (10%) indicated that they only read and did not post at all. A total of 3 parent respondents (7%) did not answer this question. Among the researchers, 5 of the 9 (56%) felt safe to post sensitive or personal information, 3 (33%) regulated what they posted, and only 1 (11%) read posts but did not post themselves.

Motivation

To understand our community's motivation for participating in this group, we gave them 6 possible response options. Table 1 lists the responses from parents and Table 2 lists the responses from researchers, followed by quotes from the open-ended questions.

Parents' Quotes

> *I never realized that as a parent I could make a difference. This group has given me the hope and proof that I can.*
>
> *I have expanded my knowledge of childhood disability—which in turn has helped me make connections with other parents. Even if their disability diagnosis and experience is different than mine, I find it helpful to see things from their point of view. I think that may be key in learning how to advocate for change not just for my own child but for any child.*

Researchers' Quotes

> *I was not aware of the impact of the daily struggles that disabilities can have in the life of families. Many of the topics brought up in the group have not been brought up in the same way in clinical encounters.*
>
> *I have also learned how eager and supportive families are of research and how willing they are to provide feedback on any issues.*

Perceived Change

Members were asked if they had changed their behavior or attitude in any way as a result of participating in the group. Table 3 lists the parents' responses and Table 4 lists the researchers' responses.

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Table 1. Parents' motivation to join the Parents Participating in Research group (n=37).

Motivation	n	%
To connect with like-minded people	35	95
To find information, eg, search for or ask a question	29	78
To have an impact on childhood disability research	28	76
To get or give emotional support	27	73
To share ideas and solicit feedback	22	59
To raise awareness about issues related to disability	19	51

Table 2. Researchers' motivation to join the Parents Participating in Research group (n=9).

Motivation	n	%
To have an impact on childhood disability research	9	100
To share ideas and solicit feedback	7	78
To connect with like-minded people	7	78
To raise awareness to issues related to childhood disability	6	67
To find information, eg, search for or ask a question	4	44
To get or give emotional support	4	44

Table 3. Parents' perceived behavior and attitude changes after participating in the Parents Participating in Research advisory community (n=34).

Changes	n	%
No changes	19	56
Toward research	11	32
Toward their child/children	8	24
Toward their family	6	18
Toward people with disabilities	6	18
Toward their friends	5	15
Toward their patients	3	9
Other (eg, more aware of my child's rights)	4	12

Table 4. Researchers' perceived behavior and attitude changes after participating in the Parents Participating in Research advisory community (n=9).

Changes	n	%
Toward research	3	33
Toward their patients	2	22
Toward people with disabilities	2	22
Toward health care professionals	2	22
Toward their child/children	1	11
Toward their family	1	11
Toward their friends	1	11
No change	1	11
Other (eg, increased awareness of true engagement of parents in research)	2	22

What Would You Change About This Group?

Respondents were asked "if you could change one thing about this group, what would it be?" The answers were coded into themes by 2 authors (OK & DR). The 2 most frequently mentioned comments are summarized in the following 2 themes. First, more researcher input: 9 respondents mentioned that they would like to see more researchers actively involved in the group. They stated that they would like information on what research is being done, including what projects may require

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partnering, and they wanted researchers to engage stakeholders in discussion on *CanChild* material already posted on the *CanChild* website. In addition, they wanted researchers to respond quicker when tagged and join the discussions not only as a professional but also with multifaceted dimensions of themselves as a whole person. They wished that the researchers wouldn't shy away from empathetic responses and talking from personal experiences, as well as presenting data and evidence-based information. Second, 5 comments were made suggesting the need to better clarify the purpose of the group, as there was a lot of discussion about patient care and family topics in addition to research topics.

Discussion

Parent-led support groups have been found to serve a vital function in supporting families of children with disabilities [22,23] but are often specific to one health condition, rarely include other stakeholders such as clinicians or researchers, and are not framed to help move a research agenda forward. Likewise, research-initiated engagement activities are often limited in their scope; include limited number of individuals or voices, reflecting a potential biased view of the issue; focus only on a specific health condition; or only bring in families at strategic points in the research cycle (eg, at the end to disseminate the findings). Camden et al summarized strategies used in the past to recruit stakeholders in rehabilitation research (primarily people with disabilities and their families) as targeted (eg, by direct invitation to individuals) or open (eg, by asking partner organizations to solicit from their membership, or by using media) [10]. Most activities were done by committees and tended to be face-to-face meetings or teleconference meetings. Our approach, which was suggested by a parent, was to use Facebook as a useful, easily accessible way of actively engaging families in the research process.

CanChild's overall mandate is to conduct clinically relevant research to improve the lives of children with disabilities and their families [24]. In order to fulfill this mandate, many of our research studies in the past have engaged youth with a disability or their family members as a collaborator and author (eg, The KIT "Keeping it Together," Youth "KIT," and Partnering for Change) [25-27]; however, we saw the opportunity to broaden our perspective by engaging a larger community of families to further address issues of importance to families, as well as create a community where there is an opportunity for ongoing meaningful dialogue.

The 4 stages of building an effective online health community as defined by Young are inception, establishment, maturity, and mitosis [16]. Using this framework, we describe the first year of our Web-based community, where we have moved through inception to having an established community

Inception Phase

Key components of the inception phase are to invite members, build relationships, establish the tone and style of interaction, and nurture an active core membership [16]. The PPR Facebook group was proposed, launched, and moderated by a parent of a child with special needs who was acting as a parent resource to *CanChild*. She immediately recruited another parent to help cofacilitate the group and began strategies to connect members and begin to build trust. The initial purpose of the group was to be an advisory to *CanChild*, and 76% of parents and all the researchers responding to the survey identified that the reason for participating in this group was to have an impact on childhood disability research. Parents were also keen to connect with like-minded people and find information, while researchers wanted to connect with like-minded people, share ideas, and elicit feedback.

Establishment Phase

When more than 50% of group content is generated by its members (as opposed to moderators), it is described as an established online community, while greater than 90% makes it a mature community [16]. The friendly icebreakers posted by the moderators were a safe and inviting way for people to begin sharing ideas, discuss common issues, and support each other. As time went on, the need for icebreakers was not as high, and members began to freely post discussion topics of their own. Members of the group (as opposed to moderators) generated 64% of initial posts, indicating that our group has transitioned into the established phase. With this shift it is important to recognize that the moderators still have an essential role to help ensure sustainability of the community [28]. The moderators readily respond to posts initiated by members or direct message, or tag others who may be able to add important perspectives to the discussion, ensuring that members feel heard and respected.

While a few researchers are active in this group, feedback from the survey highlighted the wish of parents for more researcher engagement, with ideas about what types of engagement would be welcomed.

An unexpected outcome was the shift in the emphasis of the group from acting primarily as an advisory to ongoing work at *CanChild*, to having a very active parent exchange where issues that are important to families readily came to the forefront. As one clinician researcher highlighted, the PPR Facebook group has provided a deeper understanding of what issues are important to families and the day-to-day issues they face, which don't typically come up in clinic visits. This provides an opportunity to explore issues that may not have been thought of previously and to engage with participants to review the evidence and possibly develop the ideas into a research proposal. In a recently published study in the United Kingdom looking at research impact, Morton suggests it is not always possible to predict the impact that research partnerships will have at the outset, but that working closely with research users can help give a deep understanding of the users' context, their actions to adapt research to their own needs, and the commitment to use research to make a difference [29].

Through the Facebook page, we had the opportunity to ask families for advice on a variety of issues (eg, topics and the format for *CanChild* 's Family Engagement Day; improving our website to be more parent friendly) and to ask for feedback and collaborators on papers, evidence briefs, grants and presentations. We have 3 parents from our group as authors on this paper, and 1 on a recent review of stakeholder engagement [10]. Our moderator has copresented with our researchers at

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our provincial meeting of children's rehabilitation organizations [30] and is providing a video to include in a panel discussion of family engagement at an upcoming international meeting. The moderator from our PPR group has participated in several *CanChild* research rounds, providing important family perspectives on a variety of issues.

Maturity Phase: Strategies to Move Forward

It has been suggested that, in order to be successful, communities need to have a clear purpose, have a management strategy, and foster a sense of community [16]. Feedback from the survey indicated that, even though there are terms of reference for the group, the purpose of the group still needs further clarification. This may be because this group was initially set up as an advisory to *CanChild*, but the number of researchers participating in the group is low relative to the number of parents, allowing parents to continue to use the page in a manner that best meets their needs. To do community-based research, it is important that the researchers establish trust and demonstrate commitment, spending time in the community on an ongoing basis [13]. The few research members who are actively engaging with families feel a strong sense of open exchange and community. *CanChild* is actively trying to engage more researchers into the Facebook group; however, this remains a challenge, as researchers who are not regular Facebook users are reluctant to take the time to learn and worry about the ongoing time commitment it would require. Some researchers also struggle with their professional boundaries and knowing when and how they are to interact on a more personal level with families—even though this is what parents are asking for.

Since the survey, we have instituted a number of strategies to try to increase researcher engagement. There is now a Community and Family Engagement Officer at *CanChild* who will actively monitor the site and identify researchers with expertise who might be able to respond to parent posts, even if they aren't active Facebook users. We have recently presented the results of the PPR Facebook evaluation at *CanChild* research rounds, providing examples of many of the interesting topics discussed, the impact the group has had on research members' research (eg, the ICF example), and the request from parents for more researcher involvement. In addition, we have instituted a "meet the researcher" in our Facebook page to have a specific time that a researcher will be on the page to respond directly to parents' questions. There is usually an introduction to the researchers' area of research through a paper or news link prior to the meeting time. This has proved very successful in actively engaging members and introducing new researchers into the Facebook group. We also plan to act on ideas brought forward by families for more discussion on the content of our website.

We believe that several factors have contributed to the success of this group. The group's growth from inception to an established community indicates the level of interest and engagement of its members. The importance of ongoing community conversations to maintain the interest and momentum of the group and engage members enough to feel safe to disclose personal information and provide advice cannot be underestimated. Since the moderators are parents of children with special needs who already had credibility with numerous parent groups was and still remains a real strength. Their knowing how to engage families and build a respectful, supportive environment while understanding the needs of the researchers and the overall purpose of the group were fundamental for the success of our group. The fact that the group welcomes families of children with a variety of diagnoses has allowed common issues to emerge, which are universal regardless of ability. The convenience that Facebook provides in terms of 24-hour accessibility was also seen as a positive for both busy parents and researchers as to when they can log in and participate.

Limitations of the Study

The response rate to our survey was only 51%, which leaves us with just under half our members' views not incorporated in the results. In addition, the survey was developed with the input of parent and researcher members but was not tested for reliability prior to its use. A validated tool to evaluate the Facebook community would have been very useful.

Another limitation was that our Facebook site was set up as a "group" in order to have the ability to be closed or "secret" and, in retrospect, this made harnessing accurate Facebook metrics a challenge. We tried purchasing Facebook reporting software but it was limited in its ability to provide accurate data from posts prior to purchasing it and we therefore needed to collect our data manually.

Conclusion

The experience of being part of this Facebook group made participants aware of the need to invite youth with disabilities (in addition to parents) into the group or to organize a similar group to engage specifically with youth. The perspectives brought from the lived experience and the issues raised by youth would likely be quite different from the ones raised by their parents and are important for researchers to understand. This led to a focus group with 6 youth with special needs, and it became clear that they did not want to join the parent community but will move forward in developing their own community, which will provide opportunities to exchange ideas with *CanChild* researchers and each other. This is an example of what Young [16] might refer to as mitosis.

Young also suggested that the success of Web-based communities depends on having sustained organizational support in terms of financial and human resources [16]. Based on an initial positive review of the Facebook group at 6 months, *CanChild* has successfully applied for project funding to ensure sustainability of the group and allow financial support for the parent moderator with the goal to build a Web-based community in partnership with a national center of excellence for neurodevelopmental disabilities in Canada (NeuroDevNet, 2015-2018). We will use the results of this evaluation to help improve the Facebook page to meet the needs of *CanChild*, NeuroDevNet, and the PPR members as we work together to identify needs, important research questions, and actions to improve the lives of children and their families.

By acknowledging the benefits and being cognizant of the limitations of social media platforms, researchers can begin tapping into the potential for social media to be used as a means

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of engaging parents and families in the research process. Families can connect with other families and researchers to share their experience and voice what is important to them, to ensure that research is meaningful and impactful for those who needed it most: the children and the families.

Acknowledgments

We would like to acknowledge all the members of our PPR Facebook community who so willingly share their personal experiences and eagerly work to help improve childhood disability research. This research is partially funded by NeuroDevNet, a national Network of Centres of Excellence. Funding of the Web-based community was also made possible by the generous contributions of McMaster Children's Hospital Foundation and the Scotiabank Chair in Child Health Research held by Dr Jan Willem Gorter. Funders had no involvement in review or approval of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Parents Participating in Research online survey.

[PDF File (Adobe PDF File), 154KB - jmir_v18i11e293_app1.pdf]

Multimedia Appendix 2

Rules of Engagement for the Parents Participating in Research Facebook Community.

[PDF File (Adobe PDF File), 212KB - jmir_v18i11e293_app2.pdf]

Multimedia Appendix 3

Screenshot of a sample icebreaker from the Parents Participating in Research Facebook Community.

[PDF File (Adobe PDF File), 66KB - jmir_v18i11e293_app3.pdf]

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Abbreviations

CHERRIES: Checklist for Reporting Results of Internet E-Surveys
ICF: International Classification of Functioning, Disability and Health
PPR: Parents Participating in Research

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Edited by G Eysenbach; submitted 20.05.16; peer-reviewed by K Wittmeier, C Young; comments to author 09.06.16; revised version received 29.08.16; accepted 22.10.16; published 11.11.16.

Please cite as:
Russell DJ, Sprung J, McCauley D, Kraus de Camargo O, Buchanan F, Gulko R, Martens R, Gorter JW
Knowledge Exchange and Discovery in the Age of Social Media: The Journey From Inception to Establishment of a Parent-Led Web-Based Research Advisory Community for Childhood Disability
J Med Internet Res 2016;18(11):e293
URL: http://www.jmir.org/2016/11/e293/
doi:10.2196/jmir.5994
PMID:27836818

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Original Paper

Online Concerns of Parents Suspecting Autism Spectrum Disorder in Their Child: Content Analysis of Signs and Automated Prediction of Risk

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Abstract

Background: Online communities are used as platforms by parents to verify developmental and health concerns related to their child. The increasing public awareness of autism spectrum disorders (ASD) leads more parents to suspect ASD in their child. Early identification of ASD is important for early intervention.

Objective: To characterize the symptoms mentioned in online queries posed by parents who suspect that their child might have ASD and determine whether they are age-specific. To test the efficacy of machine learning tools in classifying the child's risk of ASD based on the parent's narrative.

Methods: To this end, we analyzed online queries posed by parents who were concerned that their child might have ASD and categorized the warning signs they mentioned according to ASD-specific and non-ASD–specific domains. We then used the data to test the efficacy with which a trained machine learning tool classified the degree of ASD risk. Yahoo Answers, a social site for posting queries and finding answers, was mined for queries of parents asking the community whether their child has ASD. A total of 195 queries were sampled for this study (mean child age=38.0 months; 84.7% [160/189] boys). Content text analysis of the queries aimed to categorize the types of symptoms described and obtain clinical judgment of the child's ASD-risk level.

Results: Concerns related to repetitive and restricted behaviors and interests (RRBI) were the most prevalent (75.4%, 147/195), followed by concerns related to language (61.5%, 120/195) and emotional markers (50.3%, 98/195). Of the 195 queries, 18.5% (36/195) were rated by clinical experts as low-risk, 30.8% (60/195) as medium-risk, and 50.8% (99/195) as high-risk. Risk groups differed significantly (P<.001) in the rate of concerns in the language, social, communication, and RRBI domains. When testing whether an automatic classifier (decision tree) could predict if a query was medium- or high-risk based on the text of the query and the coded symptoms, performance reached an area under the receiver operating curve (ROC) curve of 0.67 (CI 95% 0.50-0.78), whereas predicting from the text and the coded signs resulted in an area under the curve of 0.82 (0.80-0.86).

Conclusions: Findings call for health care providers to closely listen to parental ASD-related concerns, as recommended by screening guidelines. They also demonstrate the need for Internet-based screening systems that utilize parents' narratives using a decision tree questioning method.

(J Med Internet Res 2016;18(11):e300) doi:10.2196/jmir.5439

KEYWORDS

online queries; autistic disorders; parents; machine learning; early detection

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Introduction

The increasing rate of diagnosed autism spectrum disorders (ASD) [1] along with the public's growing awareness of the disorder leads more parents to suspect ASD in their child. These early concerns can arise months before parents decide to approach a professional [2]. As the majority of parents of children with ASD report having symptom-related concerns before the child reaches the age of 3 years [3-5], it stands to reason that reporting these concerns could potentially facilitate earlier evaluation and services. Parents of infants and toddlers seek information about their child's development on online community forums, where they expect to be able to verify or discuss their concerns [6-8]. However, as the resources of health care professionals are scarce, machine learning tools could be applied to perform prescreening of parental forums where ASD concerns are voiced.

On the one hand, parents' online descriptions of their concerns regarding their child's development offer the opportunity to facilitate early referrals; whereas on the other hand, the use of a free-text format makes it difficult to determine the degree of risk for a specific diagnosis. From a public health perspective, online queries are a window into the behaviors that parents recognize as alarming signs of ASD. In turn, this information can be used to design screening procedures to help parents detect signs that are not readily noticeable. Moreover, machine learning tools may offer a way to estimate the degree of ASD risk of the child whose symptoms were described in the online query. The goals of the study were two-fold: (1) To characterize the symptoms mentioned in online queries posed by parents who suspected that their child might have ASD and categorize queries according to the level of clinical risk and the age of the child; and (2) to test the efficacy of machine learning tools in classifying the child's risk of ASD based on the parent's narrative.

The entire process from the time the parents first suspect developmental problems until an ASD diagnosis is obtained can take years [2,9,10]. Studies have demonstrated that the time between parents' first concerns and the first professional ASD consultation was between 5 and 8 months on average [2,9,10], and the average time from concern to diagnosis was more than 32 months [2,11]. ASD is behaviorally diagnosed, based on Diagnostic and Statistical Manual of Mental Disorders (DSM-V) [12] criteria describing symptoms in the domains of social-communication and repetitive and restricted behaviors and interests (RRBI). Of all neurodevelopmental disorders, early identification of ASD is particularly difficult, for the following reasons: (1) the range of what is considered typical, healthy social-communication development is very wide; (2) certain ASD symptoms such as language patterns cannot be detected and evaluated before the child reaches the age of 2 years; (3) diagnosis depends on clinical expertise rather than on a biological marker; (4) early signs of ASD and other neurodevelopmental disorders partly overlap leading to complex diagnostic issues; and (5) ASD screening tools show moderate sensitivity and specificity. Consequently, parents are often left to cope with their worries, long before a diagnosis can be made, which in turn increases their urge to approach online communities. The long-term goal of this study was to devise a computerized tool based on the parents' narrative of concerns that could estimate their child's ASD risk.

An algorithm for systematic screening of ASD, devised by the American Association of Pediatrics, is used by health care professionals to elicit parental concerns regarding their child's development to calculate a cumulative ASD-risk score and conduct closer monitoring of children who were found to be at risk [13]. Thus, parents' early concerns, which have been validated against ASD screening tools and subsequent diagnosis [14,15], constitute a source of valuable clinical information and often initiate the diagnostic process. Parental concerns are relatively easy to elicit, time-efficient, and bypass the challenges inherent in direct testing, which does not always reflect the child's true skill level. Notwithstanding these advantages, the widespread concerns of parents of young children pose a challenge for the differential prediction of ASD. In addition, parents may be biased in identifying certain signs, due to their emotional state, beliefs, and developmental knowledge. The validity of parental concerns is a subject of continuous research, and has implications for the clinical interpretation of parental concerns.

Evidence shows that the number and type of early parental concerns are predictive of a later developmental disorder [16] and specifically of ASD [15-18]. Types of concerns are classified as ASD-specific (ie, related to core ASD symptoms) and non-ASD–specific concerns. Research has shown that both types of concerns are associated with an eventual ASD diagnosis (reported in more than 18% of cases). Predictive ASD-specific concerns related to communication, language, social-emotional responses, and stereotyped behaviors; whereas non-ASD–specific concerns related to behavior or temperament, regression of skills, medical problems, or delay in milestones [9,10,15]. Studies of siblings of children with ASD indicate that the most frequent or first concern of parents involves communication development [9,15,19-21]. In a large retrospective study of parental concerns in ASD, social-emotional concerns (including nonverbal communication) were the most prevalent, followed by language and RRBIs; however, non-ASD–specific concerns were mentioned as well by at least half of the sample [10]. Retrospective parent reports of motor problems, unusual sensory and repetitive behaviors, atypical play patterns, and behavioral problems differentiated children later diagnosed with ASD from those diagnosed with other developmental disabilities [22]. However, in another study [21], parental concerns unique for children with ASD were challenging behaviors and attention problems. Parental concerns that led to a differential diagnosis of atypical development (vs ASD) were related to motor and communication problems. Looking at the presence of a combination of concerns showed that parental concerns about behavioral problems and about cognitive delay in the absence of concerns about communication were not likely predictors of an ASD diagnosis [23]. This evidence underscores the need for an automated system, which can capture the combination of concerns in risk determination. This study analyzed the ASD- and non-ASD–specific signs reported online by parents who suspected ASD warning signs in their child's development.

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Some studies associate the age of the child when the parents' concerns are first aroused with the type of signs and their predictive validity. Studies describing parental concerns in families at high risk for an ASD diagnosis concluded that the number of ASD-specific signs noted by concerned parents of 12-month-old children is a better predictor than the number of signs noted by concerned parents of 6-month-old children [15]. Research indicates that although communication was the most frequent first concern, it served to differentiate children with ASD from those with other disorders only among 24-month-old children [3]. Evidence shows that a second type of parental concern expressed frequently is in the behavior or temperament domains at 14 and 24 months and both behavior or temperament and social development domains at 36 months. This differentiation at 24 months and not earlier is in line with another study [17]. Non-ASD–specific concerns (in 53% of children) related to motor problems, anxiety, tantrums, and hyperactivity were associated with earlier parental awareness, whereas ASD-specific concerns, including social withdrawal, abnormal gaze, and poor social interaction, were associated with later parental concerns [10]. In this study, the types of concerns that alert parents of ASD were compared among different child age groups.

To summarize, the reviewed evidence supports the working hypothesis that early parental concerns from the child's second year of life predict later ASD diagnosis. However, most of the studies were based on retrospective reports of parents with children with ASD [10,24], or prospective reports in a high-risk sample [3,15,17,19,22,25]. In high-risk samples, parental concerns represent cases in which there is a truly elevated likelihood of ASD in a younger sibling, and they are already on alert for specific signs [26]. Previous evidence relied on parental responses to structured questions about early concerns in specific areas, sometimes followed by a textual description of the concern mentioned [21]. The Internet reflects the distribution of spontaneous parental ASD concerns in the general population, thus providing access to the data long before they are reported to a professional. The availability of such data makes it possible to explore the potential construction of an automated risk indicator, based on free-text descriptions.

There are several projects that use technology to enable automated early identification of developmental problems, including ASD. For example, the Modified-Checklist for Autism in Toddlers-Revised (M-CHAT-R/F), comprising an ASD screening questionnaire and follow-up interview, has been implemented electronically. The M-CHAT-R/F has proved efficient in lowering both false-positives and negatives compared with paper-format screening [27]. In another study, the online Ages and Stages Questionnaire screener was comparable with the paper version [28]. These studies support the reliance on an Internet-based screening platform, but they do not look at free-text analysis of parental concerns emerging prior to engaging in an ASD-specific screening process.

Regardless of ASD, parents, especially of young first-borns, frequently seek health- and developmental-related information online [6,29]. The Internet was identified as parents' third routine source for obtaining health information [6]. The Internet offers an anonymous round-the-clock platform for expressing concerns. The increased trend in parents' online information seeking is related to sociodemographic changes, such as living at a geographical distance from parents, decrease in support from family and friends, information from the previous generation is perceived outdated, and there is a greater demand for experience-based information [8]. The clinical quality of answers provided online to parents suspecting ASD in their child varies greatly [30]. There is a need to develop online systems to support parents in interpreting their young child's behavior, so as to validate concerns and offer further guidance to parents when appropriate, while also minimizing the risks of acting solely on nonprofessional online advice.

Machine learning tools [31] have been previously applied for predicting health-related conditions from text, but never for predicting ASD. We note that online forums pose a challenge for analysis, given their unstructured nature and users' descriptions of their symptoms in nonmedical terms. De Choudhury et al [32] investigated the ability to detect clinical depression from social media postings. Search-engines queries were used to predict mood disorder episodes [33]. In another study, adolescents at risk of being bullied were identified using online texts from MTV's A Thin Line project. Thousands of teenagers' online posts were used to develop an algorithm for identifying offensive cyber bullying, based on topic modeling methods [34]. This study built upon these works to test the possibility of devising an automated ASD-risk estimator online, based on large amounts of unstructured textual data and a machine learning algorithm.

The remainder of the paper is organized as follows. The Methods section describes the nature of the sampled queries, coding procedures, and data analysis steps. The Results section describes the types of signs mentioned by parents and their comparison between ASD risk groups and age groups. This section ends with the description of automated prediction of ASD risk from the text. The Discussion section lays out the interpretations and implications of the study.

Methods

Sample

This study utilized the Yahoo Answers platform to examine queries of parents suspecting their child has ASD. On the Yahoo Answers platform, queries are posted using natural language, answers are submitted by users, and a community forms around this interaction. A query can elicit multiple answers; one of them is rated the best answer, either by the asker or by the community. Yahoo Answers queries—rather than search-engine queries—were selected for the purpose of this study, as they consist of anonymously posted queries on a public platform and hence are more likely to represent parents' true need for an answer.

We extracted all English-language queries from Yahoo Answers that were submitted between 6 June, 2006 and 12 December, 2013 and contained the words *autism*, *Asperger*, *ASD*, or *PDD*. A total of 8681 queries met these criteria. We used crowdsourcing [35] (using CrowdFlower) to differentiate between queries posted by parents of a child diagnosed with

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autism (n=2412), queries posted by parents of a child diagnosed with autism whose sibling they suspected might have autism (n=41), queries posted by parents who suspected their child might have autism (n=1081), and queries posted by parents who did not match any of the above descriptions (n=5147).

Of the 1081 queries of suspecting parents, 195 were randomly selected and analyzed for this study. Among these, in 96.4% (188/195) of the queries that mentioned the age of the child, it was, on average, 3.2 years (SD 2.9; range 1.25 months-18 years; 60.3% [114/189] below 3 years of age). Boys were the subject of 84.7% (160/189) of the queries, girls were the subject of 15.3% (29/189), and the gender of the child was not specified in the rest.

In 4.6% (9/195) of the queries, parents reported a family history of ASD. In 30.8% (60/195) of the queries, parents did not mention reporting their concern to a health care provider.

Procedures

The content analysis of Yahoo Answers queries was conducted using the NVIVO software. Two types of content analysis processes were applied:

First, one type of content analysis was used to rate a child's risk of ASD as either low, medium, or high. To this end, a set of rules was devised for defining levels of ASD-risk from text. Medium-risk was defined by concerns related to one type of ASD-specific sign, general description of developmental delay, non-ASD–specific concern requiring evaluation and mentioning a risk factor for ASD such as a family member with ASD but no ASD-specific sign. For example:

> *My son is 19 months old & sometimes flaps his arms when excited or dancing, could he be autistic? he was born 3 months early & i do not know if this is normal behavior in a toddler or not...please help!*

High-risk was defined as concerns related to at least two types of ASD-specific sign, 1 from the RRBI domain and another from the Social and Communication domains. High-risk rating also considered the severity of the described signs and urgency expressed by the parent:

> *My son is 2 1/2 years old and he can count to 15 and sing the whole abc song but he is not speaking with meaning asking me for things like juice and so. He also repeats long sentences from cartoons all day long but has nothing to do with what he is doing at that moment...*

Low-risk was defined, by default, as queries that did not meet the above criteria, for example:

> *My child has a bent index finger on both hands. Sometimes it straightens out does this mean she has autism?*

Then, 2 clinical experts in ASD separately rated the risk level of children described in 38 (19.49%) queries and reached kappa of .72 in their differentiation of at risk queries. Finally, ASD risk in the remaining queries was rated by 1 clinical expert.

Second, another process of content analysis was conducted to identify the types of warning signs noted by parents. This process, which involved deductive and inductive analysis methods, was conducted by a different clinical expert. The deductive method implied coding the warning signs according to domains and subdomains that match DSM-V criteria for ASD. An inductive method was used to identify concerning signs that did not correspond to the DSM-V diagnosing criteria such as describing cognitive impairment or language delay. The resulting taxonomy of the concerning signs mentioned in parents' queries consisted of 12 domains and 72 subdomains (Multimedia Appendix 1). The first author and clinical expert coded 38 queries and obtained an inter-rater agreement as measured by significant kappa values between .54 and 1 across subdomains, with .71-1 values for the 12 domains. Due to challenges in agreeing on the number of manifestations pertaining to a single type of warning sign, each subdomain of sign (ie, the lowest hierarchy level within a subdomain) was coded for its presence in the query, regardless of the number of times that type was mentioned in the query (eg, "rocks, swings and sways body" is coded once for rocking). While coding, the clinical expert and the first author discussed coding dilemmas and refined the coding rules accordingly. To summarize, each query received an ASD global risk score and was coded for either presence or absence of each sign domain and its subdomains.

Data Analysis

Data regarding the age and gender of the child were extracted using a combination of automated text analyses, followed by crowdsourcing rating to correct for errors. The sample with available age data was divided into 4 age groups: 0-2 (n=62), 2-3 (n=52), 3-6 (n=58), and ≥6 years (n=18).

Only signs with an occurrence of more than 5% were included in the analyses. Alpha level (Type 1 error) was corrected using Bonferroni for multiple comparisons, such that the threshold *P* value (.05) was divided by the number of comparisons. The sign domains differentiating the 3 ASD risk groups were analyzed using chi-square tests, given their dichotomous nature and Fisher's exact tests for pairwise comparisons. The null hypothesis was that the distribution of sign domains across groups is equal. The association between the child's gender and age group and the ASD-risk level was determined using chi-square tests. The length of a query differed significantly between ASD-risk groups ($F_{2,192}$=10.93, P<.001; mean number of words associated with each risk level was as follows: low=132.57, medium=225.32, high=281.62). Bonferroni post-hoc tests indicated that the number of words was significantly (P<.05) higher in the high-risk group relative to the low-risk and medium-risk groups.

Data analysis was then conducted to assess whether children at risk of ASD could be detected from the queries using the text-coding method devised. The goal of this analysis was to differentiate between low-risk, medium-risk, and high-risk queries. To this end, each query was analyzed to determine (1) the number of times each word or word pair (bigram) appeared in the text, and, separately, (2) the warning signs, coded according to domains and subdomains, as previously explained.

Additional attributes analyzed included the child's age and gender, the number of words in the query, as well as the length

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of the query, as measured by the number of characters in it. We trained a linear classifier [31] (with a least-squares criterion) and estimated its performance in terms of the receiver operating curve (ROC) using Leave-One-Out, that is, for each query *i*, we trained a classifier using all other queries, and tested on the *i*-th query [36].

Results

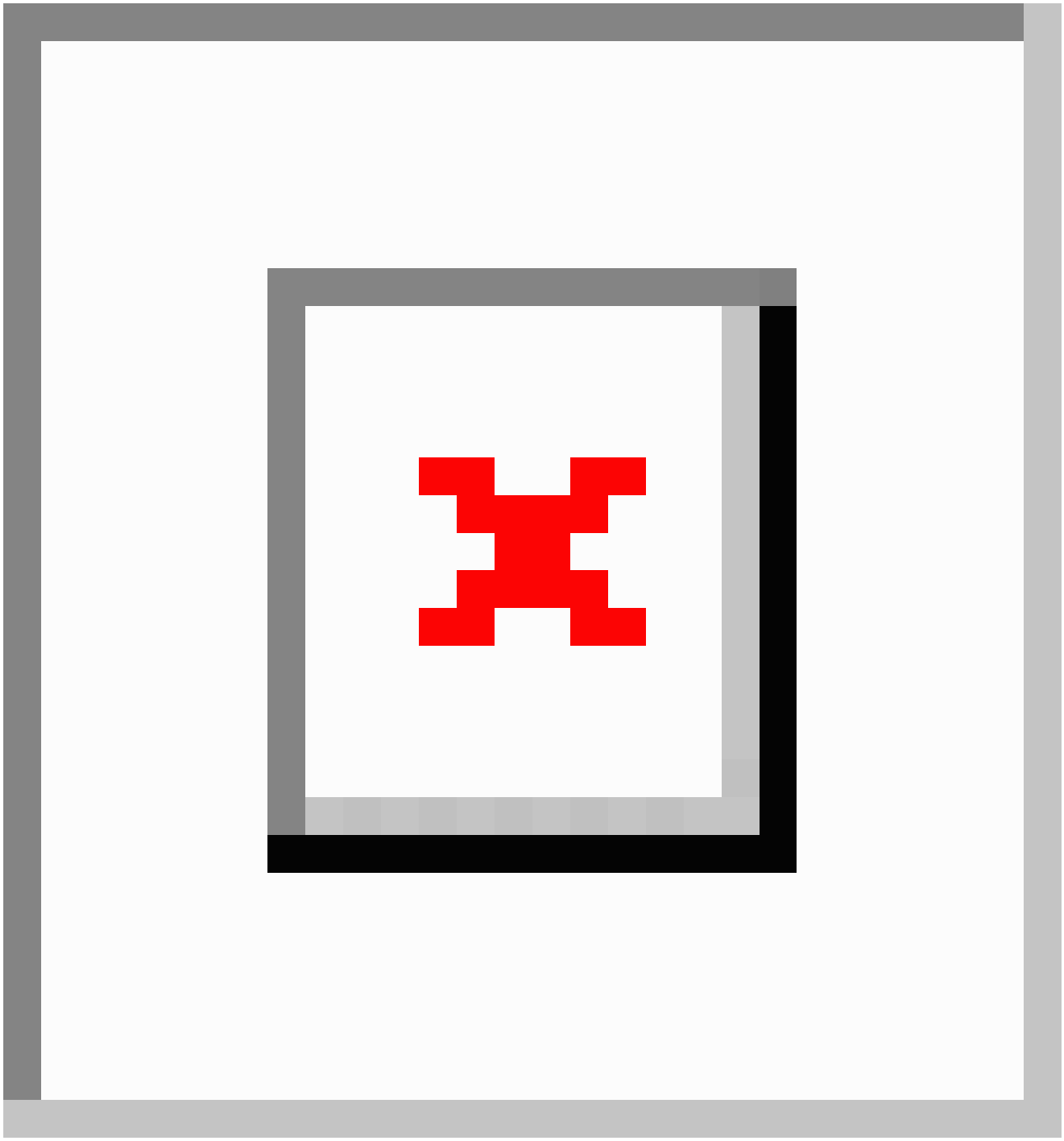
More than one third of the concerns were in ASD-specific domains: RRBI 75.4% (147/195), social 48.21% (94/195), and communication 42.05% (82/195); as well as non-ASD–specific domains: language 61.5% (120/195), emotional 50.3% (98/195), and cognitive 26.7% (52/195). Other sign domains that were mentioned in at least 5% of the queries were attention deficit hyperactivity disorder (ADHD) 18.97% (35/195), medical conditions 15.9% (31/195), motor 12.3% (24/195), activities of daily living (ADL) 11.8% (23/195), eating 8.7% (17/195), and sleeping problems 6.7% (13/195). The distribution of the types of warning signs mentioned in queries is presented in Figure 1.

The 4 most prevalent types of signs were: repetitive movements (40.5% [79/195]), speech delay (36.4% [71/195]), sensory issues (34.9% [68/195]), and difficulties making friends (30.8% [60/195]).

The distribution of queries among the 3 ASD-risk levels, as determined by clinical experts, was: low-risk (n=35), medium-risk (n=60), and high-risk (n=100). The distribution of sign domains mentioned in queries is presented in Table 1 according to the level of ASD risk; results from chi-square tests comparing groups are also shown. Fisher's exact pairwise comparisons reflected the significant difference between the high-risk and the other 2 groups in terms of ASD-specific sign domains. A surprising finding was the lack of significant difference in the types of ASD-specific concerns mentioned in low versus medium ASD-risk groups. There were significantly fewer (P<.001) language concerns in the low-risk group than in the other groups, which did not differ with regard to this domain. Exploratory analysis indicated that within each domain there were individual signs that contributed to the domain differences between the groups (Table 1).

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Figure 1. Percentage of domains and sub-domains of warning signs mentioned in ≥5% of queries. RRBI: repetitive and restricted behaviors and interests; ADHD: attention deficit hyperactivity disorder; ADL: activities of daily living



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Table 1. Distribution of domains of warning signs mentioned in queries presented according to ASD-risk levels.

Domain of signs	Risk group, n (%)			χ^2	Differentiating subdomains[a]
	Low-risk (n=35)	Medium-risk (n=60)	High-risk (n=100)		
RRBI[b]	15 (42.9)[c]	37 (61.7)[c]	95 (95.0)[d]	46.78[d]	1.3 Sensory issues 1.3.1 Over-responsivity 1.3.1.3 Tactile sensitivity 1.2 Stereotyped or repetitive use of objects 1.4 Unusual and narrow interests 1.1.13 Stimming 1.5.1. Idiosyncratic language
Social	3 (8.6)[c]	18 (30.0)[c]	73 (73.0)[d]	54.61[d]	2.1 Difficulties in making friends, 2.1.3 Social play
Communication	9 (25.7)[c]	15 (25.0)[c]	58 (58.0)[d]	21.43[d]	
Language	8 (22.9)[c]	40 (66.7)[d]	72 (72.0)[d]	27.42[d]	
Emotional	14 (40.0)	29 (48.3	55 (55.0	2.46	
Cognitive[a]	3 (8.6)	13 (21.7)	36 (36.0)	11.08	
Medical conditions	5 (14.3)	11 (18.3)	15 (15.0)	0.40	
Motor[e]	1 (2.9)	6 (10.0)	17 (17.0)	5.23	
ADL[f]	2 (5.7)	7 (11.7)	14 (14.0)	1.71	
ADHD[g]	2 (5.7)	11 (18.3)	24 (24.0)	5.66	
Sleeping[e]	2 (5.7)	2 (3.3)	9 (9.0)	2.00	
Eating	3 (8.6)	3 (5.0)	11 (11.0)	1.70	

[a]$P \leq .001$.

[b]RRBI: repetitive and restricted behaviors and interests.

[c,d]Risk groups with different subscripts differed significantly in Fisher's exact pairwise comparisons. For the significantly different domains, the signs differentiating risk groups were determined using chi-square tests with $P<.001$. Note that all hierarchies of signs with 5% occurrence and above were analyzed.

[e]Warning signs pertaining to these domains were observed in less than 5% of the queries.

[f]ADL: activities of daily living.

[g]ADHD: attention deficit hyperactivity disorder.

Looking at the association between the child's age and level of risk indicated that the percentage of queries from each risk group did not differ between the 4 age groups (χ^2_6 =11.39, P=.08). There was a significant difference in the frequency of parents reporting language-related signs (see Figure 2 for pairwise comparison results between age groups using Fisher's exact tests). Very few parents reported language signs in the oldest age group versus the other groups (16.7% [3/18] relative to 59.7% [37/62] to 75.0% [39/52] in the other age groups, χ^2_3=20.87, P<.001). Note that no significant difference was found in terms of the percentage of queries pertaining to boys versus girls in each risk group (eg, high-risk was 50% [80/160] and 58.6% [17/29], respectively, χ^2_2=6.17, P=.04).

Next, we tested the efficacy of an automated, text-based ASD-risk estimator. When distinguishing high-risk queries from low- and medium-risk queries, the Area under the ROC curve (AUC) was found to be 0.67 (0.50-0.78). The AUC for this task using coded signs was 0.82 (0.80-0.86; see Figure 3). The latter result is significantly better than that obtained using the text alone (P=.002). Using both textual descriptions and coded signs reduced the AUC compared with using coded signs alone, probably because of the high dimensionality of the data, relative to the number of queries. Distinguishing low-risk from medium- and high-risk queries, the AUC using text was 0.54 and using signs was 0.84. Thus, text was a poor predictor for this task, compared with both signs and to the low- and medium-risk versus high-risk text classification.

Finally, we created a regression model to predict the actual risk score from the text and (separately) from signs. The Spearman correlation using text was .29 (P<.001), whereas the same using signs was .61 (P<.001). Thus, the actual risk score can also be deduced with higher accuracy from signs than from the text.

Figure 4 represents the decision-tree classifier for distinguishing low- and medium-risk from high-risk queries. Each node shows

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the coding variable used for decision and the fraction of high-risk queries at the node. The numbers at the end of the branch indicate the likelihood of high-risk for that branch. Social, RRBI, communication, cognitive, and motor concern domains entered the final model. Children who were mentioned to have a social problem had a 78% (73/94) chance of being at high-risk, compared with a 27% (27/101) chance in the rest of the sample. If the parent also reported an RRBI and motor delay, they had a 100% (13/13) chance of being in the high-risk group.

Figure 2. Percentage of sign domains mentioned in queries by age groups. RRBI: repetitive and restricted behaviors and interests; ADHD: attention deficit hyperactivity disorder; ADL: activities of daily living.

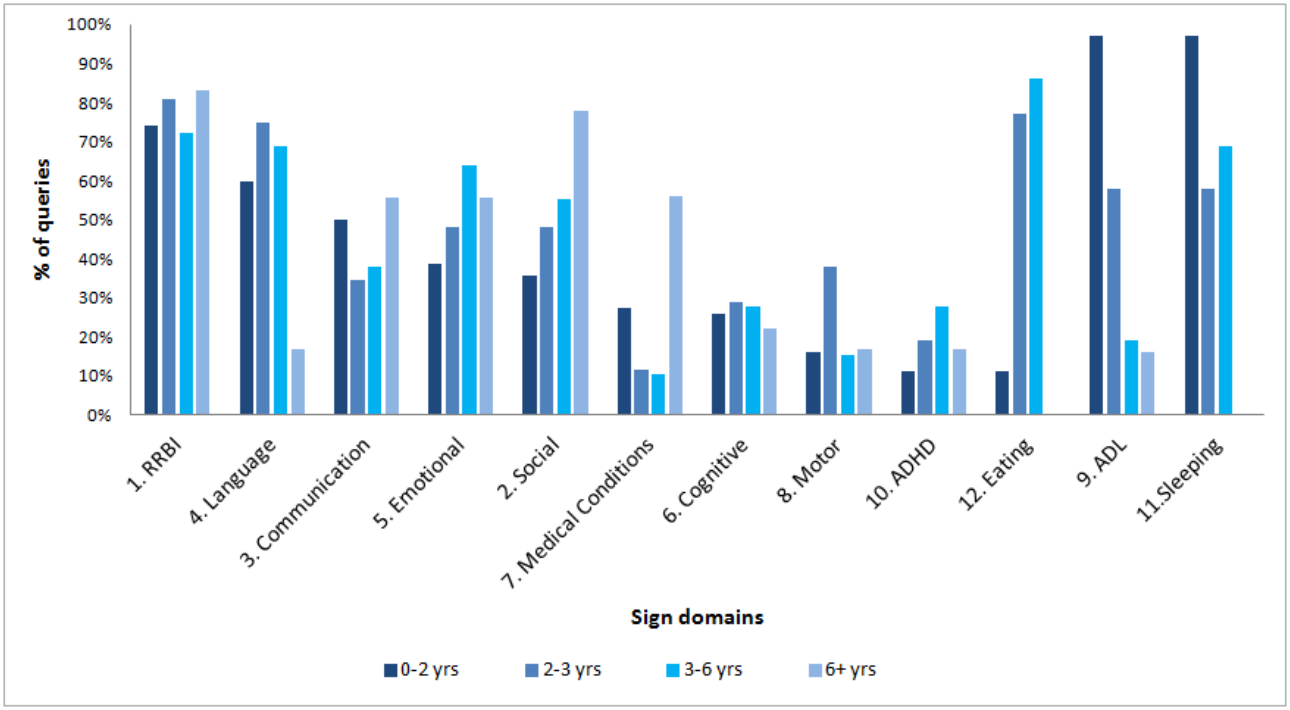
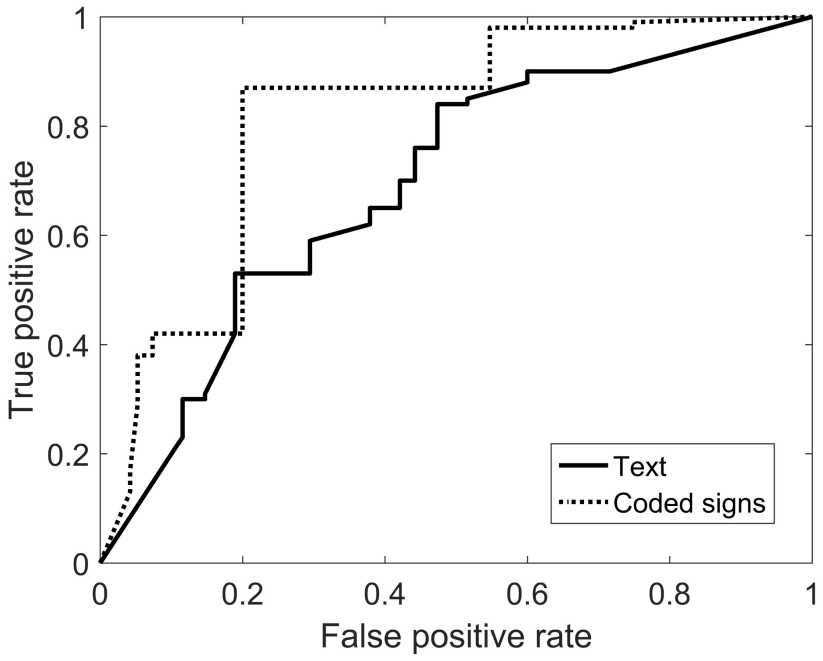
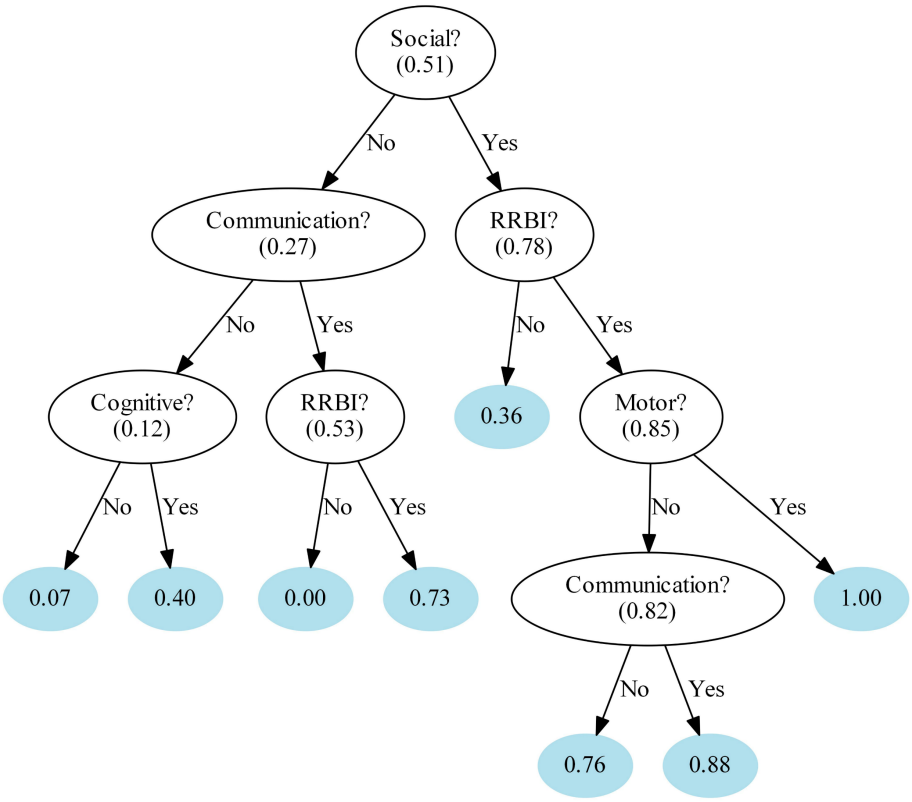


Figure 3. Receiver operating curve (ROC) plots predicting risk from text versus coded signs.



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Figure 4. Decision tree classifier for distinguishing low-risk queries from medium- and high-risk queries. RRBI: repetitive and restricted behaviors and interests.



Discussion

Principal Findings

Our study examined the nature of online queries of parents who were concerned that their child might have ASD. The Internet offers parents a venue for expressing and verifying their concerns anonymously at any time and place. The analysis of these narratives highlights signs that alert parents, in the general public, of the possibility of their children having ASD. These concerns mirror parental developmental knowledge, awareness, and expectations, as well as levels of parenting anxiety. Most of the Yahoo Answers queries were judged by clinical experts as reflecting high-risk for ASD or as medium-risk, validating parents' concerns. Differentiating ASD early in life is important, so that the child with ASD can gain the most from targeted interventions [37]. Parental concerns expressed online offer a new method for facilitating earlier screening and referral for evaluation. In the long run, an online tool which provides a gross estimate of ASD risk based on textual descriptions of warning signs and guided questions could prompt parents to approach a professional. Such a tool can harness social media to support worried parents and minimize the risk of acting on nonprofessional advice or disregarding worries.

Comparison With Prior Work

Our findings that parents with mostly no family history of ASD (95.4% [186/195]) associated a broad range of ASD-specific signs with the disorder were encouraging. The prevailing signs that parents found worrisome were within the DSM-V [12] ASD core domain of RRBI, followed by the social-communication domain. Nevertheless, more than a third of the parents sampled, expressed concerns related to domains of language, cognitive, and emotional, which according to the DSM-V are non-ASD–specific; however, they are highly prevalent in ASD. Other non-ASD–specific concerns mentioned in some of the queries related to motor development, ADL, and medical conditions. Interestingly, concerns related to motor problems entered as a meaningful domain in the decision-tree classifier. The mix of concerns from ASD and non-ASD–specific domains is consistent with previous studies documenting the types of first parental concerns of children later diagnosed with ASD [9,10,15].

The average child age at which an online concern was raised was 38.03 months, close to the average age of ASD diagnosis [38,39]. Nonetheless, this age is greater than the average age of the first concerns that was reported in ASD research, which is 10-18 months [5,9,19,21,24]. The majority of queries described sons, although analysis of queries did not reveal different types of signs for sons versus daughters, and the rate of ASD risk was not significantly higher for boys than for girls. Comparisons between age groups showed that language concerns differed in prevalence across age groups. Language problems were mentioned most frequently in queries regarding children 0-3-year-old and less in the oldest group. It is likely that parents of a nonverbal 7-year-old have reached the stage beyond suspicion and hence would be less likely to query this. Note that the peak of emotional concerns was in the 3-6 years old age group, particularly descriptions of outbursts or extreme shyness. Social concerns increased with highest prevalence in the older group. These differences between age groups can be explained in the light of the changes in developmental expectations of parents from children at different ages.

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At the extremes, there were parents who raised concerns too early to determine risk, for example:

> *My 8-week-old son has yet to flash his first true smile. I know that all babies develop differently, but i am worried about autism...*

At the other end of the spectrum, there were parents of older children who were either questioning a non-ASD diagnosis their child received or were never evaluated but always felt something was different, for example:

> *(regarding an 18-year-old child) we always knew he was different, he displays some—but not all—of the common symptoms, but we just put it down to him being different and an introvert...apart for the virtual world of computer games he is turning into a hermit...and has no social skills.*

When designing an online screening tool, the age of the child must be considered and, based on the findings, the need to continue monitoring such a child is warranted.

Although there were differences in rates of RRBI concerns across risk groups, they were mentioned in at least 75.4% [147/195] of the queries. The RRBI domain included the largest number of hierarchy levels of subdomain coding as well as individual signs (the subdomains are: repetitive movements, stereotypes and repetitive use of objects, sensory issues, unusual and narrow interests, repetitive speech, eating, difficulty with change, rigid thinking, and rituals). This reflects the diversity in types of symptoms described in the DSM-V criteria. The most prevalent RRBIs mentioned were repetitive movements, repetitive use of objects, and sensory abnormalities. The RRBIs characterizing queries of medium- or high-risk were repetitive speech, sensory issues (particularly tactile over-reactivity), unusual use of objects, repetitive speech (particularly idiosyncratic language), and repetitive interest. Interestingly, research shows that RRBIs are not the most prevalent first concerns of parents of children later diagnosed with ASD [18,22]. It may be the most reported domain in online queries, as parent's attention is more easily drawn to atypical behaviors or socially inappropriate behaviors, compared with their ability to recognize a delay in attaining a milestone. Signs within this domain can be intense and can interfere with play and participation, and thus are noticeable. The presence of some RRBIs in typical development (eg, head banging, noise sensitivity) presents a further challenge for relying on this domain to verify risk status. There is a need to increase parental awareness of the typical manifestations of RRBI during the first 3 years of life, to help parents understand when such concerns may be warranted. Online concerns reflect a parent's call for help regardless of whether a child has ASD. Therefore, there is clearly a need for interactive parenting education materials aimed at interpreting and coping with RRBIs.

Our results indicated that it is possible to predict risk from the text using machine learning methods once the text is classified into sign domains, whereas using text alone provided insufficient information (at least in our corpus) for accurate identification of children at risk. Developing an ASD-specific flowchart into which parents could insert their narratives related to certain types of concerns may provide a basis for a more accurate prediction of ASD risk from text. An automated screening tool in online forums will benefit from starting with a social concern question, and if not present then ask about communication while if present ask about the presence of RRBIs. While ASD specific questions will need to dominate such a tool, probing about cognitive and motor markers, which are not ASD-specific, is also important. Results from the decision tree indicate that the combination of signs from the social, RRBI, and motor domains predicted the highest likelihood of ASD risk from the coded text. This is in line with the evidence showing that parental concerns pertaining to a combination of several domains predicted an ASD diagnosis [3]. The prediction of high risk from text or text combined with coded signs was better for the high ASD risk group alone rather than predicting for both medium- and high-risk groups. Future research relying on a larger corpus could robustly test different combinations of concerns in predicting ASD risk. As parents seek first-level support online, developing Internet- and mobile-health tools to automate ASD screening relying on the decision-tree classification described in this study may reduce screening time, increase response to screening, and increase accuracy.

The distribution of the types of signs mentioned in online queries did not fully correspond to the signs most commonly reported in previous studies. For instance, in an ASD study, parental language and communication concerns were found to be the most prevalent early concerns, followed by social, RRBI, medical, and emotional domains [15]. Communication signs were highly prevalent among parental concerns noted in other studies as well; however, they did not consistently differentiate those later diagnosed with ASD [3,9,10,17,19,20,22]. These differences in the most common ASD concerns of parents may be explained by the fact that previous studies relied on retrospective reports and samples characterized by high genetic risk for ASD [3,15,19,22,25], as opposed to a sample with little familiarity with ASD symptomatology and a lower likelihood for the child to have ASD.

Limitations

The limitation of the current exploratory study is the lack of clinical testing for the actual ASD-risk status of the child as opposed to other neurodevelopmental disorders. The next step would be to study the external validity of risk status using standardized developmental measures, develop a structured format for parents to enter their concerns and, test our algorithm for predicting risk from text with a new corpus. Extracting signs from text has its own limitations, as in some cases it requires the clinical inference of meaning, as opposed to the ability to probe a parent and thus extract the meaning behind the concern. We attempted to minimize such bias by developing coding rules and testing coding reliability. The anonymous nature of online queries makes online parental concerns a unique resource that offers an authentic snapshot of parental ASD-related concerns, unaffected by issues of social desirability or other emotional biases.

Conclusions

Early parental concerns constitute a valuable component of early childhood screening. There is accumulating evidence that early parental concerns regarding specific ASD markers are

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associated with a higher likelihood of an eventual ASD diagnosis [3,15,40]. Our study is the first to investigate online queries describing the types of signs that lead parents to suspect ASD in their child. The fact that the clinical experts found that the majority of queries corresponded to either medium- or high-risk for ASD validated the need to facilitate the parents' earlier consultation with a professional. We showed the potential of utilizing machine learning methods for ASD screening based on parental concerns. Findings also highlight the need for designing parent-education tools regarding behaviors that are age appropriate, particularly those pertaining to the RRBI domain. Finally, it is important to empower parents' confidence in their concerns and increase their awareness of the disadvantages of relying solely on an online community for determining ASD-risk status. This study's findings support the call for health care providers to closely listen to parental ASD-related concerns, as recommended by screening guidelines [13]. Results also demonstrate the need for Internet-based screening systems that utilize parents' narratives combined with a hierarchical screening questioning. Worried parents approach online communities, comprised mostly lay person answerers, to obtain opinions regarding their child's likelihood of having an ASD diagnosis. A more efficient mechanism for supporting worried parents online is important for prompting a clinical evaluation when needed and reducing parental anxiety.

Acknowledgments

This study was funded by a Caesarea Rothschild Institute grant. ABS was funded by a Y Alon Fellowship. We thank Yael Schwartz-Klein and Neta Katz for their assistance with text analysis in this study and Danielle Wolinski for her assistance with manuscript preparation.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Taxonomy domains and sub-domains of warning signs coded from Yahoo queries.

[PDF File (Adobe PDF File), 43KB - jmir_v18i11e300_app1.pdf]

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Abbreviations

ADHD: attention deficit hyperactivity disorder
ADL: activities of daily living
ASD: autism spectrum disorders
AUC: area under the curve
DSM-V: Diagnostic and Statistical Manual of Mental Disorders
M-CHAT-R/F: Modified Checklist for Autism in Toddlers-Revised with Follow-Up
MTV: music television
ROC: receiver operating curve
RRBI: repetitive and restricted behaviors and interests

Edited by G Eysenbach; submitted 16.12.15; peer-reviewed by D Cohen, D Lee, A Venkatakrishnan; comments to author 03.04.16; revised version received 29.06.16; accepted 22.09.16; published 22.11.16.

Please cite as:
Ben-Sasson A, Yom-Tov E
Online Concerns of Parents Suspecting Autism Spectrum Disorder in Their Child: Content Analysis of Signs and Automated Prediction of Risk
J Med Internet Res 2016;18(11):e300
URL: http://www.jmir.org/2016/11/e300/
doi:10.2196/jmir.5439
PMID:27876688

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Original Paper

Using Interactive Patient Engagement Technology in Clinical Practice: A Qualitative Assessment of Nurses' Perceptions

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Abstract

Background: Research has shown patients who are more engaged in their care are likely to have better health outcomes and reduced health care costs. Health care organizations are now focusing their efforts in finding ways to improve patient engagement. At the forefront of this movement are patient engagement technology systems. In this paper, these emerging systems are described as interactive patient engagement technologies (iPET).

Objective: The objective of this descriptive study was to gain an understanding of the perceptions of nurses who are integrating these iPET systems into their daily clinical practice.

Methods: The research team interviewed 38 nurses from 2 California-based hospitals using a focused rapid ethnographic evaluation methodology to gather data.

Results: The study participants reported that using iPET systems may enhance clinical nursing practice. The 4 key findings of iPET were that it (1) is effective for distraction therapy, (2) has functionality that affects both patients and nurses, (3) has implications for clinical practice, and (4) may require additional training to improve usage.

Conclusions: With sufficient training on the iPET system, nurses believed they could use these technologies as an enhancement to their clinical practice. Additionally, nurses perceived these systems served as distraction therapy for patients. Initial findings suggest that iPET is beneficial, but more research is required to examine the usefulness of iPET systems in the inpatient settings.

(J Med Internet Res 2016;18(11):e298) doi:10.2196/jmir.5667

KEYWORDS

patient engagement; health information technology; educational technology; patient education; patient experience; primary care nursing; qualitative research

Introduction

It has been over a decade since the Institute of Medicine (IOM) first recommended that patients should have an active role in their health care [1]. Additionally, the IOM highly endorses the integration of information technology in this endeavor [1]. Health information technology (HIT) systems have long been touted as the newest intervention aimed at increasing patient engagement with the end result of improving patient outcomes [2]. Nurses have a unique role in that they are at the juncture of new technologies and patient care in the acute care setting. Historically, nurses have intersected with patients with technologies such as electronic health records (EHRs), intravenous pumps, specialty beds, monitoring and safety

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equipment, and even items as simple as call lights and television. Therefore, nurses play an integral role in identifying ways to improve patient engagement and optimize the potential benefits of new HIT systems. Initial studies about patient-centered HIT systems in the outpatient setting have shown that they have the potential to engage patients, to facilitate communication with their providers, and to encourage participation in their own care [3].

The definition of patient engagement has varied over the years. The Institute for Healthcare Improvement defined it as the "actions that people take for their health and to benefit from care" [4]. A research team in Australia also defined patient engagement as "a co-constructed process and state" [5]. They further describe patient engagement as a process of gradually connecting with each other and/or a therapeutic program, which enables the individual to become an active, committed, and invested collaborator in health care [5]. Furthermore, the Affordable Care Act identified patient engagement as a key piece in health care reform [6].

Patient engagement has been quoted as the new "blockbuster drug" aimed at improving 3 key things—patient experience, patient satisfaction, and patient outcomes—all while improving health care costs [4]. A recent study found that patients who scored low on the Patient Activation Measure (a scale designed to measure one's knowledge, skills, and confidence in managing their own health needs), were more likely to have greater health care costs compared to those patients with higher activation scores [6]. Moreover, a systematic review found that using information technology (IT) platforms to increase patient engagement could result in positive outcomes [7].

Health care organizations across the United States have enhanced their HIT systems in an effort to engage the patient [8]. Despite the supposed improvement in patient outcomes with these patient engagement technology systems, most systems are not reaching their full potential. A major barrier to IT adoption is user acceptance [9]; the technology acceptance model (TAM) states that user acceptance is highly influenced by the perceived usefulness of the system [10]. Moreover, a study conducted that looked at call-light technology found that once nurses were shown a full demonstration of the technology, nurses were more willing to use these systems to improve their workflow and, ultimately, the technology had a positive impact on patient outcomes [11].

The goal of the iPET systems is to increase patient engagement through technology. A common example is the patient portal, which allows patients to message their physician, make appointments online, or request medication refills. Although limited, early studies have shown the benefits of patient engagement systems in the inpatient setting; a systematic review indicates that these systems can deliver generic and specific patient education, enhance communication between physicians and patients, provide entertainment, and empower patient decision making [2].

This study examined nurses' perception of patient engagement technology systems on their clinical practice in the acute care setting. Our team wanted to identify barriers and promoting factors that affect utilization and usage of patient engagement technology by nurses. We refined the term "patient engagement technology systems" and are introducing a new concept called *interactive patient engagement technology* (iPET). We defined iPET as any electronic system that delivers a bundle of health self-management, communication, education, and distraction services on demand. The iPET systems are used by patients and their families in the inpatient or outpatient setting and are designed to enhance or promote patient engagement in one's own health care (see Figures 1 and 2). iPET systems may increase patient engagement by providing some or all of the following components: a portal for patient-provider communication, access to the portions of the EHR, patient education on disease processes, diagnostics, and medications (see Figure 3). Additionally iPET systems have the ability to function as distraction therapy by offering spiritual care content, music, movies, white noise, and relaxation techniques (see Figure 4). The interactive component occurs between the nurse, the patient, and the patient's family and is crucial to the successful adoption of the iPET technology. The delivery of the iPET systems in this study was through iPads in the emergency department (ED) and, in the inpatient setting, where patients had access to the system through the patient's television in the room. The iPad and television systems in this study contain a variety of entertainment options, spiritual care modules, and patient education materials.

The aim of this study was to examine nurses' perceptions of patient engagement technology systems during their clinical practice in the acute care setting.

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Figure 1. Example of an *interactive patient engagement technology* (iPET) patient menu. Reprinted with permission from SONIFI Health, Inc, Sioux Falls, SD, USA.



Figure 2. Examples of a variety *interactive patient engagement technology* (iPET) user interface devices. Reprinted with permission from SONIFI Health, Inc, Sioux Falls, SD, USA.



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Figure 3. A selection of example *interactive patient engagement technology* (iPET) self-management tools. Reprinted with permission from SONIFI Health, Inc, Sioux Falls, SD, USA.

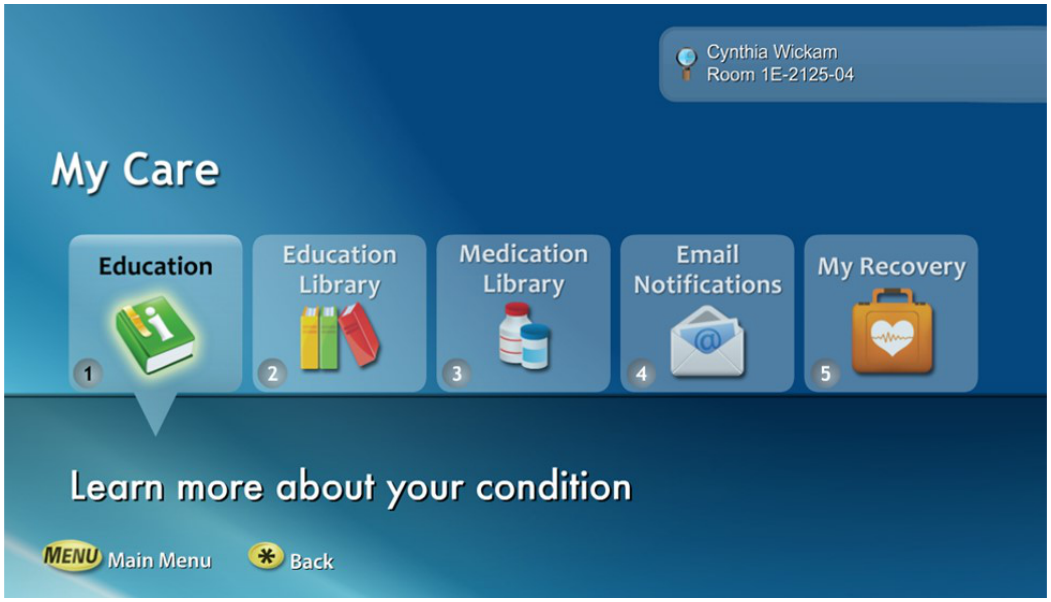


Figure 4. A selection of example distraction therapy options. Reprinted with permission from SONIFI Health, Inc, Sioux Falls, SD, USA.



Methods

Due to the emerging nature of using iPET in the clinical setting and the paucity of supporting evidence in previous literature, an ethnographic qualitative approach was chosen for the initial inquiry [12]. Because of clinical responsibilities and business requirements in the patient care units, access to research participants was limited. The nurses reported they did not have time to participate in interviews and found it difficult to participate in research during the work shift. Furthermore, keeping nurses after the end of the work shift or bringing them in on an off day was not an option due to the financial and collective bargaining contract constraints. Because of these methodological challenges, the research team looked to use a nontraditional, qualitative nursing methodology: focused or rapid ethnography. Moreover, our research team has labeled our unique method as focused rapid ethnographic evaluation (FREE). The FREE method shares many common features of traditional rapid or focused ethnography as described in the literature [13-17], with the exception of our team's extensive use of field notes in lieu of digital recordings. FREE is especially appropriate for situations where human-computer interactions occur, and where organizations are appraising emerging technologies in the work setting [14,17,18].

Participants

The authors conducted the study at 2 community hospitals in California. The researchers recruited 38 participants from both hospitals. Purposive sampling was used to include registered nurses who use the iPET as part of their daily practice [19]. To allow for a variation in perspectives on interactive technology and identify key informants, the researchers interviewed nurses who were currently practicing as well as those that fulfilled leadership roles. In an urban hospital in Southern California, the research team interviewed nurses in 2 different departments.

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In the ED, the researchers interviewed 10 participants with a range of experience from 2 to 40 years: 8 females and 2 males. Additionally, the research team observed 10 participants in the medical-surgical department, with a range of experience from 2 to 25 years: 8 females and 2 males. In an urban hospital in Northern California, the researchers interviewed 2 departments: ED and the family birth center. In the ED, researchers interviewed 10 participants with a range of experience of 5 to 25 years: 7 females and 3 males. Furthermore, in the family birth center, the researchers interviewed 8 female participants with a range of experience between 15 and 30 years.

Procedure

The research team conducted an initial review of the associated literature and applicable theories. Research that used TAM in the health care setting has consistently shown that clinicians' perception on the ease of practice and the usefulness of health information technologies determines future intentions and adoption of these systems [10,20]. Influenced by the current literature and the TAM resources, our research team developed a strategy for the project.

As recommended in the literature, prior to starting the participant interviews and observations, key individuals familiar with the newly implemented iPET system were contacted and interviewed by phone and in person [18,21]. These individuals advised the research team to the appropriate departments and suggested a strategy to observe and interview participants in a time and location for optimal data gathering. Based on the initial discussions, the research team developed a semistructured interview guide, a systematic approach to record field notes, identified areas for observation, and scheduled interviews. The final preparation was on the day before beginning the study; members of the research team toured the facility and units to become familiar with the layout and to meet managers, team leaders, and some of the potential participants.

Observations began during the first visit to the departments and continued to the final day of the project. During the course of the study, at least 2 research team members were present for all interviews. Additionally, researcher observations that occurred during the interview process—impressions of the setting, body language, appearance of the participant, use of the iPET system, and other findings—were documented as field notes [22]. The researchers observed the nursing workflow in the individual departments, in patient care areas, nursing stations, hallways, supply and utility rooms, and break rooms. Initially, there was an attempt to have nurses "drop by" the break room for formal and private interviews. However, due to the work-related requirements of the units and patient needs, the nurses spent most of the day in the clinical areas. Some interviews occurred in the quiet break room; however, most occurred at the nurses' stations located in the hall, near the medication cart, in empty patient rooms, in offices, and other locations where the nurse and interviewers could talk.

Interviews lasted anywhere from 10 minutes to 1 hour. A nurse had to cut one of the interviews short due to a "code-blue" emergency in their department. During all interviews and observations, both the researchers took extensive hand- written field notes in journals. When time allowed or at the end of each interview, the research team compared notes and made any necessary adjustments to the semistructured interview question prompts. The researchers entered empty patient rooms, observed demonstrations of the technologies by the nursing staff, and explored the iPET systems. Finally, the data collection process stopped when "saturation" was obtained or no new data or findings were noted or observed [23].

Data analysis began during the first observations and continued throughout the study. At the end of each day, the researchers compared field notes and began discussing emerging findings and areas that needed further exploration and initial thoughts on themes. Three members of the research team met to organize all data and field notes after data collection was complete and the researchers reached data saturation. The authors combined both observed and interview data, then looked for patterns in the data, and began initial coding. The research team developed a codebook to identify and define broad categories from the data, additionally creating subcategories as they emerged. The authors frequently compared their reasoning for coding specific data in a specific manner and worked as a team to come to consensus. Subsequently, the researchers uploaded the data to MAXQDA version 11 (VERBI GmbH software, Berlin, Germany) qualitative analysis software where the statements were organized and systematically indexed to facilitate categorization. When the analysis was nearly complete, a central theme was identified; the individual codes were defined, resorted, categorized, recategorized; and 4 major findings were established [24]. The 4 findings with subfindings were identified and a presentation was developed to discuss the authors' overall impression. When analysis was complete, the presentation was formally shared with key participants (unit managers and nursing team leads), and the findings were verified and confirmed as accurate in a process known as *member checking* [25] .

The researchers consulted the Institution Review Board at Dignity Health, Sacramento, CA, for approval prior to beginning this study. The researchers provided an explanation of the purpose of the study and the research methods to the nurses before the start of the interviews. Additionally, the researchers informed each participant that observations and data collected was strictly confidential, and that the authors would not identify any individual participant throughout the study. Each participant gave verbal consent, and the researchers told the nurses they could end the interview and withdraw any data contributed to the study, at any time in the process.

Throughout the entire research process, the research team practiced *reflexivity*, which is the process of identifying one's beliefs and biases related to the research [15]. Since the researcher is the data-gathering instrument in the FREE methodology, our team first shared any preconceptions with one another, questioned each other when unsure about any aspect of the process, and were transparent with each other through the entire data gathering and analysis process to assure as much rigor in the research as possible.

Results

Overall, the study participants perceived that the use of iPET systems had great potential to enhance their clinical practice.

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Through data analysis, the 4 key findings or themes identified were (1) effective for distraction therapy, (2) functionality affects both patients and nurses, (3) there are implications for clinical practice, and (4) training may improve usage.

iPET Is Effective for Distraction Therapy

One of the most powerful uses of iPET was for distraction. The authors categorized distraction into 2 areas: active and passive. Active distraction promotes the involvement of the patient during a procedure, such as games that require participation. In contrast, passive distraction therapy is much less involved, such as listening to music and/or watching television [26]. The researchers found that iPET, along with the associated entertainment, were quite helpful for distraction, especially with patients who were waiting or holding for long periods in the ED. Several of the nurses stated how helpful iPET was for distraction in the ED. One nurse mentioned, "The only problem is when it is time to move the patient to another department; they want to take the iPad with them." Another ED nurse said, "My patients seem happier and, frankly, I am answering fewer call lights since using the system." Similarly, several of the nurses revealed that patients seemed to be on their call lights less while waiting in the ED. "The system is very useful for my hold patients in the ED," said one nurse whose comments were reflected in several other nurses' responses. Conversely, the tablet computers did not have access to live televisions, which was one problem noted by several nurses in the ED: "Our patients wanted to watch the football game."

The iPET was especially useful for distraction for children and patients with various psychiatric conditions: "We have had more than one person with mental health issues where the iPads were very helpful in keeping them calm while waiting in the ED." Nurses also said that the iPET system was helpful as a distraction for some visitors who were waiting with patients in the rooms. In the medical-surgical units, nurses stated that turning on the entertainment or "white noise" portions of the iPET system helped "bedridden patients pass the time." Furthermore, whether patients used music, white noise, or movies, one of the most useful reasons for implementing the iPET system was for patient distraction and entertainment.

iPET Functionality Affects Patients and Nurses

Because of the uniqueness of the iPET implementation, functionality of the system appeared to be a common finding among the nurses interviewed. Specifically, the security of the iPad tablet computers used for iPET in the ED was one common finding. Nurses worried about patients "stealing" the iPads; indeed, 2 disappeared early in the implementation. These thefts prompted a change in policy toward the implementation of locking support arms for the iPads in the ED. The locking arms did seem to thwart the concerns over theft, but some ED nurses worried that the patients could use the arms "as weapons" by dismantling them. Additionally, nurses were concerned that the iPad thefts would fall under their liability. For example, one nurse stated, "If I sign out the iPad to a patient and then my shift ends, I won't be present to sign it back in." Several nurses reported iPad theft concerns, and the agencies involved in the research were actively working to alleviate those fears and develop a sound policy to assure future success.

The authors identified a variety of technical and implementation issues. One significant issue identified was that the implementations of the systems were dissimilar at the different hospitals. Some departments had a full complement of movies and music offered, whereas others only had select options. At an urban facility in Southern California, one nurse stated, "Many of the patients in our emergency department are from the rap culture, and there is no rap music on this system for them to listen to." In addition, others reported a limited offering of children's videos. Overall, nurses recommend customizable entertainment offerings to reflect the local patient population.

Due to the lack of fully implemented and integrated iPET systems, the nurses had several questions about its full functionality, including educational offerings. Ideally, a patient would receive educational materials, that their clinician ordered, on the iPET system, and once the patient viewed the material, the iPET system would update the patient's EHR. In the units where this functionality was fully implemented, the nurses were very impressed with the how the system could be used for patient education. One experienced labor and delivery nurse stated, "I just order the package of patient education videos, then the patient and family view the videos, and then my job is to facilitate the patient education using a teach-back methodology." Other nurses mentioned, "I never could cover all the material delivered in the [patient-specific] educational videos; the system is so helpful." During the course of the interviews, several of the nurses revealed specific videos they would like to see added to the implemented iPET system. For example, more than one medical-surgical nurse stated that videos discussing peripherally inserted percutaneous intravenous for patients transferring home would be helpful. Furthermore, the research team and unit managers will submit suggested education video requests to the vendor.

iPET Has Implications for Clinical Practice

According to the nurses interviewed, their patients really liked and appreciated the iPET system. The nurses reported that the systems were intuitive for patients to use and they were easily able to help patients who needed instruction using the technology. Nurses used the iPET system to help calm and distract agitated psychiatric patients, patients who were autistic, confused and lonely children, and older adults. Again, the nurses found the systems useful for patients who were "holding" and waiting for long periods or needed distraction for a variety of reasons. One ED nurse stated, "The system helps me calm psychiatric patients," and several others claim purposely using the system in the same manner. Many of the nurses, specifically on the medical-surgical unit, stated that patients seemed to appreciate the "white noise" feature of the system to help the patient rest and to drown out some of the unit noise.

Although most nurses reported they used the iPET system for distraction, several nurses emphasized that the patient education videos about diseases and medication would help with patient teaching. One particular nurse stated that she incorporated an introduction of the system as part of her initial patient assessment; during this assessment, she encouraged her patients to review medications and disease information specific to them as a starting ground for patient teaching. This nurse reported

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that after watching the videos, the communication was enhanced because patients had preliminary baseline teaching, which allowed for more interactive communication.

In addition to the education materials mentioned earlier, nurses can use the system to support patient's spiritual needs. Most major religions have content in the system, including religious texts, teachings, songs or hymns, and mindfulness techniques. Nurses reported encouraging patients to use the spiritual care aspects of the system when desired. Because the iPET system implementation was so new, nurses expressed the desire to have more time to explore and use the system with patients. Overall, many nurses reported that the iPET system "made their job easier."

iPET Training May Improve Usage

Because the iPET system is so closely related to familiar tablet computer (iPad) and television technologies, those implementing the system, and the nurses themselves, tended to overlook training needs. Furthermore, the iPET system implementation was so new, nurses wished they had more time to explore and use the system with patients. Nurses across all units felt they missed important training or that training was not long enough. Due to training scheduled during work hours, many said it was difficult to make time in the day to attend the training sessions. Several of the nurses interviewed reported they did not know the full capabilities of the system. Moreover, nurses reported they rarely trained their patients about the features of the system. In addition to training on the use of the iPads, the television-based units included a device that was also a call light and bed control system. Nurses trained the patients on the use of call lights and bed controls for safety. However, nurses did not consistently train patients on the navigation to the various components of the iPET system. The nurses stated the reason navigation training was overlooked was due to the lack of training themselves or a poor understanding of the system. Most nurses learned how to navigate the system from tips shared from their peers on the unit. Based on the recommendations discovered during the interviews with the nurse managers and nursing team leads, the hospitals will develop a more formal training program for the iPET system.

Discussion

Overall, the nurses perceived that iPET system could enhance patient engagement and positively affect their clinical practice. Hospitals can use iPET for distraction and anxiety reduction, patient education, and augmenting/enhancing several aspects of clinical nursing practice [27].

Enhanced Training

Advances in health care technology are common. New technologies are usually outdated by the time implementation has occurred. Nurses must learn how to incorporate new technologies into their clinical practice to optimize patient engagement [28]. Comprehensive in-service training might be considered by some as cost prohibitive, but without the proper preparation the nurses would not be exposed to the full capabilities of the iPET system.

On a larger scale, organizations considering implementing an iPET system must show full support in all aspects of implementation and postimplementation. These systems should not be seen as optional tools, but rather just as integral to their practice as the stethoscope. Hospitals must provide sufficient training for nurses on the new system. Time should be built in to allow the nurses to explore all functionalities of the system, including viewing and critiquing any patient education videos that will be available. Moreover, training should be specific to how nurses can use the technology to enhance their practice. Training should include how nurses can use this technology to interact with their patients; iPET distraction features such as music or white noise were shown in our study to calm patients down who were anxious or agitated. This interaction between the nurse and the patient in using the iPET system is imperative especially for use in patient education. Patient discharge education should be introduced at the beginning of their stay and nurses could assess the level of comprehension of education throughout their stay, allowing for opportunities to address issues and identify appropriate resources.

iPET training should be included with every new nurse orientation so that nurses are aware that this is part of their toolkit to use with patients. Nurses are at the forefront of every quality improvement measure and have been tasked with introducing these systems to their patients. If nurses are not well trained in utilizing these systems, or unaware of the benefits that they bring to their patients, there is the possibility that the system will never be used to its full potential.

Enhancing Nursing Clinical Practice

These systems have the potential to be used as an enhancement to clinical practice. Ongoing communication during the first couple of months postimplementation, including tips to share with their colleagues and training on the new system, is essential in ensuring that nurses are utilizing iPET to its full capacity. Nurses need to be able to share the ways they are using iPET with their patients. For example, several nurses in the study reported using features such as movies and or music as distraction with their anxious patients, which led to a decrease in amount of call lights and requested pain medication. Additionally the quality of patient education could be improved. If patients and their families could view information on certain diseases, new medication, or discharge instructions first through iPET, then the dialog that occurs between physicians and nurses after may be enhanced and would allow more for a collaborative discussion.

Increasing Patient Engagement

The adoption, use, and development of a strategy for the patients to remain engaged when their care is transitioned to the community are essential. For example, a patient may be more apt to use a personal health record/patient portal at home if they can become comfortable with these systems in the acute care setting. iPET systems could allow patients to choose appropriate nutritional options for their meals, allowing them to feel empowered to make their own decisions. These iPET systems could inform patients about their anticipated treatment plan, including new medications and diagnostic tests, while in the hospital. Patients report that they are unsure about their

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treatment plan [29]; the use of the iPET system could function in the same way by providing them a roadmap of what to expect while in the hospital.

Limitations

We recognize several limitations of this research. First, the implementation of all the features of both the television- and tablet-based systems differed across the institutions and units. In some units, not all modules were included in the implementation, and that may have influenced the perceptions of some of the nurses. Our study also looked at both the television- and tablet-based systems; again, they are very different ways to deliver the technology. Televisions in patient's room are common and expected. The tablet computers were novel technology, and the nursing staff was still getting used to the methods to administer and monitor their use. An additional limitation is that we studied nursing perception of these systems only. We suggest future studies to include patient and caregiver perception of the effectiveness of these systems. Lastly, as mentioned earlier in this paper, there were methodological challenges across the study. Our team worked diligently to mitigate these challenges and deliver the highest-quality data and analysis that was possible.

Conclusion

The iPET systems described in this study are just one form of the technology used to engage the acute care or inpatient health consumer. Further research will be necessary to determine the best use of these systems in the inpatient setting, especially from a patient perspective, because most of the research has been conducted in the outpatient setting [2]. At the time of this manuscript, separate research into tablet-delivered patient portals in the inpatient setting is in process and should add to this scant body of current knowledge [30]. Tablet, television-based, and other iPET systems have potential to engage patients and family members when properly implemented and incorporated into nurses' clinical practice [27].

Acknowledgments

The Research and Analytics team at Dignity Health supported this research project. Our team would like to acknowledge the kind support and participation from the nursing staff and leaders at the institutions involved in the study. The authors thank Carmen Sendis, Page West, Elise Dempsey, and Tim Melden for their assistance and guidance with this project.

Authors' Contributions

FLP was Principal Investigator for the study and PMG was co-Principal Investigator. FLP, PMG, TLR, and NLR were responsible for the conception, design, interpretation of data, revising manuscript for intellectual content, and final approval of published version. FLP, PMG, and TLR were responsible for acquisition of data; FLP, PMG, and TLR performed data analysis; FLP, PMG, and TLR drafted the paper. FLP and PMG are the guarantors of this work and, as such, had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Conflicts of Interest

None declared.

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Abbreviations

ED: emergency department
FREE: focused rapid ethnographic evaluation
HIT: health information technology
IOM: Institute of Medicine
iPET: interactive patient engagement technologies
IT: information technology
TAM: technology acceptance model

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Edited by G Eysenbach; submitted 18.02.16; peer-reviewed by K Colorafi, D Greenwood, J Jones; comments to author 16.06.16; revised version received 01.07.16; accepted 30.10.16; published 11.11.16.

Please cite as:
Patmon FL, Gee PM, Rylee TL, Readdy NL
Using Interactive Patient Engagement Technology in Clinical Practice: A Qualitative Assessment of Nurses' Perceptions
J Med Internet Res 2016;18(11):e298
URL: http://www.jmir.org/2016/11/e298/
doi:10.2196/jmir.5667
PMID:27836817

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Review

Telemedicine Technologies for Diabetes in Pregnancy: A Systematic Review and Meta-Analysis

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Abstract

Background: Diabetes in pregnancy is a global problem. Technological innovations present exciting opportunities for novel approaches to improve clinical care delivery for gestational and other forms of diabetes in pregnancy.

Objective: To perform an updated and comprehensive systematic review and meta-analysis of the literature to determine whether telemedicine solutions offer any advantages compared with the standard care for women with diabetes in pregnancy.

Methods: The review was developed using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework. Randomized controlled trials (RCT) in women with diabetes in pregnancy that compared telemedicine blood glucose monitoring with the standard care were identified. Searches were performed in SCOPUS and PubMed, limited to English language publications between January 2000 and January 2016. Trials that met the eligibility criteria were scored for risk of bias using the Cochrane Collaborations Risk of Bias Tool. A meta-analysis was performed using Review Manager software version 5.3 (Nordic Cochrane Centre, Cochrane Collaboration).

Results: A total of 7 trials were identified. Meta-analysis demonstrated a modest but statistically significant improvement in HbA1c associated with the use of a telemedicine technology. The mean HbA1c of women using telemedicine was 5.33% (SD 0.70) compared with 5.45% (SD 0.58) in the standard care group, representing a mean difference of −0.12% (95% CI −0.23% to −0.02%). When this comparison was limited to women with gestational diabetes mellitus (GDM) only, the mean HbA1c of women using telemedicine was 5.22% (SD 0.70) compared with 5.37% (SD 0.61) in the standard care group, mean difference −0.14% (95% CI −0.25% to −0.04%). There were no differences in other maternal and neonatal outcomes reported.

Conclusions: There is currently insufficient evidence that telemedicine technology is superior to standard care for women with diabetes in pregnancy; however, there was no evidence of harm. No trials were identified that assessed patient satisfaction or cost of care delivery, and it may be in these areas where these technologies may be found most valuable.

(J Med Internet Res 2016;18(11):e290) doi:10.2196/jmir.6556

KEYWORDS

pregnancy; diabetes mellitus; telemedicine; review; meta-analysis; pregnancy in diabetics

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Introduction

Diabetes in pregnancy is a global problem and innovative solutions are required to prevent adverse outcomes in the mother and the offspring [1]. The prevalence of gestational diabetes mellitus (GDM) has increased dramatically with the International Diabetes Federation estimating that 1 in 7 pregnant women had GDM in 2015 [2,3]. The aims of clinical management, whether for women with type 1, type 2, or GDM, are to normalize maternal blood glucose to reduce complications and improve maternal and pregnancy outcomes [4]. Current evidence supports regular self-blood glucose monitoring (SBGM) up to 7 times a day, dietary and lifestyle counselling, and, frequently, hypoglycemic medications with dose titration in response to glycemic control [1,5,6]. Adequacy of glycemic control is determined by reviewing SBGM results, traditionally recorded by the woman by hand in paper diaries. The frequent need for outpatient visits to review these results as pregnancy progresses places pressure on maternity and diabetic services and is an inconvenience for pregnant women and their families.

Technological innovations present exciting opportunities for novel approaches to improve clinical care delivery for women with diabetes in pregnancy. Telemedicine (also known as telehealth) is defined as the provision of health services at a distance using a range of technologies [7]. The World Health Organization recommends telemedicine systems should be introduced where there is demand from patients [8]. With 1 in 3 people on the planet predicted to own a mobile phone by the end of 2016 [9], there is great enthusiasm among both patients and health care professionals to harness digital technologies to improve human health. In line with this, the number and sophistication of apps developed specifically for women with diabetes in pregnancy has increased [10,11]. Digital technologies in this patient group have most commonly been used to record and transmit blood glucose readings to the clinical care team between outpatient visits. This can involve either synchronous (ie, real-time) or asynchronous interactions, facilitating 2-way communication between the clinical care team and the pregnant woman [12,13]. Examples of technologies to perform this task include mobile apps, short message service (SMS), automated telephone support systems, Web-based diaries and decision-support systems, and integrated systems combining multiple elements of digital communication technologies (eg, mobile apps supported by Web platforms) [10,14-21].

Despite this enthusiasm, the benefits of telemedicine in women with diabetes in pregnancy remain uncertain [22]. Before recommending routine use and scale-up, ideally, there should be some evidence of benefit, or, at least no evidence of harm, when compared with traditional models of care. In addition to clinical benefit, telemedicine may offer advantages over standard care through improved efficiency of health care delivery, better maternal satisfaction with care [23,24], and economic savings related to fewer clinical visits [25].

The field of telemedicine is rapidly changing. We aimed to perform an updated and comprehensive systematic review and meta-analysis of the literature to determine whether, in pregnant women with any form of diabetes, telemedicine solutions offer any advantages compared with standard care. Outcomes were considered with respect to (1) maternal glycemic control, (2) pregnancy complications, (3) maternal satisfaction, and (4) costs of care.

Methods

Study Design

A research protocol was developed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) framework [26].

Search Strategy

The search strategy was developed with the advice of a professional librarian, with searches performed in SCOPUS (Medline, EMBASE, and Compendex) and PubMed to identify all relevant publications published between January 2000 and January 2016. This date restriction was selected as it was thought any telemedicine systems reported prior to this time would not be comparable with contemporary technology.

Inclusion Criteria

For the purpose of this review, any pregnant woman with a diagnosis of GDM (according to any criteria) or with preexisting type 1 diabetes or type 2 diabetes was eligible for inclusion. For this paper, telemedicine was defined as any system to monitor blood glucose remotely utilizing either fixed-line phones, mobile phones, or Internet-based systems. Databases were searched using the keywords tele*, digital*, comput*, *phone*, mobile*, app*, remote*, PDA, web*, tech*, Internet*, automat*, video*, wireless, short messag*, SMS, ehealth and e-health combined with gestational diabetes, GDM, pregnan* diabetes, pregnan* DM, and pregnan* gly*. These terms were combined using Boolean operators. The full search strategy for the SCOPUS and PubMed database (Textbox 1) was complemented with another approach involving the review of reference lists of retrieved trials. We limited our search to RCT.

Exclusion Criteria

Trials were excluded if they were quasi- or non-randomized, conducted in women where pregnancy status was not clearly stated, or the comparator group was another digital technology (rather than standard care). For practical reasons, the search was limited to English language publications.

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Textbox 1. Search terms used to identify articles related to telemedicine or related technology used in gestational diabetes.

1. tele*
2. digital*
3. comput*
4. *phone*
5. mobile*
6. app
7. apps
8. remote*
9. PDA
10. web*
11. tech*
12. internet*
13. automat*
14. video*
15. wireless
16. short messag*
17. SMS
18. Ehealth
19. e-health
20. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
21. gestational diabetes
22. GDM
23. Pregnan* diabetes
24. Pregnan* DM
25. Pregnan* gly*
26. woman DM
27. 21 or 22 or 23 or 24 or 25 or 26
28. 20 and 27

Study Selection Process

One of the authors (W Ming) independently screened the titles and abstracts of identified citations for potential eligibility. Two authors (W Ming and J Hirst) independently examined the full-text articles of eligible papers and extracted information about the exposures and outcomes using a predefined data extraction table.

Outcomes

The primary outcome was maternal glycemic control. Owing to the challenges in quantifying glycemic control and lack of consensus in measuring and reporting this outcome in pregnancy, we chose to define glycemic control with respect to mean blood glucose during pregnancy monitoring (total, fasting, or 1-h or 2-h post-prandial blood, expressed in mmol/L), and final recorded HbA1c in pregnancy (reported as both % and mmol/mol).

Secondary outcomes included insulin usage (ie, the final dose of insulin in units), mode of delivery (vaginal delivery or cesarean section), and the proportion of cases of shoulder dystocia at birth. As poor glycemic control in pregnancy is associated with increased fetal size, we also compared differences in fetal size as defined by mean birth weight, rates of macrosomia (defined as birth weight >4000 g), and the proportion of babies that were large for gestational age (LGA; defined as birth weight for gestational age and gender >90th percentile using local references). Neonatal outcomes were also assessed including the need for any neonatal intensive care unit (NICU) admission, preterm birth <37 completed weeks, and neonatal hypoglycemia (defined as hypoglycemia requiring medical treatment; Multimedia Appendix 1).

Data Extraction and Quality Assessment

Information on trial design and data on the primary and secondary outcomes were extracted by 2 reviewers, independently, using a predesigned Excel spreadsheet. Each

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trial was scored for the risk of bias using the Cochrane Collaboration Risk of Bias Tool. A third reviewer was available if there was a difference in opinion in interpreting the risk of bias.

Data Synthesis and Analysis

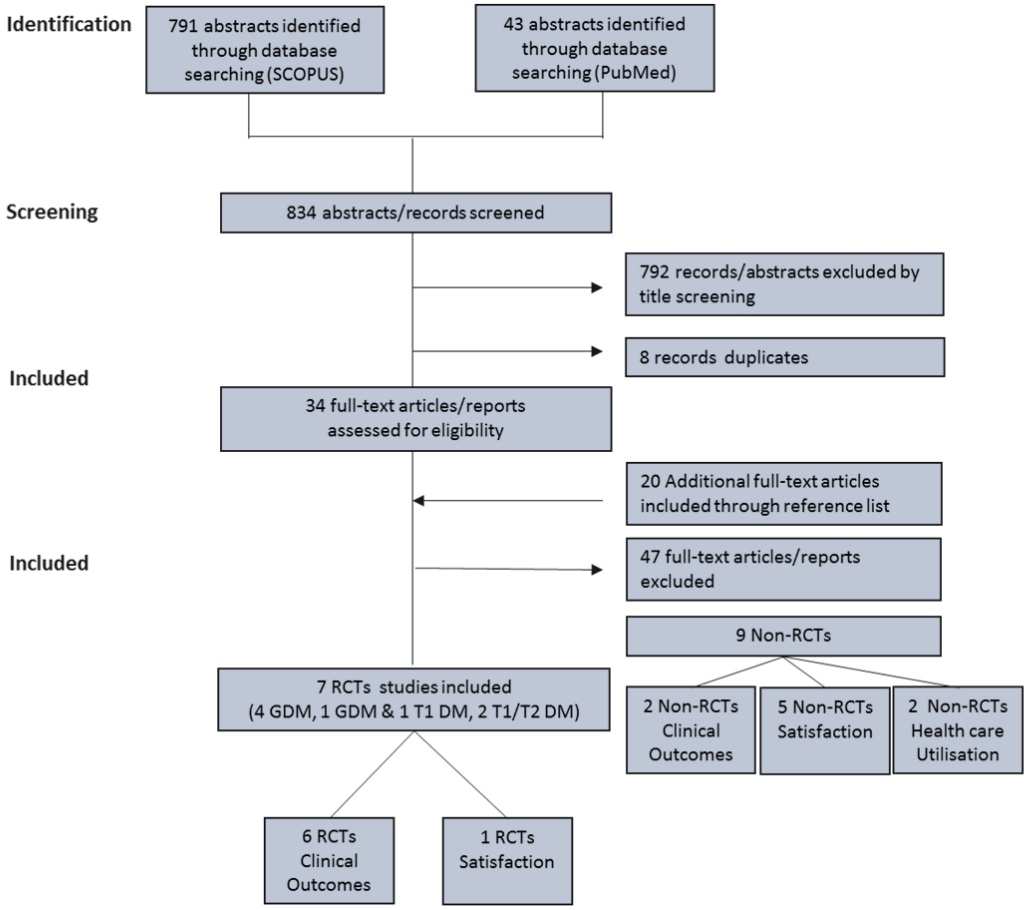
Meta-analysis was performed using Review Manager software (Version 5.3). Given that different technologies were assessed and the definitions of diabetes and standard care varied between the trials, we anticipated a large amount of heterogeneity in the results. Therefore, we applied random effects models with the I^2 statistic reported. I^2 values >50% are considered to indicate substantial heterogeneity. Results are presented as the differences in risk ratios for binary outcomes and mean difference for continuous variables, with 95% CI. Results were stratified by the diabetes type if more than 1 trial was available. For outcomes reported in only 1 trial or unable to be combined across trials, a narrative synthesis was presented.

Results

Study Selection and Study Characteristics

The search and screening strategy is shown in Figure 1. Seven of the 54 trials selected for full-text review met the inclusion criteria, involving 579 women: 496 women with GDM (5 trials) [16,21,27-29] and 83 with type 1 diabetes (3 trials) [15,21,30]. The trial of Dalfra et al presented results separately for women with GDM and type 1 diabetes; thus, for analysis we present this trial stratified by diabetes type [21]. All trials were small in size, ranging from 19 to 203 women with a median of 57 (interquartile range 32-85). The 7 trials were all conducted in high-income countries (5 in Europe and 2 in North America). See Multimedia Appendix 1.

Figure 1. Study selection. RTC: randomized controlled trial; GDM: gestational diabetes mellitus; T1 DM: type 1 diabetes mellitus; T2 DM: type 2 diabetes mellitus.



Modes of Communication and Type of Intervention

Technologies assessed were modem transmission of blood glucose readings to a central hospital computer [15], websites accessible to patients and health care professionals [17,18], a telephone system that translated blood glucose readings into audio tones to transmit them to a computer database [21], SMS transmissions of blood glucose readings to a central database [19], and a telemedicine hub located in the woman's home, which transmitted data every week to a clinical team through the Internet [16]. All trials described the comparison groups as receiving "routine care." However, this ranged from information given only about the method of blood glucose monitoring (ie, paper log books), to detailed descriptions of care pathways. The frequency of clinic visits differed between the trials, ranging from weekly to monthly visits.

Methodological Quality Assessment

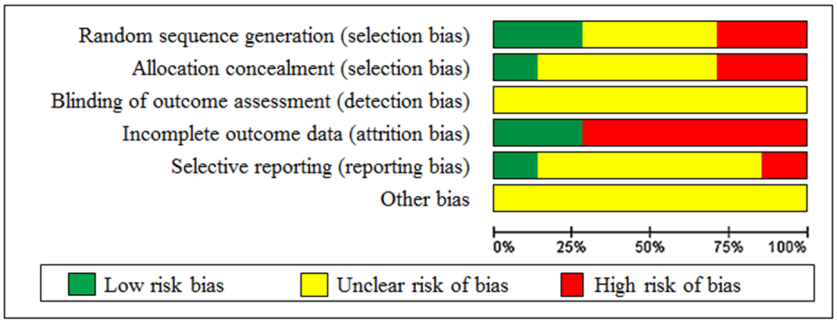
Overall, all the trials displayed potential sources of methodological bias (Figures 2 and 3). Owing to the nature of

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the intervention, blinding of participants and health care providers was not possible and therefore we elected to not include this as part of the risk of bias assessment. Considering the method of randomization, 2 trials were found to be at low risk of bias, reporting the use of computerized stratified block randomization [15,16]. The remainder either used methods that were likely to be of high risk of bias, or did not report this component. Only 1 trial reported use of an adequate allocation concealment method [17]. Two trials gave a full description of participants and losses to follow-up during their trial [16,17]. Other trials reported losses to follow-up or postrandomization exclusions, which potentially may have affected the results. Reporting bias is the selective reporting of some outcomes but not others depending on the nature and direction of the results [31]. Only 1 included trial was judged to be at low risk of reporting bias [17], reporting a comprehensive range of glucose and clinical outcomes.

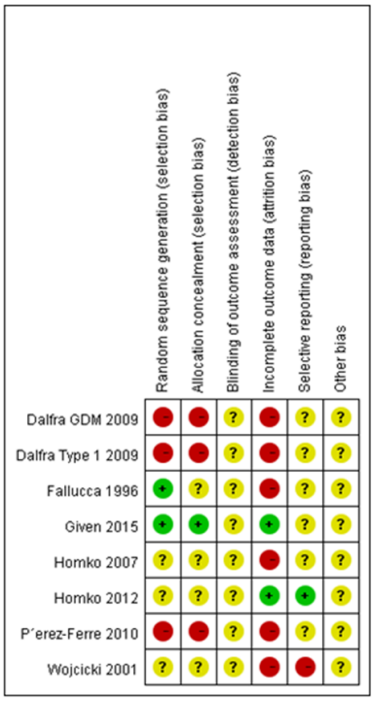
All the identified trials addressed clinical outcomes. Only 1 trial also reported maternal satisfaction; however, no comparative statistics were given between the intervention and the control groups. No trial presented any data on health economic outcomes.

Figure 2. Distribution of bias in the included trials.



Key: Green = "yes" (low risk of bias). Red = "no" (high risk of bias). Yellow = "unclear" (bias-related information is not clear or bias cannot be determined).

Figure 3. Risk of bias in the included trials.



Key: Green = "yes" (low risk of bias). Red = "no" (high risk of bias). Yellow = "unclear" (bias-related information is not clear or bias cannot be determined).

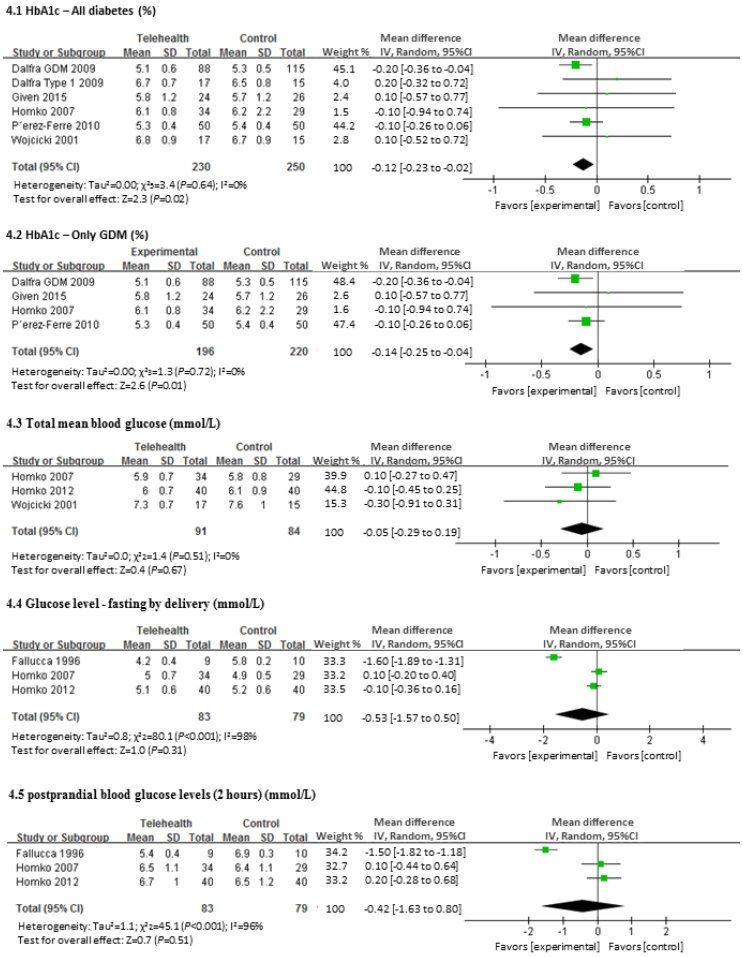
Maternal Glycemic Control

HbA1c was the most commonly reported glycemic outcome in 5 trials [21,28-30]. Meta-analysis demonstrated a modest, but statistically significant, improvement in HbA1c associated with the use of a telemedicine. The mean HbA1c of women using telemedicine was 5.33% (SD 0.70) compared with 5.45% (SD 0.58) in the standard care group, representing a mean difference of −0.12% (95% CI −0.23% to −0.02%). When this comparison was limited to the 4 trials of women with GDM only, the

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difference was slightly greater [21,28,29]. The mean HbA1c of women with GDM using telemedicine was 5.23% (SD 0.70) compared with 5.37% (SD 0.61) in the standard care group, mean difference −0.14% (95% CI −0.25% to −0.04%). Three trials (175 women: 143 GDM and 32 type 1) compared the overall mean blood glucose levels between the intervention (telemedicine) and control (standard care) groups [27,28,30]. Meta-analysis of these trials demonstrated no evidence of difference in mean blood glucose levels; however, this was in keeping with the lack of difference in HbA1c also observed in these individual trials (Figure 4). Two of these trials reported differences between fasting and 2 h postprandial blood glucose, however, no significant difference was demonstrated between the groups [15,28]. One trial in women with type 1 diabetes reported the mean units of insulin used in each group [15]. For these 19 women, the telemedicine group used a greater total dose of insulin compared with standard care, 54 units (SD 7 units) and 36 units (SD 6 units), respectively.

Figure 4. Forest plot showing the pooled HbA1c and blood glucose level (telemedicine vs control group).



Maternal and Neonatal Clinical Outcomes

Maternal outcomes were reported variously across the trials. A total of 4 trials (148 women using telemedicine and 145 controls) reported differences between rates of pregnancy-induced hypertension or preeclampsia [27-29]. In these trials, 7.5% of women overall had either of these conditions; however, there was no difference in the risk ratio between the telemedicine or control groups (Figure 5). When considering the mode of delivery, rates of Cesarean section were high in both the groups (50.0% in the telemedicine and 45.0% in the control) with no difference in the risk ratio. Only 2 trials (150 women) reported shoulder dystocia [29], however, with only 1 case of shoulder dystocia meta-analysis was not possible.

There was no significant difference between the groups with respect to mean birth weight. For the telemedicine group this was 3363 g (SD 115 g) and for the standard care group it was 3302 g (SD 121 g), with the mean gestational age at delivery of 37.9 weeks (SD 1.39 and 1.70) weeks in both groups (Figure 6). In the 2 trials that reported rates of macrosomia, there was no significant difference between the 2 groups, with an overall rate of 46% (129 cases and 159 controls, including 32 type 1 diabetic women) [21]. Three trials reported LGA as an outcome (124 women using telemedicine, and 119 with standard care) [27-29]. The overall prevalence of LGA in these 3 trials was 14.4%, with no difference demonstrated between the 2 groups.

There were 40 babies of 193 (20.7%) that were admitted to the NICU, however, this proportion was not significantly different between the 2 groups (Figure 7) [27,28]. Four trials reported the proportion of babies treated for neonatal hypoglycemia [27-29]. Overall, although 18.0% (18/100) of babies were treated

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for hypoglycemia, there was no evidence of differences between the intervention and control groups.

Figure 5. Forest plot showing the pooled clinical parameter—maternal outcomes (telemedicine vs control group).

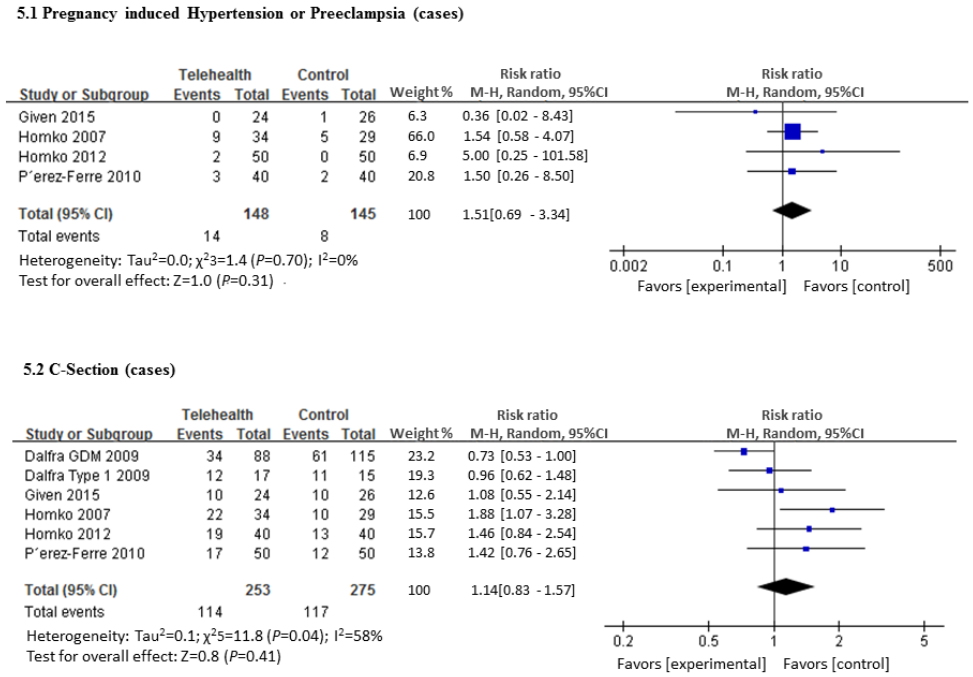
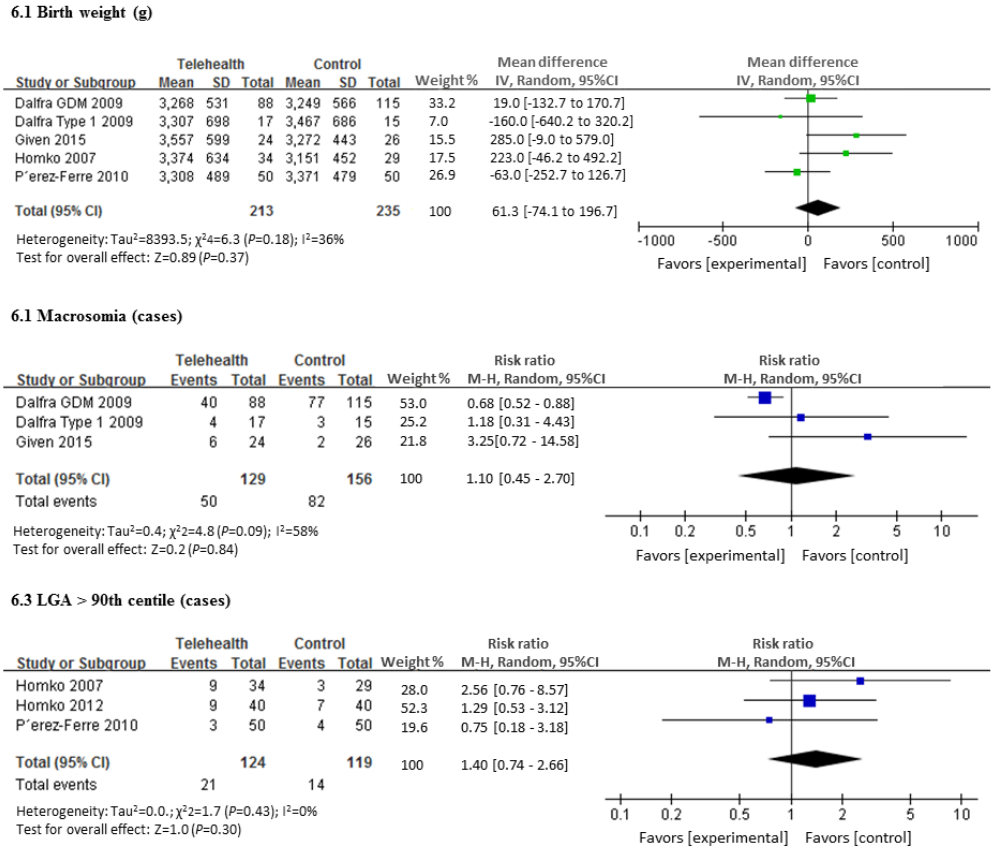
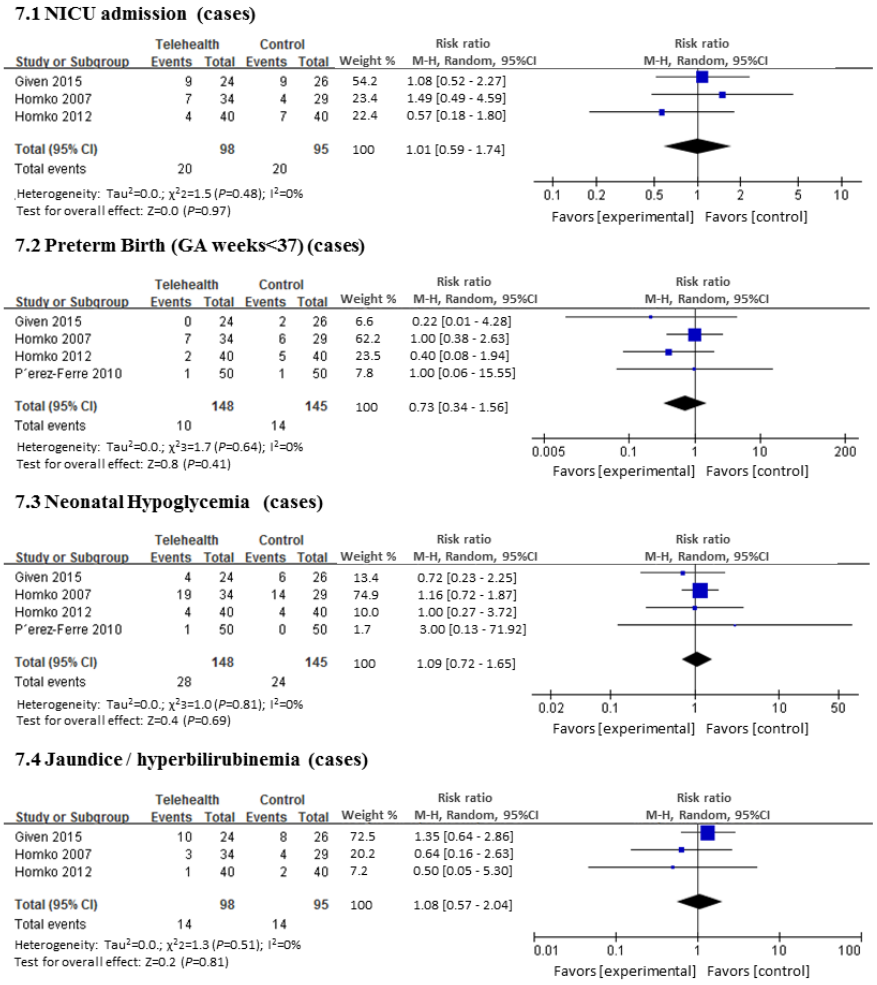


Figure 6. Forest plot showing the pooled clinical parameter at birth (telemedicine vs control group).



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Figure 7. Forest plot showing the pooled risk of neonatal complication (telemedicine vs control group).



Maternal Satisfaction

One trial reported mothers' satisfaction; however, this information was only presented for the intervention group. It reported that 90% (17/19) of women in the telemedicine group agreed or strongly agreed that they were satisfied with the system and would use it again.

Health Care Utilization

No trials provided economic or health utilization analyses. One trial described differences in the duration of clinic visits, reporting that the telemedicine visits were 8 min less than those for standard care [19].

Discussion

Principal Findings

While telemedicine may offer a little advantage in terms of glycemic control in pregnant women with diabetes, there is insufficient evidence at this time to support that it has any effect on other clinical endpoints. However, the 7 trials included in our meta-analysis were all small, assessed different technologies and were deemed to contain moderate to high potential sources of methodological bias. Thus, while it is reassuring that there is no evidence of harm associated with telemedicine, it is not possible to conclude whether it offers genuine benefits.

The strengths of our review were the robust and rigorous search strategy used, identifying 3 additional trials those that had been considered in previous reviews of this topic [22,32]. We included pregnant women with all forms of diabetes, as the benefits of these technologies may not be limited to women with only GDM. There are some limitations of this review. With no agreement between the trials on the screening method and definition of GDM, or standard treatment protocols, patient groups across trials may not be precisely comparable. This is a problem for all research in GDM, and unifying clinical practice was part of the motivation behind the World Health Organization (WHO) or International Association of Diabetes in Pregnancy Study Group (IADPSG) guidelines for the diagnosis of GDM. With the rapid development of advances in communication technology, the same system has not been compared in different populations, and there has been no evidence of sustained scale-up of any of these technologies. This makes it difficult to recommend any 1 system over another. Despite these differences, as the underlying concept of remotely communicating blood glucose readings between outpatient visits was the same across these trials, therefore we deemed these trials as suitable for meta-analysis. A further limitation of this review is that some of the outcomes examined, such as Cesarean section rates, gestational age at delivery, and admission to the NICU, may be more influenced by local practice, rather than being directly influenced by the intervention itself. The recent

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initiative by the IADPSG to attempt to standardize reporting and outcomes in diabetic pregnancy research could be a valuable advance in the future to ensure results are more comparable in this area research [33].

As stated, the sample sizes in all these trials was small. In GDM research, trials powered to detect a difference in important adverse clinical outcomes generally need to recruit around 1000 women [34,35]. Even with meta-analysis therefore, this analysis is likely to be underpowered to detect any effect on severe less common perinatal outcomes, such as shoulder dystocia and death.

Two earlier reviews on telemedicine in the management of the pregnancy with GDM have previously been published [22,32]. Mastrogiannis et al presented a narrative synthesis of trials published on telemedicine for diabetic pregnancies published before 2012. The authors concluded that telemedicine solutions for pregnant women with diabetes could reduce patient visits and potentially improve quality of life, without increasing the risk of the maternal and neonatal outcomes. Rasekaba et al presented a meta-analysis limited to women with only GDM. They identified 4 publications from 1990 to 2013 and concluded that there was insufficient evidence to support clinical benefit. Other possible benefits, such as economic savings or patient satisfaction, were not assessed. Rasekaba concluded that there was a non-significant trend to better the HbA1c of the telemedicine group [22]. By identifying and including additional trials, we have been able to demonstrate that this difference is significant both for all women with any form of diabetes in pregnancy, and those with GDM only. However, this outcome should be interpreted with caution; iron deficiency and the increased turnover of red blood cells in pregnancy can make HbA1c a less sensitive indicator of glycemic control in pregnancy [36]. Similar to our findings, Rasekaba et al did not find any difference in other clinical outcomes [22].

Whereas there were no randomized trials that assessed maternal satisfaction, there is evidence from nonrandomized trials that telemedicine is associated with high levels of satisfaction. [24] Women report these systems to be convenient to use, particularly if they live far from the hospital, have other caring responsibilities, or need to take time off work to attend appointments [1,24,37]. These observations have only been assessed in women with GDM, and ideally should be confirmed for women with type 1 and 2 diabetes among whom a reduction in clinic visits may not be desirable, however greater supervision and support may be associated with benefits in itself.

There is limited evidence that fewer outpatient visits may be needed for women with GDM using telemedicine systems [38]. We did not identify any formal health economic evaluations of telemedicine systems for gestational diabetes. In nondiabetic pregnant women, an economic analysis was conducted for a telemonitoring system designed for high-risk pregnant women in the Netherlands [39]. The system evaluated involved self-measurement and transmission of blood pressure, temperature, cardiotocography (CTG), and weight and urine albumin to a clinical care provider. This system demonstrated a cost-benefit system when compared with in-patient care. However, as this system did not measure blood glucose, and as admission for blood glucose monitoring is rare in developed countries, results cannot be extrapolated to the diabetic pregnant population. In the nonpregnant population 1 meta-analysis has assessed the economic impact of telemedicine for adults with type 2 diabetes [39,40]. The authors identified 2 papers that assessed cost-effectiveness. However, owing to small numbers and lack of consistency in the reporting of costs and outcomes, no conclusion could be drawn. A comprehensive cost analysis of direct and indirect costs is ideally needed before widespread adoption of these systems into clinical care [41].

Conclusions

There is insufficient evidence to conclude that for women with diabetes in pregnancy, telemedicine systems produce superior clinical outcomes when compared with standard care. The reasons for this may be due to the existing studies being underpowered to detect small effect sizes and heterogeneity in the available technologies and methods by which they have been assessed. It may be however that the main benefits of these technologies are in improving maternal satisfaction and streamlining clinical care delivery. High-quality research is still needed to determine the efficacy, satisfaction, burden to pregnant women and to the health care system, and economic impact of telemedicine systems for this patient group.

Acknowledgments

The authors acknowledge support from the Oxford NIHR Biomedical Research Centre. All authors had full access to all data of this study. The corresponding author (J Hirst) had the final for the responsibility for decision for publication.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Study characteristics.

[PDF File (Adobe PDF File), 41KB - jmir_v18i11e290_app1.pdf]

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Abbreviations

CTG: cardiotocography
GDM: gestational diabetes mellitus
HbA1c: hemoglobin A1c
LGA: large for gestational age
NICU: neonatal intensive care unit
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

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RCT: randomized controlled trials
SBGM: self-blood glucose monitoring
SD: standard deviation

Edited by G Eysenbach; submitted 26.08.16; peer-reviewed by T Rasekaba, B Bunting; comments to author 21.09.16; revised version received 05.10.16; accepted 07.10.16; published 09.11.16.

Please cite as:
Ming WK, Mackillop LH, Farmer AJ, Loerup L, Bartlett K, Levy JC, Tarassenko L, Velardo C, Kenworthy Y, Hirst JE
Telemedicine Technologies for Diabetes in Pregnancy: A Systematic Review and Meta-Analysis
J Med Internet Res 2016;18(11):e290
URL: http://www.jmir.org/2016/11/e290/
doi:10.2196/jmir.6556
PMID:27829574

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Original Paper

Comparing Twitter and Online Panels for Survey Recruitment of E-Cigarette Users and Smokers

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Abstract

Background: E-cigarettes have rapidly increased in popularity in recent years, driven, at least in part, by marketing and word-of-mouth discussion on Twitter. Given the rapid proliferation of e-cigarettes, researchers need timely quantitative data from e-cigarette users and smokers who may see e-cigarettes as a cessation tool. Twitter provides an ideal platform for recruiting e-cigarette users and smokers who use Twitter. Online panels offer a second method of accessing this population, but they have been criticized for recruiting too few young adults, among whom e-cigarette use rates are highest.

Objective: This study compares effectiveness of recruiting Twitter users who are e-cigarette users and smokers who have never used e-cigarettes via Twitter to online panelists provided by Qualtrics and explores how users recruited differ by demographics, e-cigarette use, and social media use.

Methods: Participants were adults who had ever used e-cigarettes (n=278; male: 57.6%, 160/278; age: mean 34.26, SD 14.16 years) and smokers (n=102; male: 38.2%, 39/102; age: mean 42.80, SD 14.16 years) with public Twitter profiles. Participants were recruited via online panel (n=190) or promoted tweets using keyword targeting for e-cigarette users (n=190). Predictor variables were demographics (age, gender, education, race/ethnicity), e-cigarette use (eg, past 30-day e-cigarette use, e-cigarette puffs per day), social media use behaviors (eg, Twitter use frequency), and days to final survey completion from survey launch for Twitter versus panel. Recruitment method (Twitter, panel) was the dependent variable.

Results: Across the total sample, participants were recruited more quickly via Twitter (incidence rate ratio=1.30, *P*=.02) than panel. Compared with young adult e-cigarette users (age 18-24 years), e-cigarette users aged 25 to 34 years (OR 0.01, 95% CI 0.00-0.60, *P*=.03) and 35 to 44 years (OR 0.01, 95% CI 0.00-0.51, *P*=.02) were more likely to be recruited via Twitter than panel. Smokers aged 35 to 44 years were less likely than those aged 18 to 24 years to be recruited via Twitter than panel (35-44: OR 0.03, 95% CI 0.00-0.49, *P*=.01). E-cigarette users who reported a greater number of e-cigarette puffs per day were more likely to be recruited via Twitter than panel compared to those who reported fewer puffs per day (OR 1.12, 95% CI 1.05-1.20, *P*=.001). With each one-unit increase in Twitter usage, e-cigarette users were 9.55 times (95% CI 2.28-40.00, *P*=.002) and smokers were 4.91 times (95% CI 1.90-12.74, *P*=.001) as likely to be recruited via Twitter than panel.

Conclusions: Twitter ads were more time efficient than an online panel in recruiting e-cigarette users and smokers. In addition, Twitter provided access to younger adults, who were heavier users of e-cigarettes and Twitter. Recruiting via social media and online panel in combination offered access to a more diverse population of participants.

(J Med Internet Res 2016;18(11):e288) doi:10.2196/jmir.6326

KEYWORDS

social media; electronic cigarettes; tobacco; Twitter

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Introduction

E-cigarettes have rapidly increased in popularity in recent years. In the United States, 13% of adults are e-cigarette users [1], marking a more than sevenfold increase from 2010 adult use rates [2]. Awareness of e-cigarettes is also widespread and has more than doubled among US adults since 2008 [3]. Many e-cigarette users believe that e-cigarettes will help with cessation [4-6], although population-based studies suggest otherwise. These studies demonstrate lower levels of cessation among smokers who use e-cigarettes compared with smokers who do not use e-cigarettes [3,7-10].

The proliferation of e-cigarettes in the United States has been driven, at least in part, by marketing and word-of-mouth discussion on Twitter [11]. Twitter content about e-cigarettes is primarily from marketers and advertisers, with two recent studies finding that at least 90% of tweets related to e-cigarettes were marketing or advertising tweets [11,12]. Although marketing and advertising expenditures for e-cigarettes have increased substantially across traditional and new media channels (television, magazines, out of home, radio, digital media)—256% between 2011 and 2013—people are most likely to hear about e-cigarettes online (41%) or from someone they know (35%) [13].

Twitter provides a free and efficient means of sharing and accessing information about e-cigarettes, making it a unique and informative vantage point from which to understand how people are using, selling, buying, accessing, and sharing information about these emerging products. At the same time, a growing body of literature demonstrates that social media provides an efficient and cost-effective space for recruiting hard-to-reach populations for survey research [14-20].

Social media sites, such as Facebook, Instagram, and Twitter, offer powerful targeting capabilities that aid in recruiting hard-to-reach populations [21,22], such as e-cigarette users and smokers, who make up 13% and 17% of the US adult population, respectively [1,23]. Targeting tools on social media allow researchers to target advertisements to users with specific demographic characteristics (eg, age, gender, income, education) and interests (eg, e-cigarettes, photography, smoking, folk music) based on their behaviors on these sites (eg, tweets, likes, comments, shares, retweets), and other third-party sites that they connect to through their social media accounts (eg, sharing an article from a news outlet's website on Twitter, logging into an e-commerce website via Facebook). These capabilities reduce the time and resources required to recruit hard-to-reach populations for participation in research.

The majority of published studies that explore the use of social media for participant recruitment have used Facebook [14,16-20]. Facebook is a powerful tool for recruiting participants, but privacy restrictions, which are a default setting for all Facebook profiles, prevent researchers from gaining access to information that people share and are exposed to on Facebook. On Twitter, such information can be accessed if the Twitter user has a public profile (more than 90% of Twitter users have public profiles [24]) and consents to share his or her public Twitter data. Studies have analyzed public Twitter users' data related to e-cigarettes [11,12], but no study to date has combined Twitter users' data related to e-cigarettes (eg, tweets, followers, Twitter handles they follow) with self-reported survey data from these users. Combining these data sources would provide a more holistic understanding of how information about e-cigarettes is disseminated to e-cigarette users and smokers on Twitter; how these individuals differ based on demographic characteristics, e-cigarette use, and social media use; and how this information may influence perceptions and behavior related to e-cigarettes.

Given the rapid proliferation of e-cigarettes, researchers need timely data from e-cigarette users and smokers who have never used e-cigarettes, but may seek out e-cigarettes for cessation. Twitter provides an efficient and effective recruitment method because it allows for access to Twitter users' public Twitter data and survey data and because it is a space where many conversations about e-cigarettes are occurring, both marketing and organic word-of-mouth conversations [11,12]. Although these features make Twitter a particularly appealing tool for participant recruitment, few published studies have used Twitter for participant recruitment [25]. Online panels offer a second method of accessing hard-to-reach populations because they have access to additional data from panel members (eg, age, smoking status, social media use) based on their responses to previous surveys. Although online panels have been criticized for recruiting too few young adults [26], among whom e-cigarette use rates are highest, they may provide a useful supplement to Twitter for recruiting smokers and e-cigarette users.

Twitter is more popular among people who are younger [27], thus we expect that younger adults will be more likely to be recruited for survey research via Twitter than online panel compared to adults older than 24 years. In addition, because e-cigarette use rates are highest among young adults [28], we expect that a larger number of e-cigarette users to be recruited via Twitter than online panel. Similarly, online panels tend to recruit people who are older on average [22] and smoking rates are highest among adults aged between 25 and 44 years [23]; thus, we expect a larger number of smokers to be recruited via online panel than Twitter. This study compares the efficacy and time efficiency of recruiting e-cigarette users and smokers via Twitter to online panel and explores how users recruited via these two methods differ by demographics, e-cigarette use, and social media use.

Methods

Participants

Eligible participants were adults who reported having ever used e-cigarettes (n=278; male: 57.6%, 160/278; age: mean 34.26, SD 14.16 years) and adult current smokers who reported current smoking every day or some days, having smoked ≥100 cigarettes in their lifetime, and having never used e-cigarettes (n=102; male: 38.2%, 39/102; age: mean 42.80, SD 14.16 years). All participants also had public Twitter profiles, lived in the United States, and gave permission to monitor their public Twitter profile. People with public Twitter profiles were recruited to explore patterns of information sharing and consumption related

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to e-cigarettes on Twitter, which will be reported in a forthcoming paper. The majority of e-cigarette users in the sample (245/278, 88.1%) were also current smokers. It is important to note that in this study e-cigarette users who were smokers were classified as e-cigarette users so that exposure to and sharing of e-cigarette tweets could be assessed for smokers who had not tried e-cigarettes, but may be using Twitter to learn about e-cigarettes. The study was approved by RTI International's Institutional Review Board.

Recruitment Method

Equal numbers of participants were intentionally recruited via Qualtrics' panel aggregator (n=190) or promoted tweets (n=190).

Panel Recruitment

Qualtrics panel aggregator was used to recruit online panel participants for this study. The Qualtrics panel aggregator provides clients with access to members of a number of market research panels and uses digital fingerprinting technology and IP address checks to ensure that participants' data are as valid and reliable as possible. Participants recruited via panel received an email from Qualtrics inviting them to participate in the study by clicking on a link to a screening questionnaire to assess eligibility. Participants recruited via the Qualtrics panel aggregator were targeted based on profiling attributes that are included in online panels that are used to guarantee that data about panel respondents are detailed and accurate. We used the following profiling attributes provided previously by participants to target participants for the survey: age, being a smoker, and being part of an online social network. Qualtrics did not have the capability to target e-cigarette users; thus, participants were not targeted based on their e-cigarette use (see Table 1 for targeting features). Panel recruitment was initiated with a soft launch that began 2 weeks before the launch of Twitter ads for recruitment and continued after the launch of Twitter ads.

Twitter Recruitment

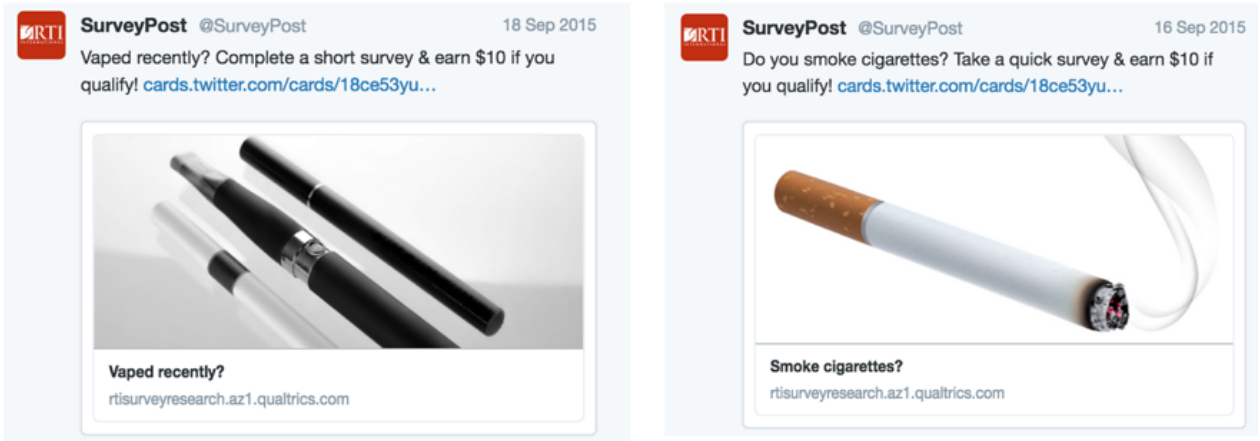
Twitter ads targeted e-cigarette users and smokers using two separate campaigns for each user group. Each ad included a brief description (e-cigarette users: "Vaped recently? [or "Ever vape?" or "Ever use e-cigarettes?"] Complete a short survey & earn $10 if you qualify!"; smokers: "Smoked recently? [or "Do you smoke cigarettes?"] Take a quick survey & earn $10 if you qualify!"), an image (e-cigarette users: e-cigarettes; smokers: cigarettes), and a link to the screening questionnaire (see Twitter ad examples in Figure 1). Twitter ads were posted by the RTI Twitter handle SurveyPost (Twitter handle used for conducting survey research at RTI), which displayed the RTI logo. These ads showed up as promoted tweets in targeted users' Twitter feeds.

Twitter ads provide a number of targeting capabilities for reaching a specific target audience. Targeting features used for ads included (1) age targeting ads to adults aged 18 or older, and (2) keyword and hashtag targeting for words and hashtagged words that Twitter users have tweeted or searched for on Twitter related to e-cigarettes and smoking (see Table 1 for targeting keywords).

Table 1. Recruitment targeting strategies by recruitment method.

Targeting feature	Panel	Twitter
Age	18 years or older	18 years or older
Smoker targeting	Smokers (smoking habit or smoke at least once per day)	Keywords/hashtags: (#)cigarettes, (#)smoking, (#)tobacco, (#)cigarette, smoker, (#)smokers, tobacco smoking, cig, cigs, ciggy
E-cigarette user targeting	No targeting available	Keywords/hashtags: e-cig, ejuice, eliquid, (#)vape, (#)vaping, (#)ecigs, (#)ecig, ecigarette, e-liquid, vaper, #vaping, #vape, #vapelyfe, vapes, #vapeislife, #vapeon, #vapelife, #vapeon
Social network use	Member of at least one online social network	Twitter users (ads appeared on Twitter)

Figure 1. Twitter ad examples targeting e-cigarette smokers (left) and cigarette smokers (right).



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Dependent Variable

Recruitment method (Twitter, panel) for completed surveys was the dependent variable.

Procedure

Panel Recruitment

Qualtrics sent email invitations to panel members who met the targeting recruitment criteria (aged 18 or older, part of an online social network, and/or smokers [to recruit smokers and/or e-cigarette users who may or may not be smokers]). The email invitation included a link to the screening questionnaire that participants then clicked and completed to assess their eligibility for participating in the survey. A feature was enabled in the survey that prevented any person with the same IP address from completing the survey more than once to prevent duplicate responses. As an added precaution to prevent duplicate responses, respondent email addresses were cross-checked for both exact email address matches and similar name matches (eg, jdoe@gmail.com, jdoe@yahoo.com, jdoe1@gmail.com) with a database of emails from participants who had already completed the survey (via Qualtrics panel or Twitter) to prevent participants who completed the survey multiple times from receiving multiple incentives and from being included in the final sample. Participants determined to be eligible based on their responses to screening questions related to age, having a public Twitter profile, and being e-cigarette users or smokers were presented with a brief consent form. Individuals who consented to participate in the study continued directly to the 20-minute Web survey where they answered questions about their demographic characteristics, tobacco product use (cigarettes, other tobacco products, e-cigarettes), cessation behaviors, e-cigarette-related perceptions, social media and Internet use, and exposure to/recall of e-cigarette content on social media. Participants who completed the survey were compensated with the standard Qualtrics panel incentive, which can be redeemed for rewards and had an estimated value of approximately US $1.50. This incentive structure and amount is standard procedure for what Qualtrics and other survey panels provide to participants as compensation for this length of survey.

Twitter Recruitment

Initial contact with potential participants occurred through Twitter ads (ie, promoted tweets) targeted at participants who were likely to be eligible using age and keyword targeting. Participants recruited via Twitter clicked on a promoted tweet in their Twitter feed and were then directed to a Web link for the screening questionnaire. The same feature was enabled in the survey that prevented any person with the same IP address from completing the survey more than once to prevent duplicate responses. The same email cross-checking procedure was used as a second precaution to prevent duplicate respondents from receiving multiple incentives and being included in the final sample. Participants then completed the same screening questionnaire as those recruited via panel, and eligible participants completed the same consent form and survey instrument as panel participants. Participants recruited via Twitter who completed the survey were compensated with a US $10 digital gift card incentive. Qualtrics incentives were the standard incentive provided for the length of survey administered and could not be altered to match incentives for Twitter participants.

Predictor Variables

Independent variables were demographics (age, gender, education, race/ethnicity), e-cigarette use (past 30-day e-cigarette use, e-cigarette puffs per day, time to first e-cigarette), and social media use (eg, Twitter use frequency, using Twitter to give and receive e-cigarette advice, using Twitter to learn about e-cigarettes, posting or sharing information about e-cigarettes online).

Statistical Analysis

Unpaired sample means tests were used to compare the percentage of people from Twitter versus the panel who completed each stage of the recruitment process. To determine which recruitment method was more efficient in recruiting participants, a series of Poisson regression analyses were conducted on the number of eligible participants who completed the full survey and provided public Twitter data and the recruitment method (Twitter vs panel) with days to survey completion (from the first day of data collection until the goal sample of 190 participants was reached for each recruitment method) for each recruitment method included as an offset variable [15]. Using the Poisson regression with days to completion as an offset variable allows for computation of recruitment efficiency as an incidence rate ratio (IRR) for time to completion. Recruitment method was the predictor in the model. Two Poisson models were conducted to compare the efficiency of the two recruitment methods. The first model included all survey completes from the 2-week soft launch of panel recruitment that occurred before the launch of Twitter ads and all completes thereafter. The second included only survey completes that occurred when both recruitment methods were active (excluding all survey completes from the 2-week panel soft launch).

A series of bivariate analyses were conducted to determine which variables differed between people recruited via Twitter and online panel. Variables related to recruitment source ($P<.25$) were included in multivariate logistic regression models [29]. Analyses were run in Stata version 13.1. Predictors included demographics, e-cigarette use variables (e-cigarette users only), and social media use variables.

Results

The Twitter ad campaigns used to recruit e-cigarette users and smokers generated a total of 590,954 impressions (ie, individual exposures to an ad) with 395,035 and 195,919 impressions generated from the smoker and e-cigarette targeted ad campaigns, respectively. Ads resulted in 2691 total clicks, with 1718 clicks on smoker-targeted ads (0.43%, 1718 clicks/395,035 exposures) and 973 clicks on e-cigarette user-targeted ads (0.50%, 973 clicks/195,919 exposures). Total cost of ads was US $6848.25 (US $4206.23 for smoker-targeted ads and US $2642.02 for e-cigarette user-targeted ads). Qualtrics panel sent 152,221 email invitations to panel members who met the target recruitment criteria and 15,262 panel members clicked on the

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survey link, demonstrating that emails sent via panel resulted in a 10.00% survey click rate. Cost comparisons could not be made between the two recruitment methods because Qualtrics was used for both panel recruitment and for programming and managing the survey (completed by all participants) and they do not provide a cost breakdown that separates out these overlapping costs to determine the cost of panel recruitment in isolation.

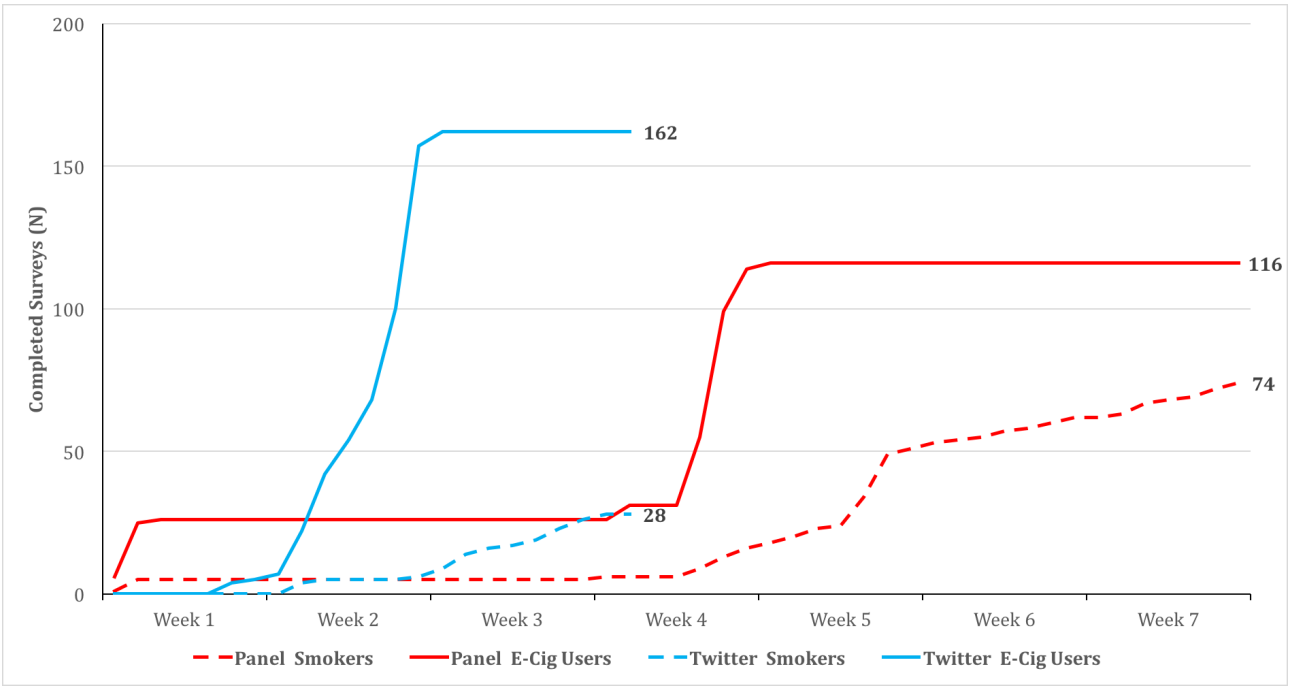
Recruitment Efficiency

Although participants were recruited in equal numbers via panel and Twitter (n=190 each), results demonstrated that the IRR for time to completion was 1.30 times faster for Twitter participants than panel participants (*P*=.02) when including only survey completes that were received during active recruitment for both Twitter and panel, and 2.13 times faster (*P*<.001) when also including survey completes from the 2-week panel soft launch that occurred before the Twitter ads launched. Figure 2 illustrates the trajectory of survey completions for each recruitment method for e-cigarette users and smokers.

Eligibility and Survey Completion

A larger percentage of people recruited via panel completed the screener than people recruited via Twitter (*P*=.02) (see Table 2 for n's and percentages). Of the participants who completed the screening questionnaire, the proportion of participants in the eligible age range did not differ significantly based on recruitment method, although a larger proportion of participants recruited via Twitter were eligible based on e-cigarette use or smoking behavior than those recruited via panel (*P*<.001). Compared with participants recruited via Twitter, a larger percentage of participants recruited via panel (1) provided their Twitter handle and consented to share their public Twitter data (*P*=.002), and (2) consented to complete the online survey (*P*<.001). Finally, compared to those recruited via panel, a larger proportion of participants recruited via Twitter (1) provided a public Twitter handle that we were able to use to extract their Twitter data (*P*<.001), and (2) completed the baseline survey (*P*<.001). Taken together, these findings show that Twitter recruitment resulted in a higher proportion of useable data and completed surveys from Twitter.

Figure 2. Timeline for completed surveys among e-cigarette users (n=190) and smokers (n=190) by recruitment method (Twitter or panel).



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Table 2. Eligibility, baseline, and follow-up completion by recruitment method.

Stage of completion	Total		Panel		Twitter		*P* value
	n (%)[a]	95% CI	n (%)[a]	95% CI	n (%)[a]	95% CI	
Completed screener	2155 (51.9)	50.4-53.3	1587 (52.9)	51.2-54.6	568 (48.8)	45.9-51.8	.02
Eligible: age	2154 (100)	99.9-100	1586 (99.9)	99.8-100	568 (100)	—	.32
Eligible: e-cigarette use/smoker	2024 (94.0)	93.0-95.0	1474 (92.9)	91.7-94.2	550 (96.8)	95.4-98.3	<.001
Consented to share Twitter data	2014 (99.5)	99.2-99.8	1474 (100)	—	540 (98.2)	97.1-99.3	.002
Consented to survey	1926 (95.6)	94.7-96.5	1452 (98.5)	97.9-99.1	474 (87.8)	85.0-90.5	<.001
Completed survey	919 (47.7)	45.5-49.9	604 (41.6)	39.1-44.1	315 (66.5)	62.2-70.7	<.001
Public Twitter handle	380 (41.3)	38.2-44.5	190 (31.5)	27.7-35.2	190 (60.3)	54.9-65.7	<.001

[a] Denominator for each column percentage is the numerator from the preceding row, with the exception of "completed screener" which uses the total number of screeners (complete and incomplete) as the denominator (total: N=4479; panel: n=3369; Twitter: n=1110).

Sample Characteristics

Characteristics of the participants are presented in Table 3.

Overall, the majority of the sample was white, non-Hispanic (255/380, 67.1% vs 77.1% in 2015 US census), with a larger percentage of white, non-Hispanic smokers (76/102, 74.5%) compared with e-cigarette users (179/278, 64.4%). Among the 16.6% (63/380) of Hispanics (vs 17.6% in 2015 US census) in the sample, a larger percentage were e-cigarette users (55/278, 19.8%) than were smokers (8/102, 7.8%). Among the 5.8% (22/380) of black, non-Hispanic participants (vs 12.6% in 2015 US census), a larger percentage were smokers (8/102, 7.8%) than e-cigarette users (14/278, 5.0%). Overall, the sample was almost evenly split by gender (52.4%, 199/380 male vs 49.2% in 2015 US census), but a larger percentage of e-cigarette users were male (160/278, 57.6%) and a larger percentage of smokers were female (63/102, 61.8%). A smaller percentage of participants had a college degree or higher (127/380, 33.4% vs 29.3% in the 2015 US census); this was true of both e-cigarette users (95/278, 34.2%) and smokers (32/102, 31.4%).

The majority of e-cigarette users reported using their first e-cigarette 30 minutes or less after waking (118/189, 62.4%). On average, e-cigarette users reported using e-cigarettes on a mean 13.99 (SD 11.99) days of the past 30 days and taking a mean 54.68 (SD 139.66) puffs per day on their e-cigarette.

On average, participants were most likely to report using Twitter daily or several times per day (mean 6.68, SD 1.94), with smokers reporting slightly higher mean Twitter use rates on average (mean 7.13, SD 1.70) than e-cigarette users (mean 6.51, SD 2.00), although this difference was not statistically signitifcant. Less than half of the sample reported using Twitter to give and receive advice about e-cigarettes (161/380, 42.4%) and to learn about e-cigarettes (171/380, 45.0%); these percentages were higher among e-cigarette users (advice: 135/278, 48.6%; learn: 142/278, 51.1%) than smokers (advice: 26/102, 25.5%; learn: 29/102, 28.4%; *P*<.001). More than one-third of participants reported that they post and share information about e-cigarettes online (146/380, 38.4%), and this number was higher among e-cigarette users (129/278, 46.4%) than smokers (17/102, 16.7%) (*P*<.001).

Bivariate Analyses

As predicted, smokers were more likely to be recruited via panel (74/102, 72.6%) than via Twitter (28/102, 27.5%, *P*<.001). Also in line with expectations, e-cigarette users were more likely to be recruited via Twitter (162/278, 58.3%) than panel (116/278, 41.7%, *P*=.01).

Overall, e-cigarette users and smokers tended to be older and male. More specifically, bivariate analyses showed that adult e-cigarette users and smokers aged 25 to 34 years (e-cigarette users: OR 0.11, 95% CI 0.04-0.29, *P*<.001; smokers: OR 0.10, 95% CI 0.02-0.61, *P*=.01), 35 to 44 years (e-cigarette users: OR 0.09, 95% CI 0.03-0.27, *P*<.001; smokers: OR .01, 95% CI 0.00-0.18, *P*=.001), 45 to 54 years (e-cigarette users: OR 0.05, 95% CI 0.02-0.17, *P*<.001; smokers: OR .08, 95% CI 0.01-0.51, *P*<.01), and 55 years or older (e-cigarette users: OR 0.06, 95% CI 0.02-0.21, *P*<.001; smokers: OR 0.08, 95% CI 0.01-0.48, *P*=.01) were less likely to be recruited via Twitter (than panel) compared with young adult e-cigarette users aged 18 to 24 years. Male e-cigarette users (OR 1.92, 95% CI 1.18-3.12, *P*=.01) and smokers (OR 2.40, 95% CI 0.99-5.84, *P*=.05) were more likely than women to be recruited by Twitter than panel. E-cigarette users who reported a college education or greater were less likely to be recruited via Twitter than panel (OR 0.34, 95% CI 0.20-0.57, *P*<.001) compared to those with less education. E-cigarette users who reported using e-cigarettes on more days of the past 30 (OR 1.05, 95% CI 1.03-1.08, *P*<.001), who took more puffs on their e-cigarette per day (OR 1.08, 95% CI 1.05-1.11, *P*<.001), and who used e-cigarettes more than 30 minutes after waking (OR 2.08, 95% CI 1.11-3.88, *P*=.02) were more likely to be recruited via Twitter than panel.

As expected, e-cigarette users and smokers who reported using Twitter more frequently were more likely to be recruited via Twitter than panel, such that with each one-unit increase in Twitter usage, e-cigarette users were 1.93 times as likely to be recruited via Twitter than panel (95% CI 1.53-2.42, *P*<.001), and smokers were 3.69 times as likely to be recruited via Twitter than panel (95% CI 1.72-7.92, *P*=.001). E-cigarette users who reported using Twitter to give or receive advice about e-cigarettes were less likely to be recruited via Twitter than panel (OR 0.47, 95% CI 0.28-0.76, *P*=.002).

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Table 3. Sample characteristics.

Characteristic	Total sample (N=380)	E-Cigarette users (n=278, 73.2%)	Smokers (n=102, 26.8%)	*P* value
Demographics				
Age (years), mean (SD)	36.55 (13.61)	34.26 (14.16)	42.80 (14.16)	<.001
Gender, n (%)				
Female	181 (47.6)	118 (42.5)	63 (61.8)	.001
Male	199 (52.4)	160 (57.6)	39 (38.2)	
Education, n (%)				
Less than college	253 (66.6)	183 (65.8)	70 (68.6)	.61
College plus	127 (33.4)	95 (34.2)	32 (31.4)	
Race/ethnicity, n (%)				
White, non-Hispanic	255 (67.1)	179 (64.4)	76 (74.5)	.05
Black, non-Hispanic	22 (5.8)	14 (5.0)	8 (7.8)	.35
Hispanic	63 (16.6)	55 (19.8)	8 (7.8)	.001
Other/multiple races	40 (10.5)	30 (10.8)	10 (9.8)	.78
E-Cigarette use (e-cigarette users only)				
Past 30-day e-cigarette use (n=205), mean (SD)	—	13.99 (11.99)	—	
E-cigarette puffs per day (n=116), mean (SD)	—	54.68 (139.66)	—	
Time to first e-cigarette				
≤30 minutes	—	118 (62.4)	—	
>30 minutes	—	71 (37.6)	—	
Cigarette use				
Smoked 100 cigarettes in lifetime, n (%)	371 (97.6)	269 (96.8)	102 (100)	<.001
Do you now smoke cigarettes...?, n (%)				
Every day	256 (67.4)	168 (60.4)	88 (86.3)	<.001
Some days	80 (21.1)	66 (23.7)	14 (13.7)	.02
Rarely	12 (3.2)	12 (4.3)	0 (0)	.001
Not at all	32 (8.4)	32 (11.5)	0 (0)	<.001
Social media use				
Twitter usage (1=never, 8=several times a day), mean (SD)	6.68 (1.94)	6.51 (2.00)	7.13 (1.70)	.37
Use Twitter to give/receive e-cigarette advice, n (%)	161 (42.4)	135 (48.6)	26 (25.5)	<.001
Use Twitter to learn about e-cigarettes, n (%)	171 (45.0)	142 (51.1)	29 (28.4)	<.001
Post/share information about e-cigarettes online, n (%)	146 (38.4)	129 (46.4)	17 (16.7)	<.001

Logistic Regression Analyses

Logistic regression models were used to compare the demographic characteristics, e-cigarette use, and social media use between people recruited via Twitter and panel (Table 4). Variables found to be related to recruitment source in bivariate analyses were included in the multivariate models ($P<.25$) [24]. As hypothesized, e-cigarette users aged 25 to 34 years (OR 0.01, 95% CI 0.00-0.60, $P=.03$) and 35 to 44 years (OR 0.01, 95% CI 0.00-0.51, $P=.02$) were less likely to be recruited via Twitter than panel compared with e-cigarette users aged 18 to 24 years. This difference did not emerge when comparing the 18 to 24 group to older adults (older than 45 years). Similarly, in line with our hypotheses, smokers aged 35 to 44 years were less likely than those aged 18 to 24 years to be recruited via Twitter than panel (OR 0.03, 95% CI 0.00-0.49, $P=.01$). E-cigarette users who reported a greater number of puffs on their e-cigarette per day were more likely to be recruited via Twitter than panel compared with e-cigarette users who reported fewer puffs per day (OR 1.12, 95% CI 1.05-1.20, $P=.001$). In addition, with each one-unit increase in Twitter usage, e-cigarette users were 9.55 times (95% CI 2.28-40.07, $P=.002$) and smokers were 4.91 times (95% CI 1.90-12.74, $P=.001$) as likely to be recruited via Twitter than panel.

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Table 4. Multivariate logistic regressions of e-cigarette users and smokers recruited via Twitter (versus panel).[a]

Variable	E-Cigarette users (n=278)		Smokers (n=102)	
	AOR (95% CI)	*P* value	AOR (95% CI)	*P* value
Demographics				
Age				
18-24 years	REF		REF	
25-34 years	0.01 (0.00-0.60)	.03	0.23 (0.03-1.65)	.15
35-44 years	0.01 (0.00-0.51)	.02	0.03 (0.00-0.49)	.01
45-54 years	0.02 (0.00-1.98)	.09	0.47 (0.06-3.88)	.48
≥55 years	0.02 (0.15-8.13)	.08	0.34 (0.04-2.73)	.31
Gender				
Female	REF		REF	
Male	1.10 (0.02-7.41)	.92	3.25 (0.84-12.55)	.09
Race/Ethnicity				
White, non-Hispanic	REF		REF	
Black, non-Hispanic	1.00 (—)	—	3.24 (0.37-28.19)	.29
Hispanic	0.41 (0.02-7.41)	.54	1.01 (0.07-14.71)	.99
Other/multiple races	9.04 (0.30-274.33)	.21	3.00 (0.48-18.58)	.24
Education				
Less than college	REF		REF	
College plus	0.17 (0.03-1.03)	.05	2.01 (0.58-6.96)	.27
E-Cigarette use (e-cigarette users only)				
Past 30-day e-cigarette use	1.02 (0.93-1.12)	.67	—	—
E-cigarette puffs per day	1.12 (1.05-1.20)	.001	—	—
Time to first e-cigarette				
≤30 minutes	REF		—	—
>30 minutes	1.48 (0.20-10.72)	.70	—	—
Social media use				
Twitter usage	9.55 (2.28-40.07)	.002	4.91 (1.90-12.74)	.001
Use Twitter to give/receive e-cigarette advice				
No	REF		—	—
Yes	0.28 (0.03-2.40)	.25	—	—

[a] Predictors include variables related to recruitment methods in univariate analyses ($P<.25$).

For both e-cigarette users and smokers, those aged 18 to 24 years and individuals who were heavier users of Twitter were more likely to be recruited via Twitter than adults aged between 35 and 44 years. E-cigarette users aged between 18 and 24 years were also more likely than those aged between 25 and 35 years to be recruited via Twitter, but the same was not true of smokers.

Discussion

Principal Results

E-cigarette users and smokers were recruited more quickly via Twitter than online panel. A larger percentage of people recruited via Twitter were eligible to participate in the study based on their e-cigarette use or smoking behavior compared with participants recruited via panel, suggesting that Twitter recruitment provided a more direct way (ie, requiring that fewer people need to be screened to reach eligible participants) to reach the target populations. Participants recruited via panel were more likely to consent to participate in the survey than those recruited via Twitter, which makes sense because panel members are already experienced with completing online surveys for incentives. In contrast, a larger percentage of participants recruited via Twitter completed the survey and provided public Twitter handles (which was an eligibility requirement for accessing their Twitter data) compared to those recruited via panel.

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Consistent with our predictions, as well as research suggesting that smoking rates are highest among adults aged between 25 and 44 years [23] and that panel use is higher among older adults [22], our findings demonstrated that smokers were more likely to be recruited via panel. Similarly, in line with research showing e-cigarette and Twitter use rates to be highest among young adults [27,28], findings show that e-cigarette users were more likely to be recruited via Twitter.

Twitter and online panel recruitment methods provided access to different subgroups of e-cigarette users and smokers. Consistent with our predictions and research showing that Twitter is more popular among younger adults [27], Twitter ads recruited e-cigarette users and smokers who were younger and were heavier users of Twitter than people recruited via panel. Twitter also recruited e-cigarette users who reported taking more e-cigarette puffs per day than people recruited via panel. Recruiting participant populations via Twitter along with online panel offered access to a more diverse population than using a single recruitment method.

Overall, findings from this study suggest that recruiting participants directly from Twitter provided the most effective means of accessing people who would both complete a survey and a provide public Twitter handles for extracting Twitter data. In addition, participants recruited via Twitter reported being heavier users of Twitter, suggesting that recruiting participants in this way provides access to a population for whom questions about e-cigarette information exposure and sharing on Twitter are most relevant.

Twitter provides highly specific targeting features that allow users to be targeted based on demographics, interests, and other characteristics, which in the case of this research included age and use of keywords related to e-cigarettes and smoking. These features make Twitter a more efficient resource for reaching the target population than an online panel because panel participants could only be targeted based on age, membership in any online social network, and smoking behavior (and could not be targeted based on e-cigarette use).

Comparison With Prior Work

This study expands the literature on using social media to recruit hard-to-reach populations in several ways. First, this study demonstrates the efficacy of using Twitter for participant recruitment, which has been shown in few published research studies to date [25]. Second, to our knowledge, this is the first study to collect both users' self-reported survey data and their social media data in combination to provide a more holistic picture of how participants who provide data from this combination of sources differ based on demographic and other characteristics, and how it may influence perceptions and behavior. These data will be used in a separate, forthcoming paper to illuminate how information about an emerging product is disseminated on social media. Third, this research expands the literature on comparing social media recruitment methods to traditional recruitment methods by demonstrating important differences in recruitment effectiveness and efficiency, and demographic and other characteristics of participants recruited via Twitter compared with an online panel.

Limitations

Although this study provides important insights into the usefulness of online panels and Twitter for recruiting hard-to-reach participant populations, this research has several limitations. First, both samples recruited for this study are not representative of the US population of e-cigarette users and smokers, and findings may not generalize to a national sample of e-cigarette users and smokers. Second, only one online panel provider was compared to Twitter recruitment and, thus, findings may not generalize to recruitment efforts using other online panels. Third, people could have been exposed to both Twitter and panel recruitment materials because recruitment efforts for the study were conducted simultaneously. Fourth, panel and Twitter incentives provided to participants were not equivalent (panel participants received the standard incentive of panel points and Twitter participants received a US $10 digital gift card) suggesting the possibility that the findings reported here may be driven by differences in incentives received by participants between the two recruitment methods. Fifth, cost comparisons could not be made between the two recruitment methods to determine whether one method is more cost efficient for participant recruitment. A final limitation of this research, and any research conducted using social media to recruit participants [15], is that the algorithms used for ad placement on social media are based on private user data and are constantly changing, making it difficult for researchers to determine which participant characteristics are most important for targeting advertisements to a desired participant population.

Conclusions

Our findings demonstrate that Twitter ads were more efficient than an online panel in recruiting e-cigarette users and smokers with a substantially larger number of eligible participants completing surveys and other eligibility requirements. In addition, Twitter and online panels provide access to different subgroups of these hard-to-reach populations. Twitter provided access to younger adults, who were heavier users of Twitter and e-cigarettes (e-cigarette users only). Recruiting participants via social media along with online panel offered access to a broader population from which to understand e-cigarette use than would one of the two recruitment sources alone.

Acknowledgments

This work was funded by the National Cancer Institue, National Institutes of Health, through Grant Number RO1CA192240.

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Authors' Contributions

JG and AK conceptualized the study and led study implementation, interpretation of findings, and writing of the manuscript. JG, AK, JM, and YH developed survey measures. JG developed social media methods and led social media data collection. YH led panel data collection. JG and BB led data analysis. JN, JM, and YH assisted in interpretation of findings and writing of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

IRR: incidence rate ratio

Edited by G Eysenbach; submitted 07.07.16; peer-reviewed by S Oesterle, B Curtis; comments to author 28.07.16; revised version received 27.09.16; accepted 15.10.16; published 15.11.16.

Please cite as:
Guillory J, Kim A, Murphy J, Bradfield B, Nonnemaker J, Hsieh Y
Comparing Twitter and Online Panels for Survey Recruitment of E-Cigarette Users and Smokers
J Med Internet Res 2016;18(11):e288
URL: http://www.jmir.org/2016/11/e288/
doi:10.2196/jmir.6326
PMID:27847353

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Original Paper

Survey Email Scheduling and Monitoring in eRCTs (SESAMe): A Digital Tool to Improve Data Collection in Randomized Controlled Clinical Trials

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Abstract

Background: Electronic questionnaires can ease data collection in randomized controlled trials (RCTs) in clinical practice. We found no existing software that could automate the sending of emails to participants enrolled into an RCT at different study participant inclusion time points.

Objective: Our aim was to develop suitable software to facilitate data collection in an ongoing multicenter RCT of low back pain (the Acuback study). For the Acuback study, we determined that we would need to send a total of 5130 emails to 270 patients recruited at different centers and at 19 different time points.

Methods: The first version of the software was tested in a pilot study in November 2013 but was unable to deliver multiuser or Web-based access. We resolved these shortcomings in the next version, which we tested on the Web in February 2014. Our new version was able to schedule and send the required emails in the full-scale Acuback trial that started in March 2014. The system architecture evolved through an iterative, inductive process between the project study leader and the software programmer. The program was tested and updated when errors occurred. To evaluate the development of the software, we used a logbook, a research assistant dialogue, and Acuback trial participant queries.

Results: We have developed a Web-based app, Survey Email Scheduling and Monitoring in eRCTs (SESAMe), that monitors responses in electronic surveys and sends reminders by emails or text messages (short message service, SMS) to participants. The overall response rate for the 19 surveys in the Acuback study increased from 76.4% (655/857) before we introduced reminders to 93.11% (1149/1234) after the new function (P<.001). Further development will aim at securing encryption and data storage.

Conclusions: The SESAMe software facilitates consecutive patient data collection in RCTs and can be used to increase response rates and quality of research, both in general practice and in other clinical trial settings.

(J Med Internet Res 2016;18(11):e311) doi:10.2196/jmir.6560

KEYWORDS

randomized controlled trials; data collection; surveys and questionnaires; quality improvement; sample size; Internet; email; text messaging

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Introduction

A common problem for clinical research in general practice is the ability to conduct randomized controlled trials (RCTs) with large enough sample sizes [1]. Interventions usually take place in small and busy practices, and researchers often need to organize their study by themselves [1-3]. Funding is often insufficient for employing research assistants who can conduct telephone interviews and send out reminders, unless the research is organized in a dedicated network [4,5]. A high degree of response in a trial is essential to keep the sample size sufficient, and a substantial level of nonresponse may lead to bias and less accurate data [6]. Such factors are limiting the quality, number, and progression of conducting RCTs in general practice [7]. Electronic surveys (e-surveys) greatly facilitate data collection by combining survey research and modern technology [8]. A major advantage of the use of e-surveys in research is their potential to increase the amount of data that can be collected at a low cost [9]. However, a disadvantage is that it can be challenging to secure a high response rate [9]. Jansen et al stated that questionnaires based on emails are effective methods to acquire time-specific responses, even if the compliance at specific time points might be affected [10].

Documentation of how new digital tools for clinical trials have been developed is scarce [11,12], but recent evaluations of some digital tools are available [13-15]. During the 2nd Clinical Trials Methodology Conference in 2013, McPherson et al discussed whether to use a commercial system or build one's own software for use in clinical trials [16]. Keding et al [17] examined the effectiveness of short message service (SMS) [18] reminders on patient response rates, and rather surprisingly concluded that such reminders did not improve the response rates substantially. In a Cochrane review from 2009, Edwards et al explored different ways to increase response rates in postal and electronic questionnaires [6]. They identified 32 trials with 27 different strategies to increase response in electronic questionnaires, but none of them was about reminders. However, for postal surveys with SMS reminders, the odds of response increased by half compared with a postcard reminder.

When planning a multicenter RCT carried out in general practice [19], we struggled to find existing software that could help automate the email distribution of survey forms. We searched for, and tested, several software apps enabling survey deployment by using email software. Some of the apps were free (shareware), while others could be purchased or needed a subscription. However, all the software we tested required either that every participant had to receive the same email at the same time, or that each email had to be set up individually.

The power calculation for our study determined that we needed to include 270 patients consecutively. To collect data by electronic questionnaires at 19 specific time points within a predefined period before treatment and at a 1-year follow-up, we would have needed to send out 5130 separate emails for all questionnaires—a process that necessarily had to be automated. In the absence of adequate programs that were able to do this, we decided to develop our own software.

We aimed to develop software that would automate sending of emails with links to e-surveys, thus improving the quality of data collection and increasing the response rate to secure sufficient statistical power. This paper describes the results.

Methods

The first version of the software was tested in a pilot study in November 2013. We developed 2 software components: an Excel (Microsoft Corporation) spreadsheet written in Microsoft Visual Basic and a server component based on Red Hat (a server operating system; Red Hat, Inc), PHP (a programming language), and MySQL (a database; Oracle Corporation). The connectivity between the user interface (the Excel spreadsheet) and the server was achieved using Open Database Connectivity. This required that the program needed to be downloaded and run from a designated laptop computer with Internet access. Every time a participant was included, the project leader (TS) had to log on to the computer and open the program to initiate the sending of emails. The software could schedule the sending of the emails with links to the surveys made in the open source program LimeSurvey (LimeSurvey GmbH) and was called Survey Email Scheduler or SES. However, in addition to the vulnerability discussed above, the software was unable to deliver multiuser and Web-based access, thereby limiting its use in larger RCTs. We solved this in the next version of the program, which we tested on the Web in February 2014. It now schedules and sends the required emails in the full-scale Acuback trial that started in March 2014 (trial registration NCT01439412) [19].

The system architecture evolved through an iterative, inductive process between the project leader (TS) and the software programmer (FS). The researcher defined the premises and the software needs for sending out multiple emails at predefined time points, and the programmer offered solutions based on the technical possibilities. The researcher was naive to programming and the programmer was research naive. Through this mutual process, they uncovered the limitations both in practical research and in programming. The program was tested, improved, and retested. This process was iterated throughout the main study, made possible by using different versions of the program, one on a development server and another on a production server.

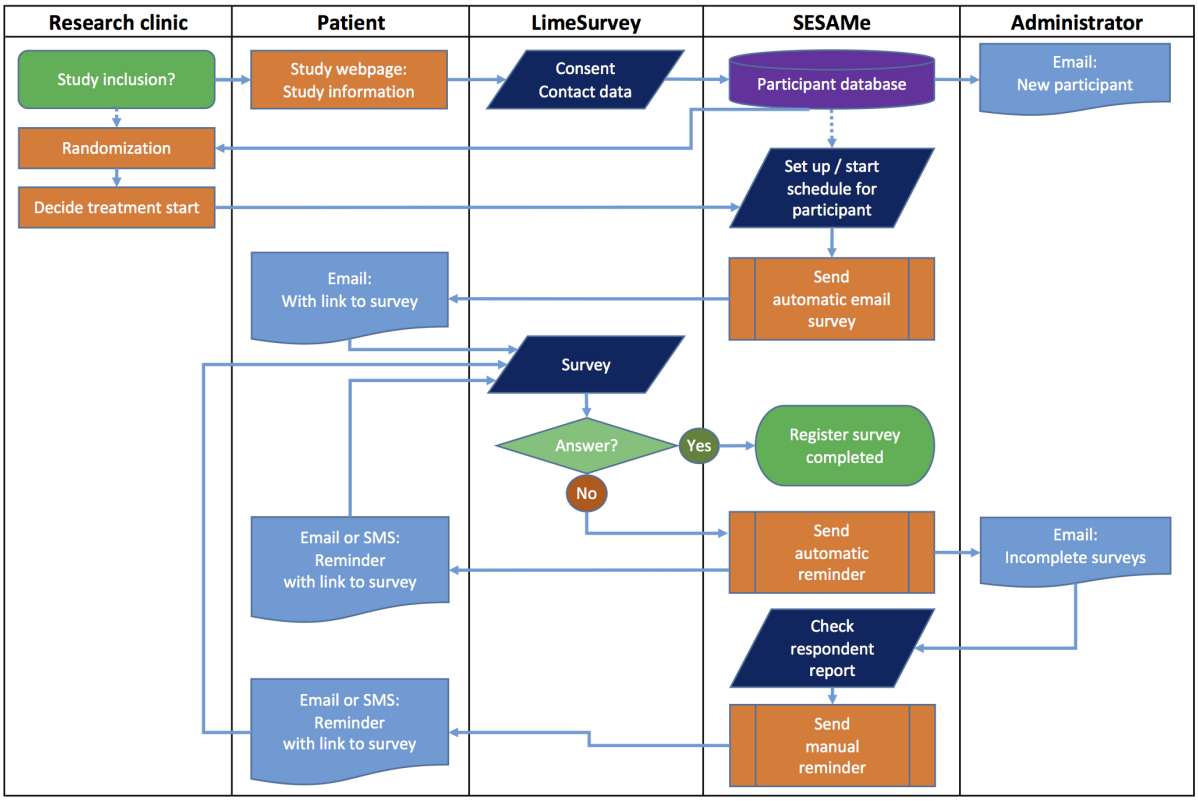
The software is now able to send reminders by either email or SMS. Reminders can be sent automatically at a given time point after the expected completion of the survey or manually through the respondent report. The project leader receives a report with the number of uncompleted surveys sent the previous day. With this improved function, all data collection and monitoring have become Internet based. We suggest signifying this type of data collection and monitoring in RCTs as an electronic randomized controlled trial (eRCT). Consequently, we also renamed the software app *Survey Email Scheduling and Monitoring in eRCTs* (SESAMe). Figure 1 illustrates the information flow during data collection, including automatic and manual reminders.

To evaluate the development of the software, we used several information sources, such as a logbook, for specific encounters and problems. We asked the research assistants using the software in the inclusion process about their experiences. We

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queried the participants in the Acuback trial on day 28 about how they experienced the emails and questionnaires. The continual and repeated evaluation by the software users on different levels has led to constant improvements, so we define the software development as an iterative process [20].

Figure 1. Flow chart showing the information flow during data collection in the *Survey Email Scheduling and Monitoring in eRCTs* (SESAMe) software app. SMS: short message service.



Results

The Software App

We developed a Web-based software app that schedules and sends automated emails with links to e-surveys in LimeSurvey, an open source program used by many colleges and universities worldwide. Our system is able to set a schedule either manually or by use of a template set up for the specific study.

Even if electronic questionnaires have advantages in data collection, missing data and dropouts are still a challenge. We noticed a problem with emails being registered as spam, as the participants had problems in finding them, and in using the links to the surveys. The first 11 participants in the Acuback trial received an extra questionnaire, asking whether they had experienced this problem, which email program they were using, and whether the problems had been solved. In total, 8 participants answered, and 4 of them had received 1 or more of the emails in their spam folder. We made some changes that decreased the spam grade from 2.7 to 0.0, where 5.0 is the highest possible grade [21].

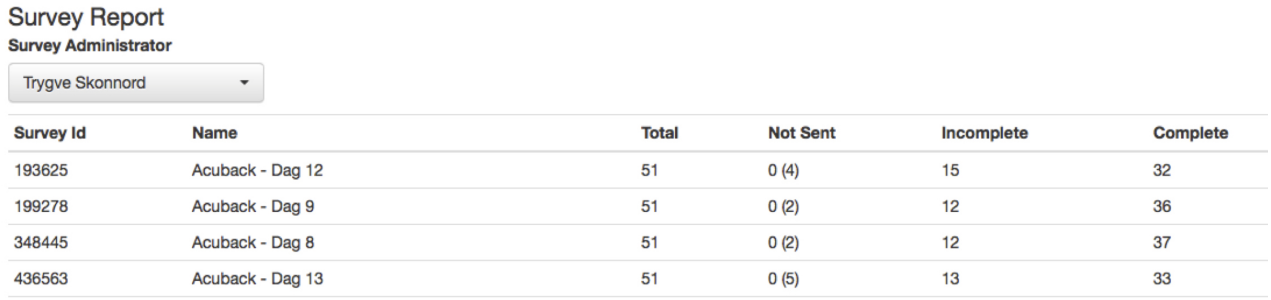
Monitoring and Reminding

To improve the response rate, we also developed a study monitoring function for detecting missing responses. The survey report (Figure 2) shows exactly how many completed and uncompleted questionnaires have been sent from the system.

A respondent report (Figure 3) shows who has not answered the survey in a given period. The report can be extended for an individual respondent, giving data for when emails and SMSs were sent both for this specific survey and for all the surveys the participant has received.

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Figure 2. Screen dump of the survey report showing the number of completed and uncompleted surveys.



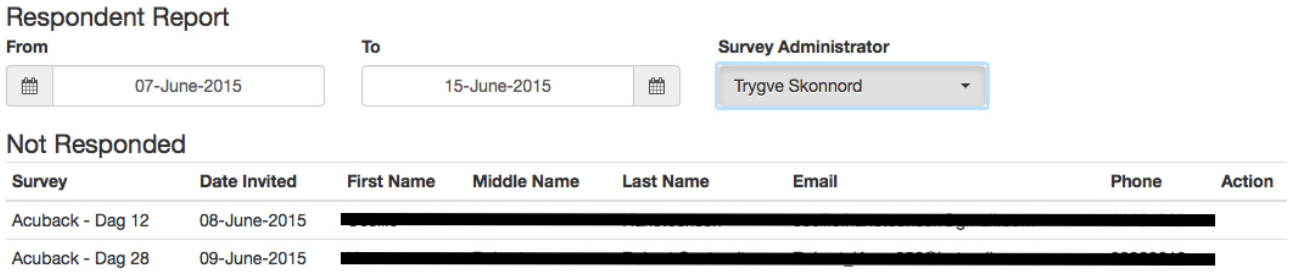
Survey Report

Survey Administrator

Trygve Skonnord

Survey Id	Name	Total	Not Sent	Incomplete	Complete
193625	Acuback - Dag 12	51	0 (4)	15	32
199278	Acuback - Dag 9	51	0 (2)	12	36
348445	Acuback - Dag 8	51	0 (2)	12	37
436563	Acuback - Dag 13	51	0 (5)	13	33

Figure 3. Screen dump of the respondent report showing participants who have not responded to a survey during a specified time period.



Respondent Report

From 07-June-2015 To 15-June-2015 Survey Administrator Trygve Skonnord

Not Responded

Survey	Date Invited	First Name	Middle Name	Last Name	Email	Phone	Action
Acuback - Dag 12	08-June-2015	[redacted]					
Acuback - Dag 28	09-June-2015	[redacted]					

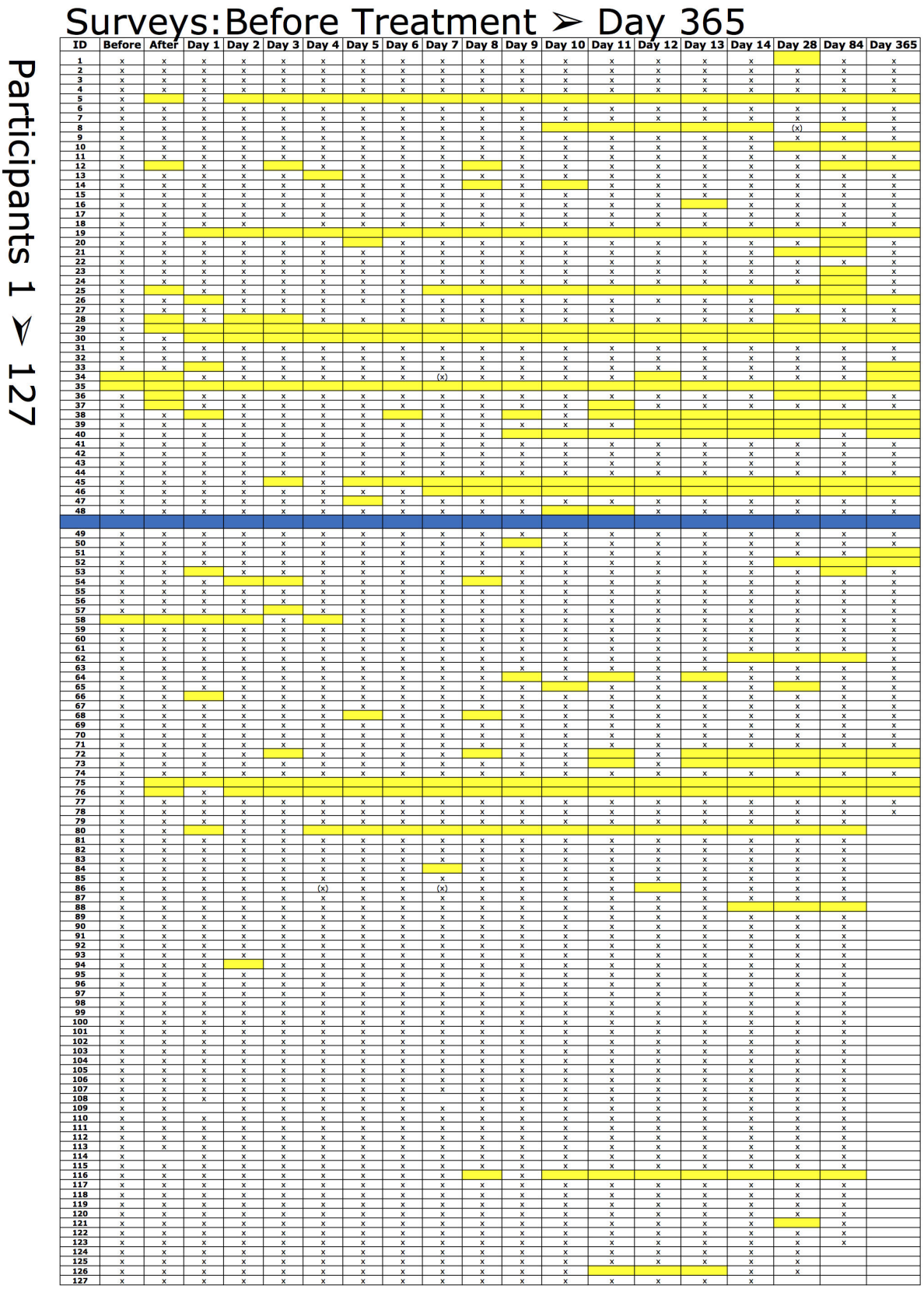
Increased Response Rate

The survey report in SESAMe contains information about how many surveys have been distributed, how many have not yet been sent out, and how many have been completed or not completed. We used this to compare the response rate for the surveys before and after we introduced the possibilities to send out manual or automatic reminders by email or SMS (October 11, 2014). We included 51 participants before this date and 66 participants from that date to January 21, 2016, giving a total of 117 participants. Of these, 57 (48.7%) were men and 43 (36.87%) had an education >13 years. Mean age for the participants was 43 years for men and 37 years for women.

With 18 surveys in the first period (no participant reached day 365), 857 emails were sent and 655 surveys were answered: a response rate of 76.4%. For the second period, 1149 of 1234 surveys were answered: a response rate of 93.11% (P<.001 between periods by chi square test). Figure 4 shows the increased response rate, with fewer missing answers after the software had been upgraded (blue line).

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Figure 4. Missing answers, marked with yellow, before and after monitoring function (blue line).



Preferences

On day 28 (survey number 17), we posted 4 extra questions to the participants about their experiences with the questionnaires. By November 10, 2015, a total of 69 of 96 (72%) had submitted their answers to the questions. Table 1 summarizes the results. Most were satisfied with the questionnaires. When asked whether anything did not function as it should have, 9 of the 69 respondents replied "yes." Their comments taught us that some links to the questionnaires did not function in the beginning,

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and 3 of them said that the emails had defaulted into their email spam folder. Most participants preferred electronic questionnaires, but this is a selected group, as they had already agreed to participate in an e-survey. We also found that participants used several kinds of devices to answer the questionnaires.

Table 1. The participants' experiences and preferences with electronic questionnaires (n=69).

Questions and responses	n
In total, how satisfied were you with the functionality of these questionnaires?	
Very satisfied	15
Satisfied	29
Neither satisfied nor dissatisfied	23
Somewhat dissatisfied	2
Very dissatisfied	0
Was there anything about the emails or questionnaires that did not function as it should?	
No	60
Yes	9
Did you experience that it was fine to use electronic questionnaires, or would you have preferred to use paper questionnaires?	
I prefer electronic questionnaires	62
It doesn't matter	7
I prefer paper questionnaires	0
What kind of electronic devices did you use to answer the surveys?	
Desktop computer	17
Portable computer	35
Tablet	20
Smartphone	29
Other (smart TV)	1

Experiences From the Users of SESAMe

In the Acuback trial, research assistants at the general practice clinics enrolled and randomly allocated the participants, and then used SESAMe to deploy emails. Finally, they answered a survey to ensure that they had completed the inclusion and reported any eventual problems with the program. For the first 111 completed surveys, only 14 assistants reported problems with randomization or email processing: 4 of them did not report the nature of the problem and 2 generalized it to be caused by "using SESAMe." Of the research assistants, 3 reported the patients' problem to be email being sent to the spam folder, and 2 patients did not receive the first email at all (solved by sending an SMS manually). On one occasion, the mapping from the content survey failed, and twice a patient was doubly registered through the mapping. In addition, the server once shut down during inclusion.

Discussion

During the planning of our RCT to be conducted in general practice, we lacked appropriate software to carry out repeated electronic data collection from patients continually enrolled over a long time. Instead of converting the data collection scheme back to being paper based, we developed the software needed to automate the scheduling and sending of the emails in our trial. Such an automation process is required when participants who are consecutively included in a trial receive emails in a specific order at different time points, especially when a large number of participants is required. Using the iterative, inductive process described above, we developed a tool that we named SESAMe, which other researchers might be able to use in facilitating their data collection. For the ongoing Acuback study, SESAMe has proved to be a highly significant improvement in the follow-up of participants. The SESAMe monitoring function automates and reduces time spent on necessary control functions for project leaders of RCTs. This is of especial importance in general practice research, but other clinical researchers may also save time and cost using this tool. We presented the project at the WONCA Europe conference in Copenhagen June 2016 (Multimedia Appendix 1).

While Edwards et al found an effect of SMS reminders for postal questionnaires [6], Keding et al reported that SMS reminders for electronic questionnaires did not improve the response rates substantially [17]. This is contrary to our findings, where the response rate increased from 76% to 93% when we introduced manual and automatic reminders by email and SMS. We chose to use both messaging systems. People with mobile phones might wish to answer an SMS at once if the survey is not too extensive, but if it does not suit them to answer right away, they might forget the SMS. On the other hand, emails can be read and marked as "unread" and might be remembered later more easily.

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Automatic reminders require little work and contact with the participants by the researchers, but we wonder whether this might be negative as well. Do we lose something important by reducing the "human factor" in the trial? The real-life contact between the general practitioner or research assistant and the patient might increase the response rate. In our experience, sometimes the patients forgot to answer, did not understand the questions, or got tired of the surveys. When contacted, they continued to answer the surveys because of the contact with a person who could explain the topic. SESAMe can help to identify such dropouts and can be combined with personal follow-up, either by the study administrator or by the local health personnel, who may know the patients. Unfortunately, we have not registered the number of participants receiving personal contact. Telephone calls or repeated mailing has been shown to increase the response rate when participants don't answer the first questionnaire [6].

When participants are excluded, or withdraw from the study, we have had to delete them from the program to prevent further emails from being sent to them. To keep a good research log and flow diagram of the included participants, these participants' records should be marked as deleted and transferred to a trash folder, together with the cause of this categorization, rather than being completely deleted. Future versions of SESAMe will provide this function.

During the process of data collection in the Acuback trial, we have observed that the type of communication and language used can be important for the response rate. This is especially relevant during the inclusion process, in each of the questionnaires, and in the emails to the participants. The researchers should ensure that all included participants understand the content of the study. If language is a problem for the target group, surveys in different languages should be considered. E-surveys are suitable for deploying parallel questionnaires. The administration of SESAMe surveys is in English, and the SMS texts can be written in different languages in the software. The surveys and email texts are arranged in LimeSurvey and can be in different languages. SESAMe can organize different languages in a trial by administrating them as parallel studies or using parallel questionnaires within LimeSurvey.

Limitations and Strengths

The evaluation of the development process of the SESAMe software is limited because it has been a practical programming process, not anchored in validated programming theories. The increase in response rate from 76% to 93% after introducing reminders is statistically significant, using the chi square test, but we might have introduced a methodological bias because the trial included more participants in the first period after the study start, making it more difficult to follow up manually. This could have been easier later on, when fewer participants were included per week. Concerning the question of satisfaction with electronic or paper questionnaires, we admit that there was a selection bias, as we asked participants who had already agreed to use electronic forms.

The strengths of this study include the process of practical development during the initial phase of the trial, and the iterative, inductive process between the research project leader and the software developer. Furthermore, we used the practical hands-on experiences of both the researchers and the other users of the program, including the participants in the study, as input into the development process.

Security and Further Work

The security of the data now follows strong rules, with encryption of all data from each keystroke to the server and safe storage at a well-known and serious service provider [22]. The project follows the Norwegian Health Research Act, and ethical approval was given by the Regional Ethics Committee of South-Eastern Norway (reference 2013/611/REK sør-øst A). Logging on to SESAMe demands a secure password, and you are automatically logged out after an inactive period. Persons with different roles in the trial have different levels of access to the functions. Only the study administrator has access to the monitoring function and can send out the reminders, while the health personnel who enroll patients cannot see any data after the inclusion is completed. One weakness in the present version is that each study administrator also has access to the control of other eventual trials administered in SESAMe.

In the further development of our software, we will expand it to a multiuser version, where different trials will be conducted completely separate from each other in SESAMe. We aim to further secure encryption of data transportation and to use secure data storage. Data will be transferred to 2 different servers during data collection, with 1 server made inaccessible to the researcher to prevent data manipulation. Data will be released when the trial is finished. This will prevent manipulation of the data by the researchers, which is technologically feasible today. Our final aim is to make our software available for other clinical researchers.

Conclusions

The SESAMe software app improves study logistics by automating and monitoring data collection. This opens doors to conducting large-scale RCTs, enabling researchers to conduct high-quality clinical trials, not only in a general practice setting, as in this project, but also in other settings.

Acknowledgments

The Department of General Practice, University of Oslo, contributed to the costs of this software development.

Conflicts of Interest

None declared.

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Multimedia Appendix 1

Presentation of the project at the Wonca Europe Conference 15-18 June 2016, Copenhagen, Denmark.

[PPT File (Microsoft PowerPoint Presentation), 9MB - jmir_v18i11e311_app1.ppt]

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Abbreviations

e-survey: electronic survey
eRCT: electronic randomized controlled trial
RCT: randomized controlled trial
SESAMe: Survey Email Scheduling and Monitoring in eRCTs
SMS: short message service

Edited by CL Parra-Calderón, G Eysenbach; submitted 27.08.16; peer-reviewed by S Van de Velde; comments to author 19.09.16; revised version received 31.10.16; accepted 08.11.16; published 22.11.16.

Please cite as:
Skonnord T, Steen F, Skjeie H, Fetveit A, Brekke M, Klovning A
Survey Email Scheduling and Monitoring in eRCTs (SESAMe): A Digital Tool to Improve Data Collection in Randomized Controlled Clinical Trials
J Med Internet Res 2016;18(11):e311
URL: http://www.jmir.org/2016/11/e311/
doi:10.2196/jmir.6560
PMID:27876689

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Original Paper

Methods for Evaluating Respondent Attrition in Web-Based Surveys

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Abstract

Background: Electronic surveys are convenient, cost effective, and increasingly popular tools for collecting information. While the online platform allows researchers to recruit and enroll more participants, there is an increased risk of participant dropout in Web-based research. Often, these dropout trends are simply reported, adjusted for, or ignored altogether.

Objective: To propose a conceptual framework that analyzes respondent attrition and demonstrates the utility of these methods with existing survey data.

Methods: First, we suggest visualization of attrition trends using bar charts and survival curves. Next, we propose a generalized linear mixed model (GLMM) to detect or confirm significant attrition points. Finally, we suggest applications of existing statistical methods to investigate the effect of internal survey characteristics and patient characteristics on dropout. In order to apply this framework, we conducted a case study; a seventeen-item Informed Decision-Making (IDM) module addressing how and why patients make decisions about cancer screening.

Results: Using the framework, we were able to find significant attrition points at Questions 4, 6, 7, and 9, and were also able to identify participant responses and characteristics associated with dropout at these points and overall.

Conclusions: When these methods were applied to survey data, significant attrition trends were revealed, both visually and empirically, that can inspire researchers to investigate the factors associated with survey dropout, address whether survey completion is associated with health outcomes, and compare attrition patterns between groups. The framework can be used to extract information beyond simple responses, can be useful during survey development, and can help determine the external validity of survey results.

(J Med Internet Res 2016;18(11):e301) doi:10.2196/jmir.6342

KEYWORDS

patient dropouts; surveys and questionnaires; electronic health records

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Introduction

Background

Web-based surveys are convenient and cost-effective means for collecting research information. Researchers can reach a large number of participants quickly through electronic media, such as email and websites, when compared with conventional paper-based surveys. Applications like REDCap (REDCap Consortium) and SurveyMonkey (SurveyMonkey, Inc) automate the data collection and storage process as well as provide the capability to capture survey paradata or metadata. Web-based paradata allow researchers to capture respondent actions in addition to responses and to track the time participants spend on particular questions [1]. By linking surveys to clinical databases such as electronic health records (EHR), participant characteristics and other information (eg, biomarkers, medical history, laboratory results) can be used to customize questions posed to respondents.

This technology's relative ease in soliciting survey participants is coupled with an increased risk of survey attrition—participants dropping out. Potential respondents may ignore solicitations, whereas others may skip questions or exit the survey before answering all the questions. Proper testing before administration, such as completion of a principal component analysis or factor analysis of survey items [2,3], helps ensure the validity, internal consistency, and reliability of the proposed survey instrument. Although we encourage researchers to engage in formative research and test their survey to address the issue of attrition before administering a survey instrument, we have seen in other research and experienced firsthand that these measures are sometimes not enough to prevent attrition from occurring.

Attrition can occur through different mechanisms and produce different types of bias. Nonusage or nonresponse attrition occurs when participants are solicited but choose not to participate in a survey [4,5] and this has been studied extensively [6,7], whereas dropout attrition occurs when a participant begins a survey but does not complete it [4,5]. These 2 types of attrition also occur in randomized controlled trials (RCTs) and longitudinal studies conducted both in person and on the Web. Prior research in this area has investigated both the degree to which attrition from clinical trials occurs and methods for retaining participants [8-12]. In this paper, dropout attrition in the RCT setting and nonresponse attrition are not considered, as we are specifically interested in dropout attrition in surveys or questionnaires.

Respondent fatigue is another factor which leads to dropout attrition, especially when questions seem inappropriate or inapplicable [13-15]. Although subject attrition is an issue in all types of health services research, dropout in Web-based health research can exceed expectations, reducing statistical power and potentially introducing bias [4]. Additionally, dropout is often ill reported or presented in a way that prevents readers from being able to fully understand attrition [5]. In 2005, after observing a large proportion of dropouts in several eHealth interventions, Eysenbach called for a "science of attrition" and more appropriate models for reporting and analyzing this phenomenon [4]. This science has 2 facets: survey techniques for minimizing survey attrition and methods for analyzing attrition patterns within particular studies. This paper focuses on the latter. Survey attrition research has generally focused on nonresponse attrition—when those invited to complete a survey choose not to participate—and on ways to increase overall participation. When Christensen and Mackinnon called for better methods to model the patterns, causes, and consequences of attrition, Eysenbach added that authors should explicitly state attrition rates and analyze dropout whenever possible, providing insight into why and for whom the intervention or survey did or did not work [16,17]. The potential for electronically delivered surveys to capture detailed information beyond the survey responses make them ideal for these types of attrition analyses.

Objectives

This paper discusses novel ways to measure and investigate "dropout attrition" [4] for online surveys. We propose a conceptual approach to analyze attrition that begins with visualizing where attrition occurs and is followed by identifying attrition trends or patterns and examining factors associated with attrition. The methods proposed here are not intended to be exhaustive, but rather to serve as a starting point for establishing the science of dropout attrition. The methods were illustrated through a Web-based survey administered to patients who were eligible or overdue for breast, colorectal, or prostate cancer screenings [18].

Methods

Methods for Evaluating Attrition

Our proposed approach for evaluating dropout attrition includes 3 steps that are as follows: (1) visualization, (2) confirmation, and (3) factor identification. These steps are arranged in the order of increasing thoroughness for investigating attrition, with each step providing a more nuanced and detailed picture. Thus, investigators can work through these steps as far as their needs require.

Visualizing Attrition

The graphic representation of participant dropout could help visualize attrition trends or patterns. We proposed 2 visualization types—bar charts and survival-type curves—each with several variations to highlight different attrition trends.

Bar charts that described the amount (proportion, percentage, or number) of respondents or dropouts for each survey item provided multiple perspectives to explore dropout patterns. They allowed identification of differences between sequential questions, isolation of questions of specific interest, and discovery of overall trends. Plotting the percentage or proportion of respondents or dropouts was useful for identifying potentially significant attrition trends. Whether one plots respondents or dropouts depends on personal interest, although these might not be the exact inverses if the survey allows respondents to skip items. Plotting the raw number of dropouts was useful for finding other points of attrition that were not obvious when plotting proportions. Although not statistically significant, these trends provided information about when respondents left the

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survey, information that could be useful while testing a new survey instrument. Further, the stacked bar chart, which added the percentage of skips in each question, helped to better visualize attrition for surveys with skip patterns. Grouped bar charts were useful for comparing attrition visually between groups. As these final 2 types of bar charts may not be applicable, we suggest, at minimum, plotting the percentage of respondents or dropouts, along with the raw number of dropouts, to visualize attrition patterns.

Survival-type curves (or step functions) provided another way to visualize attrition. Unlike traditional survival curves, which stipulate decreasing patterns, these plots could incorporate situations in which the number of responses increased (eg, when a large number of respondents skip a particular item). These plots provided visual comparison of several groups with more clarity than the grouped bar chart, especially when comparing more than 3 groups. This visualization type was also useful for identifying what Eysenbach describes as the sigmoidal attrition curve, a pattern that includes a "curiosity plateau" at the beginning of the survey when response rates are high, an attrition phase when response rates decrease, and a stable participation phase when response rates are relatively constant for the remainder of the survey [4].

Confirming Significant Attrition

The second step was to determine whether any visually identified attrition patterns were statistically significant. A statistical model could determine the attrition changes from question to question. For example, a generalized linear mixed model (GLMM)—a broad set of models that includes logistic and Poisson regression—could incorporate both fixed and random effects to test if the proportion of patient responses decreases between subsequent questions [19]. Unlike simpler approaches (such as a chi-square test), GLMMs can account for the subject-level dependence due to previous attrition, which determines whether a subject responds to subsequent questions.

We applied a GLMM to test the hypothesis that the proportion of respondents is equal between 2 sequential questions. In our model, the outcome is binary, whether or not a person answered the survey questions (yes or no). An indicator for identifying the previous or subsequent question was included as a fixed effect and a subject-level random effect was included to account for within-subject dependence between response rates. The GLIMMIX procedure in the SAS software (SAS Institute) can be used to fit the GLMM to each pair of sequential questions. To transform the results into the difference in proportions, the IML procedure is needed to apply the multivariate delta method and thereby obtain a point estimate of the difference in response rates, along with the standard error and 95% CI for each comparison. The NLMIXED procedure could also be used to directly obtain point estimates of the difference in response rates between subsequent questions, but it does not allow for the covariance structure necessary to model more than 2 questions at a time.

Identifying Respondent Factors Associated With Attrition

The final step was to examine different factors that may be associated with attrition, such as patient characteristics (eg, age, gender), health outcomes (eg, cancer screening), survey responses, and survey metadata. Knowing that significant attrition trends exist in the dataset, we investigated factors associated with the observed dropout; high attrition rates could be attributable to any number of factors, including the survey itself. Results could also be stratified by population subgroups, such as gender, race, and ethnicity. In addition to looking at attrition question by question, we could also consider the overall attrition as a binary variable (ie, survey completers vs noncompleters).

We proposed 3 general methods for examining factors suspected to be associated with attrition: chi-square analyses (or Fisher's exact test), the log-rank test, and Cox proportional hazards regression. Whereas previous research has used chi-square analyses to compare completers and noncompleters by demographics and lifestyle characteristics [20], we proposed the additional use of EHR data as well as survey characteristics, optimizing the use of an online platform to gather more information regarding attrition patterns.

We adopted Eysenbach's suggestion for survival analysis [4] and used both the log-rank test and Cox proportional hazards regression to compare the overall trends in attrition. By comparing subsets of respondents, survival analysis helped us to verify that factors such as the language and content of the survey were not biased against particular groups. The log-rank test compared the overall attrition trends between mutually exclusive groups when survival trends were monotone (strictly decreasing). Cox proportional hazards regression was then used to adjust for other covariates that might confound or modify differences in survival trends; a significant covariate suggested confounding and a significant interaction suggested effect modification. For both the log-rank and Cox proportional hazards models, survival was defined as survey completion; respondents who completed the survey were deemed censored after the final question. This method has been previously used to compare groups in both the dropout attrition and nonusage attrition settings [20,21].

Test Case

The survey—entitled the Informed Decision-Making (IDM) module—was designed by our research team to explore how people approach potentially difficult decisions about breast, colorectal, and prostate cancer screenings. It was developed in 2013 through intensive stakeholder engagement, including working with patients to ensure questions were in an understandable format that was easy to answer [18]. The survey consisted of 17 questions that explored patients' awareness of cancer screening, chief concerns, and next steps [18]. Screenshots of these questions are provided in Multimedia Appendix 1. The IDM module also examined the patient's agenda in discussing screening at their next appointment, including the format in which they preferred to receive information.

The study was conducted between January and August, 2014 at 12 primary care practices in northern Virginia that used the interactive online patient portal *MyPreventiveCare* (MPC) [22-25], which links directly to the practices' EHR. The IDM module was programmed to query the EHR database to identify

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3 groups of patients with MPC accounts: women aged 40-49 years who had not had a mammogram within 2 years, men aged 55-69 years who had not had a prostate-specific antigen test within 2 years, and adults aged 50-74 years who were not up-to-date with colorectal cancer screening. Those eligible for more than one screening test at the time of recruitment were invited to select which module they wanted to complete (see Multimedia Appendix 1). Patients were prompted to complete the IDM module during 3 distinct phases. In phase 1, patients meeting inclusion criteria were prompted to complete the module when using MPC for other reasons. During phase 2, eligible patients with an upcoming wellness visit were emailed up to 3 invitations to participate. In phase 3, every eligible patient in the practices' EHR database, irrespective of whether they had a scheduled appointment, was emailed up to 3 invitations to complete the IDM module. Data for this study include patients' responses to the IDM module supplemented with demographic information from the practices' EHR.

Most questions in the IDM module had several subquestions. The system did not force respondents to answer all questions and allowed patients to skip questions. Five questions were directed to a subset of patients based on their answer to a previous question. Although these questions were imperative to our original study goals, we excluded them from this attrition analysis. The study was funded by the Patient Centered Outcomes Research Institute in 2012 and approved by the Virginia Commonwealth University Institutional Review Board [26].

All statistical analyses were conducted using SAS version 9.4 (SAS Institute), whereas all graphs were created using R version 3.1.1 (R Foundation for Statistical Computing) with the *rms, survival, ggplot2, gridExtra, rColorBrewer, and survminer* packages. Inferences were made at 5% significance level.

Results

Visualizing Attrition

During the study period, 2355 patients started the IDM module: 638 from the breast cancer cohort, 1249 from the colorectal cancer cohort, and 468 from the prostate cancer cohort. A bar chart displayed the percentage of respondents for each succeeding question in the module (Figure 1, left panel). It shows that the largest declines in the percentage of respondents occurred between Questions 2 and 4 and between Questions 4 and 6 (Questions 3 and 5 were ignored because they were directed only to specific subsets of subjects). After Question 6, the percentage of respondents remained relatively constant. Eysenbach's curiosity plateau appeared to last until Question 2 [4]. The attrition phase began at Question 2 and ended after Question 6. This was followed by the stable participation phase, where the overall attrition rate converged to about 60%.

The bar chart reveals an increase in the percentage of patients who answered Question 8, which occurred because patients were able to skip questions. A stacked bar chart demonstrates that some participants skipped Questions 4, 6, 7, 9, and 12 (Figure 1, right panel).

The right panel of Figure 2, which plots the dropout rates for each question, again shows that the percentage of dropouts increased drastically between Questions 2 and 6, leveling off thereafter. The left panel of Figure 2, which plots the absolute number of dropouts by question, yet again shows that most attrition occurred at Questions 4 and 6 but also reveals a second wave of attrition around Question 10 that was not obvious in prior figures.

We used grouped bar plots as per Ekman [1] to compare the number of dropouts by type of cancer screening (Figure 3, left). Whereas the general trends are consistent across cohorts, between-group comparisons are skewed due to the unequal sample sizes of each group (the colorectal cancer cohort was larger than both the breast and prostate cancer cohorts combined). Therefore, the right panel of Figure 3 compares the percentages of dropouts in each cohort with a grouped bar plot to adjust for differences in sample size. This plot shows that the breast cancer cohort had the highest attrition at each question while the prostate cancer cohort had the lowest attrition rate.

The top panel of Figure 4 displays the survival-like attrition curves for each cohort and overall, showing large vertical drops (ie, increased attrition) at Questions 4 and 6. This plot also highlights that the proportion of answers increased between Questions 7 and 8, a trend especially pronounced in the prostate cancer cohort. Overall dropout was highest in the breast cancer cohort and lowest in the prostate cancer cohort. The bottom panel of Figure 4 uses shading to display skips (as in the right panel of Figure 1) and vertical lines to highlight our estimation of the curiosity, attrition and stable phases per Eysenbach.

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Figure 1. Bar charts for percent of answers for all cancer types without skips (left) and with skips (right).

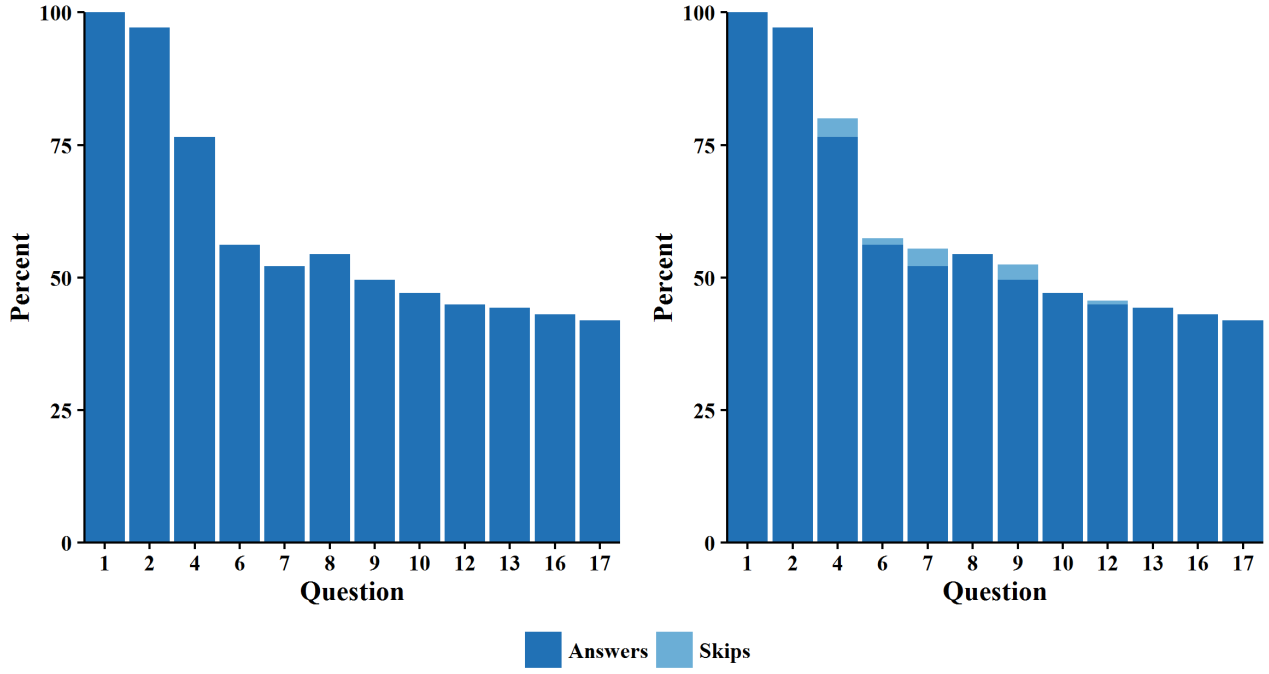
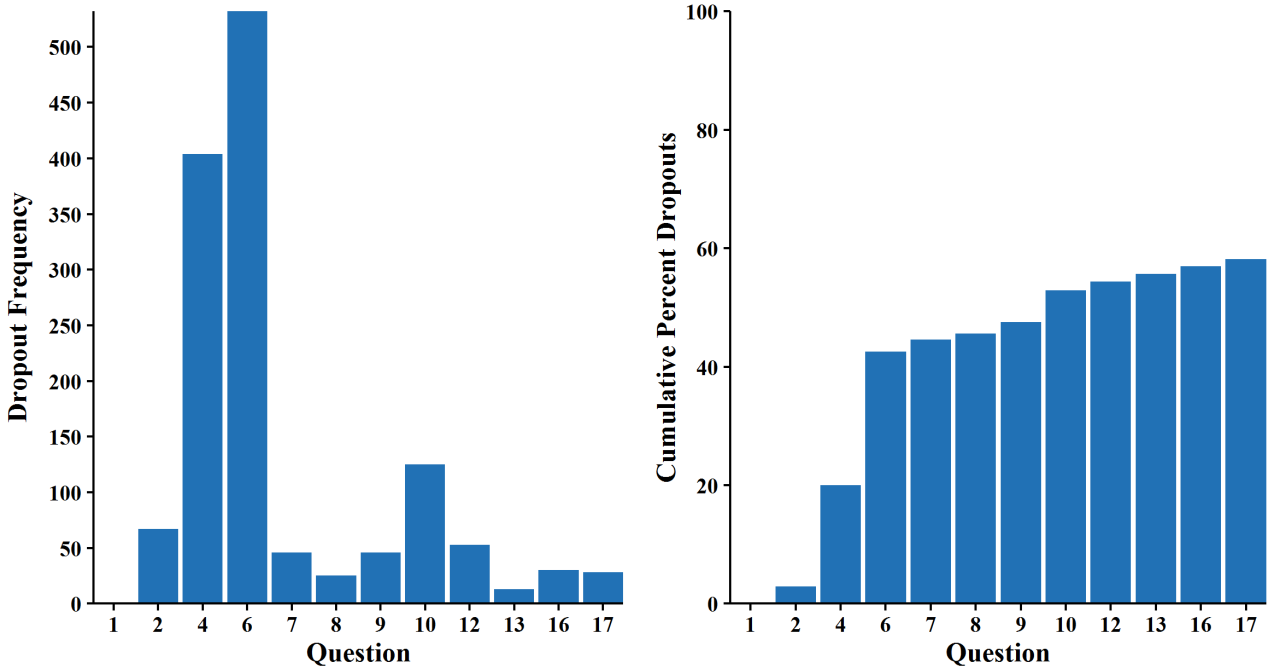


Figure 2. Bar charts for number of dropouts (left) and percent of dropouts (right).



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Figure 3. Grouped bar charts for the number of dropouts (left) and percent of dropouts (right).

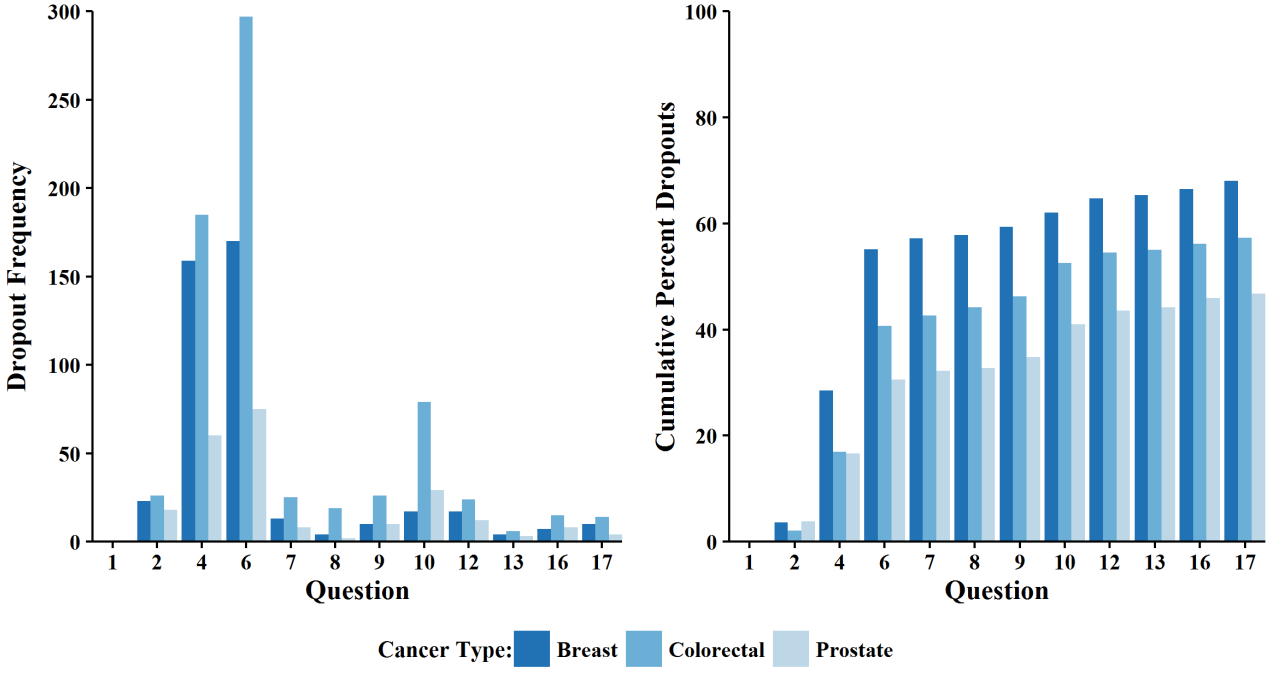
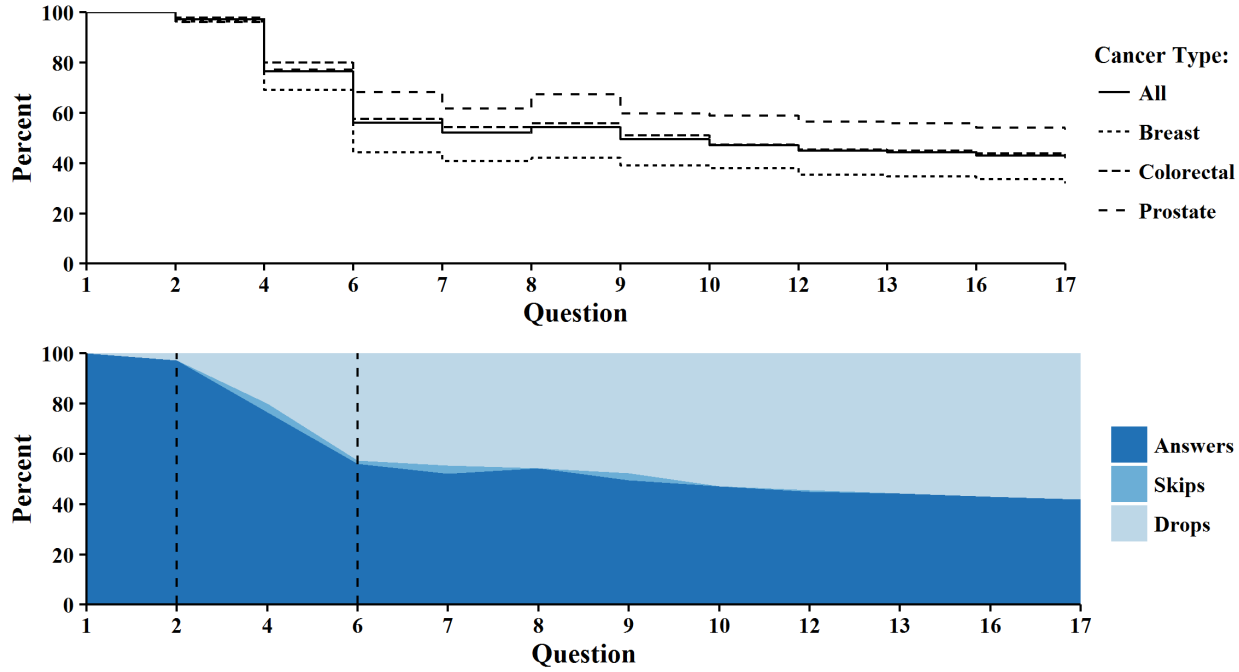


Figure 4. Step function comparing all cohorts (top) and attrition curve of all cancer types (bottom).



Confirming Significant Attrition

As observed through visualization, the GLMM results suggest that the attrition that occurred between Questions 2 and 4, 4 and 6, 6 and 7, and 8 and 9 were statistically significant (P<.05, Table 1). These pairs of questions also exhibited the largest decreases in response rates (20.68%, 20.33%, 3.99%, and 4.88%, respectively). Between-question differences in response proportions were mostly positive, indicating that the response rates generally decreased (and attrition increased). An exception was the change in response rates between Questions 7 and 8 (52.14% and 54.39%, respectively), which increased and led to a negative difference (–2.25%). This pattern, observed visually in Figures 1 and 4, was due to some respondents skipping questions.

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Table 1. Generalized linear mixed model (GLMM) results.

Analysis	p_1	p_2	p_1-p_2	Standard error	95% CI	*P* value
Q1 to Q2	1.00	0.97	0.03	0.660	−1.264 to 1.321	.99
Q2 to Q4	0.97	0.76	0.21	0.001	0.206 to 0.208	<.001
Q4 to Q6	0.76	0.56	0.20	0.001	0.203 to 0.204	<.001
Q6 to Q7	0.56	0.52	0.04	0.001	0.039 to 0.041	.006
Q7 to Q8	0.52	0.54	−0.02	0.001	−0.023 to −0.022	.12
Q8 to Q9	0.54	0.49	0.05	0.001	0.048 to 0.049	<.001
Q9 to Q10	0.49	0.47	0.02	0.001	0.023 to 0.024	.10
Q10 to Q12	0.47	0.45	0.02	0.001	0.022 to 0.023	.12
Q12 to Q13	0.45	0.44	0.01	0.001	0.005 to 0.006	.70
Q13 to Q16	0.44	0.43	0.01	0.001	0.012 to 0.013	.38
Q16 to Q17	0.43	0.42	0.01	0.001	0.011 to 0.012	.41

Identifying Respondent Factors Associated With Attrition

We used the chi-square test to determine if a respondent's answer to a particular question was associated with dropout in the next question and found that patients in the middle of the decision-making process—having indicated on Question 2 that they were either thinking about or close to making a decision (Multimedia Appendix 1)—were significantly less likely to drop out compared with those who had already made a choice or had not yet given the issue any thought (Table 2). Chi-square testing of subsequent screening behavior revealed that patients who completed the survey were more likely to get the screening test that their survey addressed than the noncompleters (22.37% and 17.42%, respectively, *P*=.003).

Table 2. Determining if a patient's response to Question 2 ("How far along are you with making a decision about cancer screening?") was associated with answering the next question.[a]

Response to Question 2	Answered Question 4	
	Yes (%)	No (%)
I have not yet thought about the choice.	79.47	20.53
I am thinking about the choice.	85.54	14.46
I am close to making a choice.	84.72	15.28
I have already made a choice.	75.24	24.76

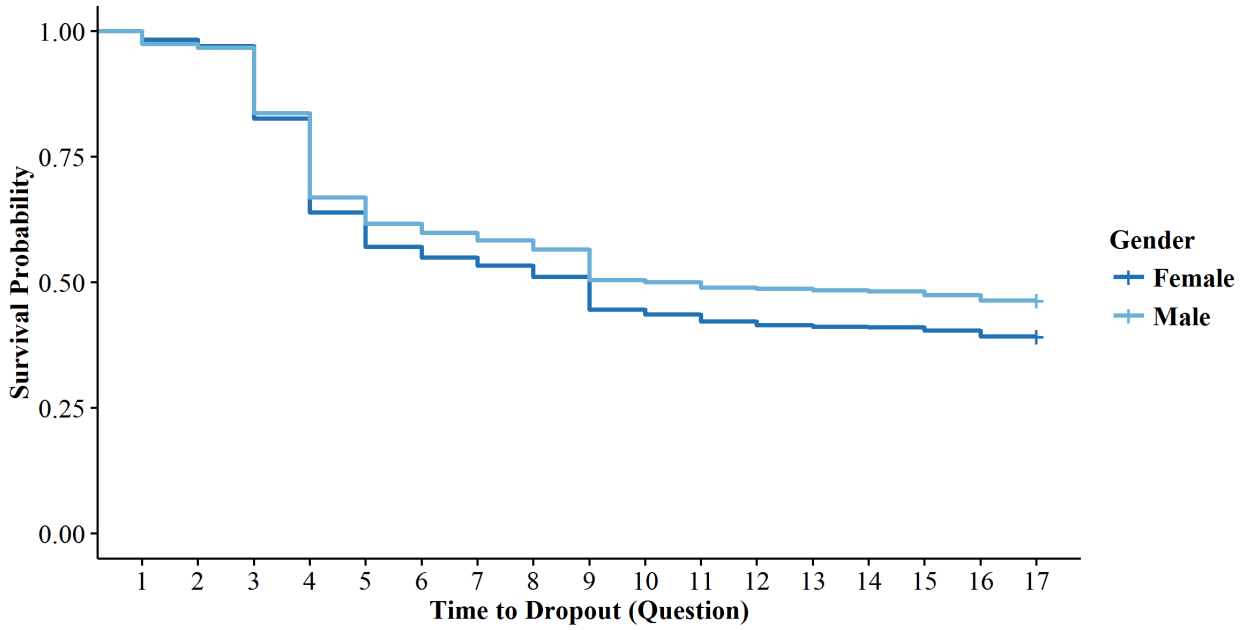
[a]Overall chi-square test: *P*<.001

We applied the log-rank test to determine if the overall attrition pattern differed by gender within the colorectal cancer cohort (the only cohort that included both men and women) and found that the dropout pattern differed significantly (*P*=.02). The Kaplan-Meier curves show that females tended to have higher attrition rates than males (Figure 5), especially after Question 5.

We performed a Cox proportional hazards regression to examine whether the relationship between gender and dropout was confounded by demographic and other patient characteristics. Bivariate analyses of ethnicity, race, preferred language, recruitment phase, insurance type, and age, when compared with time to dropout, suggested that recruitment phase was the only covariate associated with survey completion (*P*=.03). After checking the proportional hazards assumption, gender, recruitment phase, and their interaction were entered into a multivariate model. The interaction was not significant, thus recruitment phase was determined to not be an effect modifier (*P*=.98). In the final model, which was adjusted for recruitment phase, it was found that gender was not significantly associated with time to dropout (*P*=.07), suggesting that attrition patterns did not differ by gender when adjusting for the recruitment phase.

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Figure 5. Kaplan-Meier survival curves by gender within colorectal cancer cohort.



Discussion

Principal Findings

Using our test case, visualization allowed us to identify the two most obvious points of attrition, Questions 4 and 6, with the overall attrition rate converging to approximately 60%. The use of the GLMM helped confirm these as points of significant attrition and chi-square analyses suggest that participant responses from prior questions were associated with dropping out at these points. Overall, survival analyses suggested that IDM module dropout was significantly associated with gender, implying that survey content was biased toward men, but not after accounting for recruitment phase. Furthermore, survey completion was positively associated with getting the cancer screening test. Despite the yearlong effort to create the IDM module, including focus groups, question testing, and several revisions [18], our use of the proposed framework show that this new instrument can be improved.

The proposed framework suggests that we plot overall attrition to identify patterns, analyze these patterns for significance, and then investigate potential reasons for dropout throughout the module. As the first step in evaluating attrition, visualization provides a broad view of dropout patterns throughout a survey, such as visual approximations of Eysenbach's curiosity, attrition, and stable use phases [4]. Even if questions that appear to have high dropout in this step do not turn out to be statistically significant points of attrition, this step still highlights questions that might be too complex, poorly worded, or provide enough information that participants do not feel the need to continue further.

Prior work in this area has encountered challenges. For example, Ekman plotted the number of dropouts per question on 2 surveys in a bar chart, revealing that most of the dropout occurred within the first 8 questions [1]. Although the grouped bar chart was informative in this instance, this type of plot has the limitation of appearing crowded and is difficult to interpret if it includes several groups. Ekman also employed the use of step functions, although high response rates made it difficult to identify questions with high attrition [1]. Whereas the survival-type curve can be a useful visualization tool, it may be less informative when attrition is low. Hoerger used a step function to compare attrition between 6 surveys, but inconsistent survey lengths made it difficult to compare the attrition rates [15]. An advantage of step functions and survival-type curves is that they can display skip patterns, whereas the survival analysis setting does not allow researchers to take this into account.

The second stage of our dropout attrition framework is designed to confirm whether certain drops in response rates are significant. These formal statistical analyses can not only confirm observed trends from the visualizations, but also locate differences that were not observable.

The last stage proposes an examination of possible causes of participant dropout. Collecting and adjusting for demographic characteristics (especially those previously suggested as predictive of survey completion including gender, age, education, and ethnicity) [13,20] may identify biases in the survey content or wording of survey items. The association between participant responses and dropout in the next question may suggest which patients are most interested in the survey or what content retains more respondents. Prior research suggests that relevant survey content is actually more predictive of dropout attrition than overall survey length [13-15]. This framework allows researchers to identify "problem questions" and adjust content when appropriate.

Limitations

As noted in the Introduction, the methods proposed here are meant only as a starting point. These methods could additionally be considered as a part of the survey testing process in helping to refine the instrument and retain the maximum number of participants. This paper does not discuss other forms of attrition that apply to online surveys, such as nonresponse attrition,

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attrition in longitudinal surveys, or methods to minimize attrition or correct for potential bias introduced by high attrition rates.

Future Work

Although not exemplified in this paper, discrete time survival analysis would be a more appropriate though more complex method to identify this type of survival pattern as patients can only drop out at discrete time points (ie, after each question). We applied the GLMM pairwise to our case study but it is also possible to fit a single model to the entire survey, though this complex modeling would require more sophisticated parameterization (eg, dependence structures) that may affect estimator accuracy and convergence. The indicator used in our GLMM distinguished whether a patient answered a survey question or not, but could have instead indicated whether the respondent dropped out at a particular question. Results will not be the exact inverse in cases where respondents are allowed to skip questions.

These analyses can be enhanced by linking responses to subject characteristics or metadata. Online surveys provide additional information not previously available in paper-based surveys, perhaps most notably metadata. The amount of time a patient spends on each question, the time of day a survey is taken, and Internet browser version compatibility are all examples of metadata that could also affect attrition patterns.

Survey characteristics associated with overall completion, such as survey relevance, could also be examined question by question [13]. In addition, although we suggest several types of factors that may be associated with attrition (and analyzed them separately in our test case), we acknowledge that it may also be useful to look at these factors simultaneously. It is up to the discretion of the researcher to determine whether or not to look at these factors separately or together in a model-based method, such as multiple logistic regression.

Conclusions

We contend that simply reporting attrition rates is not enough; we must dig deeper to examine where and why attrition occurs. Our contribution here is to advocate advances in the science of attrition. The framework outlined in this manuscript is especially important when fielding new surveys that have not been previously tested or validated. This framework is best applied as both part of the survey development process and as a tool for interpreting survey results. We encourage researchers to engage with these steps throughout the research process as we work as a community to establish a “law of attrition.”

Acknowledgments

This project was funded by the Patient Centered Outcomes Institute (PCORI Grant Number IP2PI000516-01) and National Center for Advancing Translational Sciences (CTSA Grant Number ULTR00058). The opinions expressed in this paper are those of the authors and do not necessarily reflect those of the funders.

The authors thank the research teams and Dr Robert Perera, Paulette Kashiri, and Eric Peele for their valuable efforts.

Furthermore, the authors thank their practice partners at Privia Medical Group and the Fairfax Family Practice Centers, including Broadlands Family Practice, Family Medicine of Clifton and Centreville, Fairfax Family Practice, Herndon Family Medicine, Lorton Stations Family Medicine, Prince William Family Medicine, South Riding Family Medicine, Town Center Family Medicine, and Vienna Family Medicine for their insights and hard work.

Conflicts of Interest

None declared.

Multimedia Appendix 1

MyQuestions Informed Decision Making Module.

[PDF File (Adobe PDF File), 2MB - jmir_v18i11e301_app1.pdf]

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Abbreviations

EHR: electronic health records
GLMM: generalized linear mixed model
IDM: informed Decision-Making
MPC: MyPreventiveCare
RCT: randomized controlled trial

Edited by G Eysenbach; submitted 12.07.16; peer-reviewed by D Guertler, J Alpert, R Kok; comments to author 04.08.16; revised version received 12.09.16; accepted 07.10.16; published 22.11.16.

Please cite as:
Hochheimer CJ, Sabo RT, Krist AH, Day T, Cyrus J, Woolf SH
Methods for Evaluating Respondent Attrition in Web-Based Surveys
J Med Internet Res 2016;18(11):e301
URL: http://www.jmir.org/2016/11/e301/
doi:10.2196/jmir.6342
PMID:27876687

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Original Paper

Do We Still Have a Digital Divide in Mental Health? A Five-Year Survey Follow-up

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Abstract

Background: Nearly everyone in society uses the Internet in one form or another. The Internet is heralded as an efficient way of providing mental health treatments and services. However, some people are still excluded from using Internet-enabled technology through lack of resources, skills, and confidence.

Objective: Five years ago, we showed that people with severe mental illness were at risk of digital exclusion, especially middle-aged patients with psychosis and/or people from black or minority ethnic groups with psychosis. An understanding of the breadth of potential digital exclusion is vital for the implementation of digital health services. The aim of this study is to understand the context of digital exclusion for people who experience mental illness.

Methods: We conducted a survey involving people with a primary diagnosis of psychosis or depression in London, United Kingdom. A total of 241 participants were recruited: 121 with psychosis and 120 with depression. The majority of surveys were collected face-to-face (psychosis: n=109; depression: n=71). Participants answered questions regarding familiarity, access, use, motivation, and confidence with Internet-enabled technologies (ie, computers and mobile phones). Variables predicting digital exclusion were identified in regression analyses. The results were compared with the survey conducted in 2011.

Results: Digital exclusion has declined since 2011. Online survey collection introduced biases into the sample, masking those who were likely to be excluded. Only 18.3% (20/109) of people with psychosis in our sample were digitally excluded, compared with 30% (28/93) in 2011 (χ^2_1=3.8, *P*=.04). People with psychosis had less confidence in using the Internet than people with depression (χ^2_1=7.4, *P*=.004). Only 9.9% (24/241) of participants in the total sample were digitally excluded, but the majority of these people had psychosis (n=20). Those with psychosis who were digitally excluded were significantly older than their included peers (t_{30}=3.3, *P*=.002) and had used services for longer (t_{97}=2.5, *P*=.02). Younger people were more likely to use mobile phones. Digitally excluded participants cited a lack of knowledge as a barrier to digital inclusion, and most wanted to use the Internet via computers (rather than mobile phones).

Conclusions: Digital exclusion is lower, but some remain excluded. Facilitating inclusion among this population means helping them develop skills and confidence in using technology, and providing them with access. Providing mobile phones without basic information technology training may be counterproductive because excluded people may be excluded from mobile technology too. An evidence-based digital inclusion strategy is needed within the National Health Service to help digitally excluded populations access Internet-enabled services.

(J Med Internet Res 2016;18(11):e309) doi:10.2196/jmir.6511

KEYWORDS

digital divide; socioeconomic factors; technology; mobile phone; psychotic disorders; distance counseling

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Introduction

Online services are integral to the future of the UK National Health Service (NHS) [1]. The Internet is almost ubiquitous. Between 2000 and 2016, worldwide use increased by 900% [2]; 86% of the UK population have access and more than three-quarters use it on a near-daily basis [3]. Nonetheless, these figures hide a digitally excluded minority: approximately 10% of the UK population have never used the Internet [4]. Reducing digital exclusion in this minority has been highlighted as an NHS priority [5].

Mental illness, particularly depression and anxiety, have long been targets for online interventions. Cognitive behavioral therapy tools have been available online for many years, such as "Beating the Blues." Computer literacy and familiarity with the Internet are essential for online interventions to be effective. A survey conducted in 2011 of people with mental illness (the majority of whom experienced psychosis) demonstrated that people who had been unwell for longer were at risk of digital exclusion, and that service users from black and minority ethnic (BME) groups were more likely to access public Internet facilities rather than personal devices [6], which may affect the privacy of their health data. Other studies indicate that people with longer-term psychotic illnesses have showed higher rates of independent use of digital tools than people using early intervention services [7]

The nature of the digital divide is complex and varies over time [8]. Technological developments in the last five years have been dramatic; more than three-quarters of the UK population now own an Internet-enabled mobile phone [9], whereas traditional public sources of the Internet (eg, libraries) are suffering from reduced funding [10]. There is a lack of recent information on digital exclusion in those who use mental health services, and this information is important for those developing and implementing eHealth services and therapies [11-13]. A recent online survey of people with psychosis identified high proportions accessing Internet-enabled devices, but it only included people who were already using the Internet [14]. The aim of this study is to update conceptions of digital exclusion in people with two different mental illness diagnoses (psychosis and unipolar depression). The hypotheses of the study were

1. Digital exclusion is less in 2016 than in 2011 due to the increased availability of Internet-enabled mobile phones;

2. People with psychosis are at higher risk of exclusion compared to people with depression; and

3. People at higher risk of digital exclusion (eg, people with psychosis, those with a longer duration of illness, people from BME groups) will still show higher rates of exclusion.

In addition, we wanted to understand the sorts of barriers that need to be overcome to make any digital health service available to the largest proportion of patients.

Methods

Design and Setting

We collected data from a cross-sectional survey of Internet technology use among people with a primary diagnosis of psychosis or unipolar depression. The study took place at a large UK secondary mental health care provider. Data were compared with the same data collected in a 2011 survey [6].

Sample and Recruitment

We recruited participants with a primary clinical diagnosis of either psychosis (schizophrenia or schizoaffective disorder) or unipolar depression, confirmed through case notes.

Measures

We collected demographic and clinical data via survey and from case notes.

The Digital Inclusion Survey included items from the 2011 version [6]. The domains of Internet use included were Internet access, familiarity, confidence, daily use, and motivation to use Internet-enabled technology. The Digital Inclusion Survey included items on barriers to using technology, including lack of knowledge, availability, lack of credit on pay-as-you-go phones (or lack of money to purchase credit), Internet access, wanting to use technology, and security concerns. We also investigated the use of social media.

Survey terminology was updated or adapted to reflect technology developments since 2011. The survey could be completed face-to-face or online. It was assessed for acceptability and feasibility with service users who were attending "drop-in" Internet practice sessions organized by the NHS Trust [15].

Procedure

To access those who have different patterns of service use, we recruited participants from inpatient units, outpatient community psychosis teams, early intervention services (for psychosis), and community services for people with depression. We also used an online research register [16]. All register participants were contacted using their preferred method of contact; those who responded by email were offered the option of completing the survey online.

Ethical approval was granted by the London Camden and Kings Cross Research Ethics Committee (reference: 10/H0722/79).

Data Analysis

Sampling Effects

We explored whether the diagnosis samples differed in their characteristics and across different methods of data collection (face-to-face or online).

Exploring Internet Use

Chi-square tests (two-sided) were used to explore differences in Internet use and motivation to use the Internet between diagnostic groups. Descriptive statistics were used to analyze self-reported barriers to Internet access and use of social media.

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Those who completed the survey face-to-face were analyzed separately from those who completed it online.

Characterizing Digital Exclusion

"Lacking access to Internet technology" and "lacking confidence in using Internet technology" are potential indicators of digital exclusion. Logistic regression analyses were conducted to identify whether three candidate variables (each identified from previous research) predicted exclusion: age, ethnicity, and chronicity of illness. We completed separate regression analyses to see if these factors predicted exclusion from (1) all Internet-enabled devices, (2) computers, and (3) Internet-enabled mobile phones.

Digital exclusion was defined as anyone lacking access to any Internet-enabled device (or lacking confidence in using any Internet-enabled device) *and* accessing social media sites infrequently (ie, monthly or less than monthly). We investigated the characteristics of this group and examined differences between this group and the remainder using chi-square tests.

Examining Differences Over Time

People with psychosis were compared with those from the 2011 sample. To ensure consistency across the samples, we only included participants from the 2011 survey who had a primary clinical diagnosis of schizophrenia or schizoaffective disorder, and excluded participants from the 2016 sample who had completed the survey online. Two-sided *t* tests and chi-square tests were used to compare demographics. One-sided chi-square tests were used to compare digital exclusion over time.

Results

Sample Characteristics

A total of 241 participants were recruited: 166 through visits to outpatient clinical teams, 22 from inpatient units, and 53 from research registers. Demographic and clinical information (along with comparisons between the two diagnostic groups) are presented in Table 1.

Table 1. Sample characteristics.

Variable	2011	2016[a]				
	Psychosis (n=93)	Psychosis (n=121)	Depression (n=120)	χ^2_1	*t* (df)	*P* (2-sided)
Age (years), mean (SD)	34.6 (11.6)	38.2 (13.2)	39.1 (13.4)		0.55 (234)	.59
Gender (male), n (%)	65 (70)	81 (67)	53 (44)	12.7		<.001
Illness duration (years), mean (SD)	—	10.1 (10.0)	4.3 (6.9)		–4.97 (215)	<.001
Ethnicity, n (%)						
BME	58 (62)	75 (62)	29 (24.2)			
White	35 (38)	46 (38)	88 (73.3)			
Location, n (%)						
Community team	67 (72)	67 (55.4)	24 (20)			
Early intervention	24 (26)	27 (22.3)	73 (60.8)			
Other	—	27 (22.3)	23 (19.2)			

[a] Comparisons made within 2016 sample only.

The groups were balanced for age, but those with psychosis had a longer history of illness. The psychosis group contained more people from BME backgrounds (χ^2_1=33.5, *P*<.001) and more men.

In all, 180 participants completed the survey face-to-face (109 people with psychosis, 71 with depression) and 61 completed the survey online (12 with psychosis, 49 with depression). There were no significant demographic differences between different modes of completion for either diagnostic group. Among people with psychosis only, those who completed the online survey had more confidence with computers (χ^2_1=3.7, *P*=.07), better access to mobile phones (χ^2_1=4.5, *P*=.06), and were more confident using a mobile phone (χ^2_1=3.6, *P*=.07). These tests showed imbalances within the sample despite the fact that these associations did not reach statistical significance. Therefore, subsequent analysis of Internet use was completed separately for the two modes of survey completion.

Exploring Internet Use

For face-to-face survey completion, Internet use among people with psychosis and depression is presented in Figure 1. Fewer people with psychosis had access to the Internet (χ^2_1=3.4, *P*=.08), either via computers (χ^2_1=5.6, *P*=.02) or mobile phones (χ^2_1=24.6, *P*<.001). Fewer people with psychosis were confident in using the Internet (χ^2_1=7.4, *P*=.004) with computers (χ^2_1=5.6, *P*=.02) or mobile phones (χ^2_1=20.5, *P*<.001). Conversely, people with psychosis had higher motivation to increase their use of the Internet (χ^2_1=31.5, *P*<.001), computers (χ^2_1=25.5, *P*<.001), and mobile phones (χ^2_1=16.8, *P*<.001) than those with depression. There was a significant negative correlation between Internet access and desire to increase Internet use (*r*=–.152, *P*=.04). This suggests that those who used the Internet already did not want to increase their use (or they were already using it frequently). Only one association was significant when looking

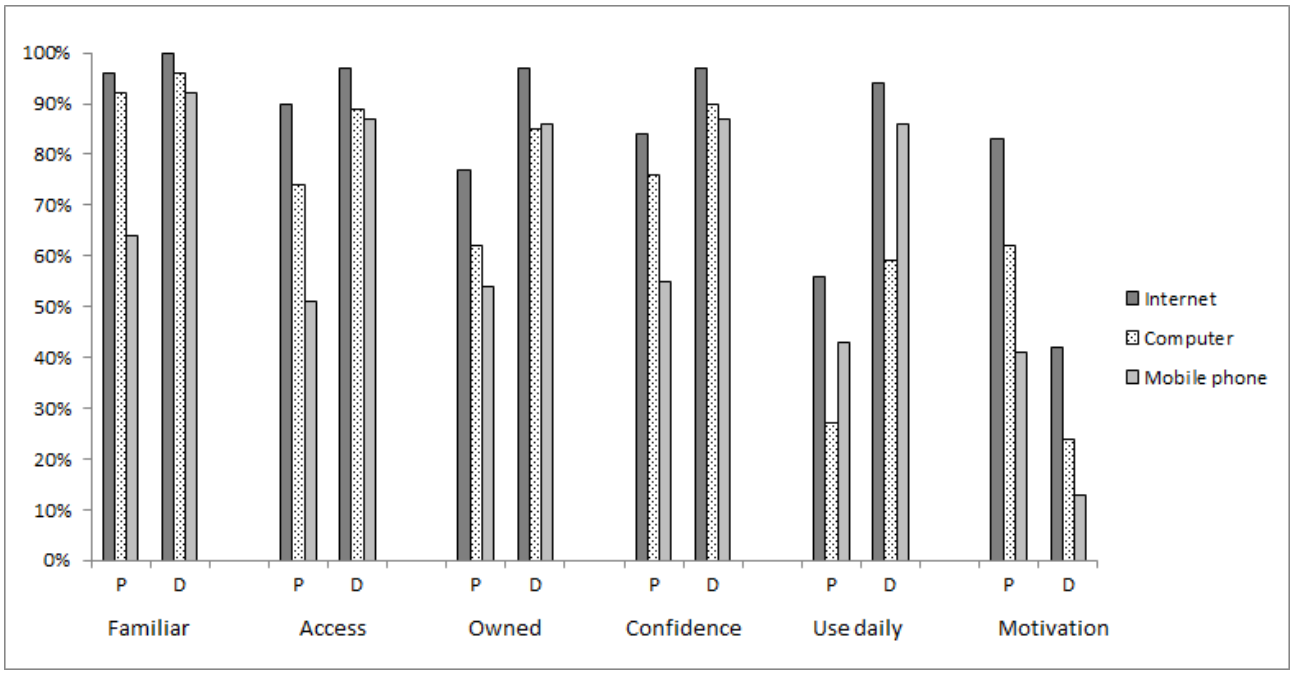
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at the participants who completed the survey online: people with psychosis had higher motivation to increase their use of the Internet than people with depression (χ^2_1=5.1, *P*=.03).

For face-to-face survey completion (psychosis: n=109), the most common barriers to using the Internet were security concerns (45.9%, 50/109), lack of credit/money (45%, 49/109), lack of knowledge (40.4%, 44/109), lack of places to access the Internet (35.8%, 39/109), and lack of availability (33.9%, 37/109). Only 15.6% (17/109) cited not wanting to use the Internet as a barrier. Among the equivalent sample with depression (n=71), the most common barriers to using the Internet were security concerns (49%, 35/71) followed by lack of credit/money (30%, 21/71). The same concerns were evident in the individuals who completed the online survey.

For people with psychosis, 55% (60/109) reported having a social media account (eg, Facebook or Twitter), 32.1% (35/109) used social media at least daily, and 45.9% (50/109) the sample reported never using it. In comparison, 82% (58/71) of the depression sample had a social media account, with 63% (45/71) using it at least daily and only 16% (11/71) never using it. The pattern of results in the online sample was similar for people with depression, but a higher proportion of people with psychosis in the online sample had a social media account (10/12) and used social media at least daily (9/12).

Figure 1. Proportion of people with a diagnosis of psychosis (P; n=109) or depression (D; n=71) using Internet-enabled devices in 2016.



Characterizing Digital Exclusion: Who Is Excluded?

Older age predicted reduced confidence with mobile phones for people with psychosis (beta=–.1, OR 0.90, 95% CI 0.84-0.95, *P*<.001), reduced access to mobile phones for people with psychosis (beta=–.05, OR 0.95, 95% CI 0.91-0.99, *P*=.04), and reduced access to computers for people with depression (beta=–.12, OR 0.89, 95% CI 0.80-0.98, *P*=.02). Ethnicity and duration of service use did not predict digital exclusion.

In all, 24 participants met the criteria for digital exclusion, of which 23 completed the survey face-to-face. Twenty digitally excluded participants had a primary diagnosis of psychosis. In comparison to "digitally included" peers, this group was significantly older (excluded: mean 45.7, SD 9.7 years; included: mean 36.8, SD 12.7 years; t_{30}=3.3, *P*=.002; equal variances not assumed) and had used mental health services for longer (excluded: mean 14.1, SD 9.2 years; included: mean 8.7, SD 8.3 years; t_{97}=2.5, *P*=.02). There were no other clinical or demographic differences. Table 2 shows that the rate of digital exclusion was higher in older people, in those with longer-term illnesses, and in people from BME groups. This was the case in both diagnostic groups.

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Table 2. Digital exclusion according to key variables.

Group variable	Psychosis		Depression	
	n	Excluded, n (%)	n	Excluded, n (%)
Age (≥36 years)	62	15 (24)	37	3 (8)
Age (<36 years)	44	3 (7)	32	0
Duration of illness (≥3 years)	74	17 (23)	27	2 (7)
Duration of illness (<3 years)	25	1 (4)	37	0
White	41	6 (15)	48	1 (2)
BME	54	14 (21)	19	2 (10)

Despite being digitally excluded, people with psychosis said that they wanted to use the Internet more often (yes=17, no=3), particularly through computers (yes=16, no=4) rather than mobile phones (yes=8, no=12). The most commonly reported barrier to using the Internet was lack of knowledge followed by lack of credit/money.

Likewise, those with depression who met the criteria for digital exclusion (n=4), were older (excluded: mean 53, SD 11 years; included: mean 39, SD 13 years) and had been using mental health services for longer (10 years vs 4 years). The sample was too small to test for statistical significance. The pattern of motivation to increase use and to use Internet-enabled devices appeared similar to that of the psychosis group.

Examining Digital Exclusion Over Time

The only significant difference between the 2011 and the 2016 samples was in age; the 2011 sample were younger (2011: mean 34.6, SD 11.6 years; 2016: n=106, mean 38.3, SD 12.7 years; t_{197}=2.1, *P*=.03).

Only 18.3% (20/109) of people with psychosis in the 2016 sample were digitally excluded compared to 30% (28/93) from 2011 and this difference was statistically significant (χ^2_1=3.8, *P*=.04). The demographics of the digitally excluded group in the 2011 were similar to those of the excluded group in 2016, in terms of age, gender, and proportion from a BME background. No differences were found in access or confidence with computers. However, there was a significant increase in mobile phone access (χ^2_1=6.7, *P*=.01) and confidence in using them (χ^2_1=28.8, *P*<.001). People were more motivated to use technology in 2016 than in 2011 with 62.4% (68/109) wanting to increase use of computers in 2016 compared to 48% (45/93) in 2011 (χ^2_1=4.0, *P*=.03). Equivalent figures for mobile phones were 41.3% (45/109) and 18% (17/93), respectively (χ^2_1=12.5, *P*<.001).

The 2016 sample showed a greater proportion used the Internet daily (56%, 61/109) compared to 35% (33/93) in 2011 and this difference was significant (χ^2_1=8.5, *P*=.005). This is due to the increase in the daily use of Internet-enabled mobile phones to 43.1% (47/109), up from 9% (8/93) in 2011 (χ^2_1=30.2, *P*<.001), as there were no significant differences in daily computer use across the samples.

Discussion

Two new findings appear since the last time we carried out this survey in 2011. First, only collecting data from online surveys is likely to produce biased results, particularly among people with psychosis. Second, digital exclusion has decreased over time, but has not disappeared. The methodological differences are important because new methods of providing mental health services using mobile devices depend on data estimating breadth of coverage. Studies only using online surveys [14] overestimate digital inclusion, access, and confidence with Internet-enabled devices among people with psychosis. The fact that there has been a reduction in digital exclusion is to be celebrated, but the fact that older individuals with more chronic conditions (eg, psychosis) have higher rates of digital exclusion is pause for thought. These people are the exact group who may benefit the most from digital health support to supplement current care.

The good news is that the majority of the 2016 sample claimed to have Internet access. The bad news is that digital inequality still exists. Daily use in the general UK population has been reported as 78% [3], higher than in the sample of people with psychosis. People with psychosis reported less confidence, access, use, and familiarity with the Internet (and devices) than people with depression. They also reported higher motivation to use the Internet more often.

There is still a digitally excluded minority without access to any Internet-enabled device and/or without confidence in using the Internet, and their characteristics were similar to those identified five years previously. They are excluded because they lack the knowledge, skill, and financial resources, not because they lack the willingness. This echoes previous findings [6,17,18], although the digitally excluded sample was even more motivated to use technology than five years ago.

The prevalence of Internet-enabled mobile phones has been the major change in online habits in the last five years, the potential of mobile phones for reducing digital exclusion cannot be taken for granted. Mobile phone use has been mainly adopted by younger service users who suffer less from digital exclusion and are more likely to use social media [19]. Individuals who are digitally excluded also preferred the idea of connecting to the Internet via a computer rather than a mobile phone. Mobile technology itself can exclude middle-aged and older people with psychosis [20], which explains our finding relating to the lack of motivation to use the Internet through mobile phones

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among digitally excluded individuals. If this is the case, then mobile phones could further exclude those who are already digitally excluded.

This study shows how difficult it is to overcome the digital divide. Providing digitally excluded people with mobile phones will not facilitate inclusion. For people who have never used the Internet, a mobile phone may initially seem even more daunting than a computer. Reducing digital exclusion will undoubtedly require training on mobile phones, but also requires intermediate steps. This may include training in basic Internet skills (possibly using computers), through the facilitation of structured information technology skills classes delivered specifically as part of a wider community service for people with psychosis [15]. This is possible to complete in conjunction with training in the use of mobile phones and the mobile Internet, as has been shown successfully in the past [13].

The sample is large enough to identify subgroups for analysis, but low numbers of digitally excluded people limit the power of statistical tests for the subsample. There were demographic differences between diagnostic groups, but such differences reflect demographic differences in the prevalence of these illnesses. Lastly, the 2011 sample was slightly (but significantly) younger than the 2016 sample, which adds further support to our findings because younger people are less likely to be digitally excluded.

Digital exclusion is common enough to cause problems for health service providers working with particular populations. It occurs more frequently among long-term users of psychosis services. The development of eHealth interventions in psychosis must account for this. Although the majority will be able to use these services, a minority will need extra support and the opportunity to learn basic information technology skills. An evidence-based digital inclusion strategy is needed to prevent digitally excluded populations becoming excluded from increasingly digital NHS services and from society in general.

Acknowledgments

The authors would like to acknowledge Zoe Bright, Sarah Joseph, Sheri Oduola, Bartlomiej Pliszka, and Gabriella Trimblett for their support in collecting data, and Liam Ennis who collected the data in 2011. We are grateful for the support of clinical teams across South London and Maudsley NHS Foundation Trust.

The authors would like to acknowledge the support the National Institute for Health Research (NIHR) Mental Health Biomedical Research Centre at South London and Maudsley NHS Foundation Trust. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health.

Authors' Contributions

DR and TW designed the study and formulated the research question. SS and LD collected the data. DR, TW, and SS developed the analysis strategy. DR, SS, and LD conducted analyses. DR and TW led the writing of the final manuscript with support from the other authors. All authors critically revised drafts and the final manuscript. All authors approved the final manuscript for submission.

Conflicts of Interest

None declared.

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Abbreviations

BME: black and minority ethnic
NHS: National Health Service

Edited by G Eysenbach; submitted 18.08.16; peer-reviewed by J Torous, K Kannisto, M Jaensson; comments to author 07.09.16; accepted 21.09.16; published 22.11.16.

Please cite as:
Robotham D, Satkunanathan S, Doughty L, Wykes T
Do We Still Have a Digital Divide in Mental Health? A Five-Year Survey Follow-up
J Med Internet Res 2016;18(11):e309
URL: http://www.jmir.org/2016/11/e309/
doi:10.2196/jmir.6511
PMID:27876684

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Original Paper

Older Veteran Digital Disparities: Examining the Potential for Solutions Within Social Networks

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Abstract

Background: Older adults typically have less access to the Internet than other age groups, and older Veterans may use the Internet even less due to economic and geographic reasons.

Objective: To explore solutions to this problem, our study examined older Veterans' reported ability to access technology through their close social ties.

Methods: Data were collected via mail survey from a sample of Veterans aged 65 years and older (N=266).

Results: Nearly half (44.0%, 117/266) of the sample reported having no Internet access. Yet, among those without current access, older Veterans reported having a median of 5 (IQR 7) close social ties with home Internet access. These older Veterans also reported that they would feel comfortable asking a median of 2 (IQR 4) social ties for help to access the Internet, and that a median of 2 (IQR 4) social ties would directly access the Internet for the older Veteran to help with health management.

Conclusions: Findings suggest that even older Veterans without current Internet access have at least two social ties with home Internet who could be called upon for technology support. Thus, older Veterans may be willing to call upon these "surrogate seekers" for technology assistance and support in health management. This has implications for the digital divide, technology design, and health care policy.

(J Med Internet Res 2016;18(11):e296) doi:10.2196/jmir.6385

KEYWORDS

Internet; digital divide; social network; Veterans

Introduction

It is well documented that a "digital divide" exists whereby older adults are less likely to access the Internet than other age groups [1-5]. Recent statistics suggest that 59% of US adults aged 65 years or older use the Internet, compared to 86% of all US adults older than 18 years [6]. There are a number of reasons cited for this discrepancy in the literature [4-7]. For example, older adults may have insufficient digital skills to use the Internet, inadequate finances to purchase equipment or an Internet service, or perceive limited personal benefit to using the Internet and other technologies [4,7]. Yet, there is variation of use even among the elderly; older adults who do use the Internet are typically wealthier, more educated, and reside in more urban areas compared to older adult nonusers [6,8]. In fact, there appears to be two burgeoning groups of older adults in the United States: younger, wealthier technology adopters and their older, less affluent counterparts [6]. Veterans older

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than age 65 years, who represent approximately 46% of the US Veteran population [9], typically earn a lower income than their civilian counterparts [10-12], which may point to an even greater disparity in Internet use. Thus, this paper aims to examine the digital divide in an aging group of Veterans to begin to understand technology adoption in this vulnerable group.

The digital divide is particularly concerning due to the fact that health information technologies (HIT), such as Web-based patient portals, mobile apps, or telehealth systems, are increasingly implemented to provide patients with improved access to their health care providers and self-management resources [13-16]. Such technologies can offer patients and health care providers real-time information about health conditions [17-19], enhance patient-provider communication by allowing information sharing and electronic messaging between involved parties [19,20], and improve patient outcomes by allowing patients access to health information and tools which can aid problem solving, decision making, and goal setting [18,19]. The Veteran's Health Administration (VHA) has been a leader in developing HIT to supplement and enhance face-to-face health care visits, including the MyHealth*e*Vet patient portal which features health information and asynchronous secure messaging, the Care Coordination Telehealth Program to provide in-home remote monitoring and consults for chronic disease, and VHA mobile apps that range from weight management coaching to a summary of personal VHA medical information [15,21,22]. With many health care systems turning to technology to facilitate information sharing, communication, and remote monitoring critical to continuity of care, patients without access to technology may find themselves excluded from these promising innovations.

As previously mentioned, older US Veterans are a particularly useful group in which to study barriers to technology access because the social and economic factors that contribute to digital disparities are more common among Veterans. For example, Veterans typically earn a lower income and live in more rural areas than their civilian counterparts [10-12], both of which are associated with a lower rate of technology adoption. In addition, Veterans cope with more health conditions and report poorer health than civilians [10-12], indicating an even greater need for the support of HIT. We examine a group of older Veterans who have yet to adopt the VHA's patient portal in order to begin to explore the practical barriers to using health information technology in this population.

Many older Veterans have family or informal caregivers who help them to manage their health care [23-26]. Thus, an examination of older Veterans is incomplete without consideration of their social context. Research on social networks suggests that people are connected to one another by strong ties (eg, family, close friends) and weak ties (eg, coworkers, acquaintances) [27-30]. For older adults, the presence of social ties has been associated with a lower risk of mortality [31], fewer depressive symptoms [32], and a reduced rate of cognitive decline [33-35]. Conversely, a lack of ties has been associated with poorer self-rated health [36], higher blood pressure [37], and higher systemic inflammation [37]. Social ties play a role in health and behavior by (1) providing emotional, tangible, or informational support; (2) reinforcing group attitudes and social norms for behaviors; (3) promoting social engagement and participation; and (4) providing access to material resources [27,30,38].

As health care systems such as VHA promote use of patient-facing technology, patients without access to a resource such as the Internet may find themselves at a disadvantage. New solutions for linking patients to technology are needed to ensure that the digital divide does not inadvertently widen, especially in the health arena. Our study examined a sample of older Veterans in order to study the digital divide among a population of lower socioeconomic status older adults with complex health needs, and quantify whether older Veterans might gain access to technology through their social contacts for the concrete purpose of managing their health. Thus, we conducted a 1-year, VHA-funded pilot study to

1. Describe access to and use of technology among a purposeful sample of older Veterans, and

2. Examine older Veterans' reported ability to access the Internet through their social ties for the purpose of health management.

Methods

Setting and Sample

The sample was drawn from the VHA system of electronic health records available through the VHA Corporate Data Warehouse. Veterans of the US armed services aged 65 years and older who had at least two outpatient care visits at a VHA facility between October 1, 2012 and August 1, 2013 were eligible for inclusion. Given the potential for cognitive deficits to influence technology use and shape informal caregiving needs in ways that would not be analogous to other participants, older Veterans with a documented diagnosis of dementia were excluded from participation. Older Veterans were also excluded from the cohort if they were already registered with VHA's personal health record, MyHealth*e*Vet. This criterion was used to ensure a sufficient number of older Veterans with limited computer skills or interest among the sample.

Eligible older Veterans were purposefully sampled according to race (white, black, or Hispanic/Latino), marital status (married or single/divorced/widowed), and US geographic location (Northeast, Midwest, South, or West) to allow for a sample of varied demographics. A total of 1500 eligible older Veterans were randomly identified as potential participants and their contact information (name and address) was obtained from the electronic health record. The study was approved by the Institutional Review Board at the Edith Nourse Rogers Veterans Hospital in Bedford, MA.

Survey Procedure and Rates of Response

Survey items were drawn from three previously fielded US telephone or mail surveys examining device ownership, technology use, and health in the civilian population. The surveys included the Computer-Email-Web Fluency Scale [39], Internet Use Among Midlife and Older Adults [40], and the Pew Research Center's Internet Project Tracking Survey [41]. Items related to Internet access through social ties were developed by the research team. The survey was piloted by a

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small convenience sample (N=7) who provided written responses regarding the format, organization, and readability of the items. Items were then refined by the research team to produce the final mail survey.

To encourage response to the survey, potential Veteran participants were mailed an introductory letter that explained the purpose and procedures of the study. Two weeks after the initial letter, participants received a token incentive (a miniature calendar), a paper copy of the survey, and a stamped return envelope through the mail. Surveys were fielded between December 2013 and July 2014. A total of 121 surveys were returned as a result of outdated contact information or patient death. In total, 19.29% (266/1379) of the sample completed the survey and were included in analyses.

Survey Variables

Demographics

Participants responded to several questions about their race, education, annual household income, marital status, and self-reported health status. Information on age, gender, race, geographic location (rural/urban), and number of chronic conditions was obtained from the VHA Corporate Data Warehouse system of records to compare with self-reported demographics and to supplement survey data. Finally, participants responded to two items related to health literacy that assessed the extent to which they needed help reading hospital materials and their confidence in filling out medical forms for themselves [42].

Technology Engagement

Participants reported information about their technology engagement by responding to items regarding (1) technological devices used in the past month, (2) methods of Internet access (eg, home computer, library, senior center), (3) Internet experience (ie, comfort with the Internet, typical activities, average use per day), and (4) cellular phone use for text messaging. For each of these questions, participants were instructed to mark all response options that applied to their personal ownership, use, or interest. As a result, the frequencies that we report are not mutually exclusive and represent the percentage of participants who endorsed each response option.

Self-Reports of Social Ties

Participants were asked to report about three distinct categories of social ties: adult children, extended family, and friends. Participants estimated (1) the total number of ties with whom they had spoken in the past 4 weeks, (2) the number of ties with home Internet access (eg, through a computer or smartphone), (3) the number of ties who would allow the older Veteran to use their device to access the Internet for the purpose of health management, (4) the number of ties whom the Veteran would feel comfortable asking for help to use the Internet for health management, and (5) the number of ties who would be willing to use the Internet on behalf of the older Veteran for health management.

Analyses

We used SPSS version 20 to calculate frequencies and measures of central tendency to describe the older Veteran sample and their personal access to and use of technology and the Internet. Participants marked all response options that applied to their personal ownership and use of technology. As a result, the frequencies that we report are not mutually exclusive and represent the percentage of participants who endorsed each response option. Then, participants were characterized based on their response to the following question: “How do you currently access the Internet?” Veterans who reported having no Internet access were compared to Veterans with current Internet access (eg, via home computer, library, or senior center) by utilizing chi-square tests for independence adjusted by Bonferroni correction and post hoc *z* tests. Listwise deletion was employed to handle missing responses. Next, we used descriptive statistics to examine older Veterans’ perceived ability to access the Internet through their social ties. We summed participant responses for each social tie category (adult children, extended family, and friends) to create an overall score for each social tie survey item (see Survey Variables in Methods section). We report social tie data for the entire sample as well as a focus on those Veterans without Internet access. To further investigate participants without Internet access, we grouped these older Veterans according to their reported number of ties with Internet access (no ties, at least one tie, two or more ties).

Results

Veteran Respondent Characteristics

Veteran respondents were predominantly male (95.9%, 255/266) and white (77.4%, 206/266; black: 14.3%, 38/266; Hispanic/Latino: 8.3%, 22/266) with a mean age of 75.7 (SD 7.9, range 65-96) years. A quarter of respondents (25.6%, 68/266) resided in rural areas, and 59.0% (157/266) were married or partnered. One-third had a high school education or less (31.6%, 84/266), and 80.5% (214/266) earned an income of less than US $45,000 annually. Nearly half (45.5%, 121/266) of respondents reported being in good health. Respondents were diagnosed with mean of 3.4 (SD 4.3, range 0-17) chronic conditions.

Technology Access and Use

Nearly half (44.0%, 117/266) of respondents reported that they did not have access to the Internet. Veterans without Internet access were more likely to be older, unmarried, have completed less education, and earn a lower annual income than those Veterans reporting current Internet access (see Table 1). In addition, Veterans without Internet access were less likely to report being in good health and less likely to be confident in filling out medical forms without assistance, a marker of poorer health literacy.

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Table 1. Veteran demographic characteristics compared by Internet access (N=266).

Variables	Older Veterans with current Internet access, n (%) (n=149)	Older Veterans with no Internet access, n (%) (n=117)	*P* value (*z* test)
Age (years)			
65-75	89 (59.7)	41 (35.0)	<.001
76-85	49 (32.9)	52 (44.4)	.05
≥86	11 (7.4)	24 (20.5)	.002
Gender			
Male	144 (96.6)	111 (94.9)	.47
Female	5 (3.4)	6 (5.1)	.47
Race/Ethnicity			
Black	20 (13.4)	18 (15.4)	.65
White	117 (78.5)	89 (76.1)	.47
Hispanic	12 (8.1)	10 (8.5)	.63
Marital status			
Married/partnered	97 (65.1)	60 (51.3)	.02
Unmarried (single, divorced, or widowed)	52 (34.9)	57 (48.7)	.02
Rural status			
Urban	114 (77.6)	82 (70.1)	.24
Rural	33 (22.4)	35 (29.9)	.15
Education			
Elementary	1 (0.7)	2 (1.7)	.42
Middle	7 (4.8)	10 (8.6)	.20
High school	27 (18.5)	37 (31.9)	.01
Some college/vocational	48 (32.9)	41 (35.3)	.62
Associates	13 (8.9)	8 (6.9)	.57
College degree	27 (18.5)	11 (9.5)	.04
Graduate degree	23 (15.8)	7 (6.0)	.02
Income (US $)			
5000-10,000	4 (3.0)	13 (12.5)	.005
10,001-15,000	11 (7.4)	24 (23.1)	.002
15,001-25,000	20 (13.4)	27 (26.0)	.04
25,001-35,000	38 (25.5)	21 (20.2)	.14
35,001-45,000	16 (10.7)	10 (9.6)	.55
>$45,000	43 (28.9)	9 (8.7)	<.001
Health status			
Very poor	2 (1.4)	6 (5.2)	.07
Poor	8 (5.4)	13 (11.2)	.09
Fair	48 (32.7)	49 (42.2)	.10
Good	77 (52.4)	44 (37.9)	.02
Excellent	12 (8.2)	4 (3.4)	.11

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Variables	Older Veterans with current Internet access, n (%) (n=149)	Older Veterans with no Internet access, n (%) (n=117)	*P* value (*z* test)
Need help reading hospital materials? (health literacy)			
Always	14 (9.4)	22 (19.3)	.03
Often	7 (4.7)	6 (5.3)	.87
Sometimes	17 (11.4)	11 (9.6)	.60
Occasionally	28 (18.8)	19 (16.7)	.60
Never	83 (55.7)	56 (49.1)	.20
Confident filling out medical forms? (health literacy)			
Not at all	13 (8.7)	23 (20.2)	.01
A little bit	8 (5.4)	14 (12.3)	.05
Somewhat	26 (17.4)	29 (25.4)	.14
Quite a bit	45 (30.2)	23 (20.2)	.05
Extremely	57 (38.3)	25 (21.9)	.003

Across the entire sample, 45.5% (121/266) of respondents reported gaining Internet access through a home computer, whereas 11.7% (31/266) of respondents gained Internet access through a smartphone or tablet. Few respondents reported gaining Internet access through community settings, such as a library (4.5%, 12/266) or senior center (1.5%, 4/266). Others reported gaining direct Internet access by using a family member's (13.2%, 35/266) or a friend's (3.0%, 8/266) computer.

When asked about their technology use in the past month, 66.8% (175/262) of respondents had used a cellular phone, whereas 17.6% (46/262) of respondents had used a smartphone. Among these older Veterans, 21.8% (57/262) reported sending text messages from their phone, sending texts to their children, friends, and spouse most frequently. In terms of computing devices, 37.8% (99/262) of all respondents had used a desktop computer in the past month, 20.2% (53/262) had used a laptop computer, and 9.9% (26/262) had used a tablet.

Table 2 compares the technology use of older Veterans based on their current Internet access. Veterans reporting no Internet access were also more likely to report being very uncomfortable using the Internet (χ^2_4=82.3, *P*<.001), and less likely to report having used a smartphone (χ^2_1=39.4, *P*<.001), tablet (χ^2_4=18.8, *P*<.001), desktop computer (χ^2_1=113.3, *P*<.001), or laptop computer (χ^2_1=43.4, *P*<.001) in the past 4 weeks than those with current access. Of note, there was no significant difference in the proportion of older Veterans using a cellular phone in the past 4 weeks based on current Internet access (χ^2_1=1.6, *P*=.20). However, there was a significant difference in the proportion of older Veterans who sent text messages on their cell phone (χ^2_1=17.2, *P*<.001); only 6.8% (8/115) without Internet access sent text messages.

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Table 2. Technology use of Veterans compared by Internet access.

Variables	Older Veterans with current Internet access, n (%) (n=147)	Older Veterans with no Internet access, n (%) (n=95/115)[a]	*P* value (*z* test)
Comfort using the Internet			
Very comfortable	54 (36.7)	5 (5.3)	.001
Somewhat comfortable	37 (25.2)	7 (7.4)	.001
Neither comfortable nor uncomfortable	21 (14.3)	17 (17.9)	.45
Somewhat uncomfortable	18 (12.2)	7 (7.4)	.22
Very uncomfortable	17 (11.6)	59 (62.1)	.001
Devices used in the past month			
None	7 (4.8)	42 (36.5)	.001
Cellular phone	103 (70.1)	72 (62.6)	.20
Smartphone	45 (30.6)	1 (0.9)	.001
Desktop computer	97 (66.0)	2 (1.7)	.001
Laptop	51 (34.7)	2 (1.7)	.001
Tablet	25 (17.0)	1 (0.9)	.001
Sends text messages			
Yes	48 (32.7)	8 (7.0)	.001
No	89 (60.5)	74 (64.3)	.53

[a] Devices used in past month and sends text messages: n=115.

Access Through Social Ties

We examined respondents' reported ability for Internet access through social ties (see Figure 1). Older Veterans reported a median of 8 (IQR 9) social ties with home Internet access when asked to consider the people that they had spoken to in the past 4 weeks. Among those social ties with Internet access, older Veterans reported that a median of 3 (IQR 8) social ties would share use of a technological device to allow them to use the Internet for the purpose of health management. Older Veterans felt comfortable asking a median of 4 (IQR 6) social ties for help to use the Internet for health management. Finally, older Veterans reported that a median of 4 (IQR 7) social ties would be willing to use the Internet for them to manage their health.

Focusing on those Veterans without Internet access (which directly represents the digital divide; n=117), we found that these older Veterans still reported a median of 5 (IQR 7) social ties with home Internet access. Similarly, those older Veterans without Internet access reported a median of 1 (IQR 4) social tie who would share use of a technological device for health management. Older Veterans without Internet access also reported feeling comfortable asking a median of 2 (IQR 4) social ties for help to use the Internet and median of 2 (IQR 4) social ties that would use the Internet for the older Veteran for the purpose of health management.

A closer examination of those older Veterans without Internet access showed that the majority (81.2%, 95/117) reported having two or more social ties with home Internet access (see Table 3). In addition, slightly more than half (54.7%, 64/117) reported having two or more ties that they would feel comfortable asking for help to use the Internet and two or more ties that would use the Internet for them (56.4%, 66/117).

Table 3. Proportions of reported social ties by older Veterans without Internet access (N=117).

Variables	No reported ties/missing, n (%)	1 tie, n (%)	≥2 Ties, n (%)
Social ties with home Internet access	13 (11.1)	9 (7.7)	95 (81.2)
Social ties would share use of a device	60 (51.3)	15 (12.8)	42 (35.9)
Social ties that Veteran would ask for help with Internet	35 (29.9)	18 (15.4)	64 (54.7)
Social ties would access the Internet for the Veteran	35 (29.9)	16 (13.7)	66 (56.4)

Figure 2 shows the reported Internet access through social ties by specific tie category (eg, adult child, extended family member, and friend). Those older Veterans without Internet access still reported a median of 2 (IQR 4) adult children, a median of 1 (IQR 3) extended family member, and a median of 1 (IQR 2) friend with home Internet access. Furthermore, Veterans without Internet access reported a median of 1 (IQR 2) adult child and a median of 1 (IQR 2) extended family

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member whom the older Veteran would feel comfortable asking for help to use the Internet. Veterans without Internet access also reported a median of 1 (IQR 2) adult child and a median of 1 (IQR 2) extended family member who would use the Internet for the respondent.

Figure 1. Older Veterans' reported Internet access through social ties (n=170).

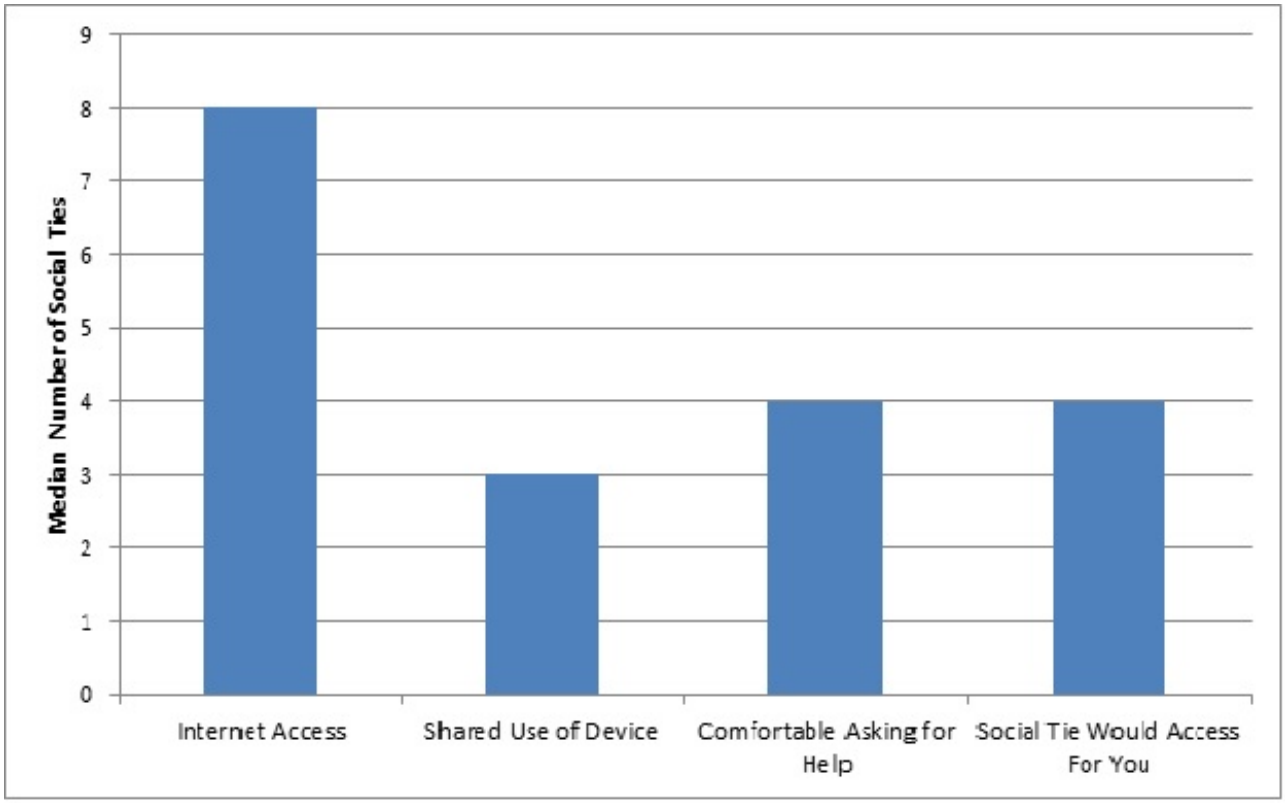
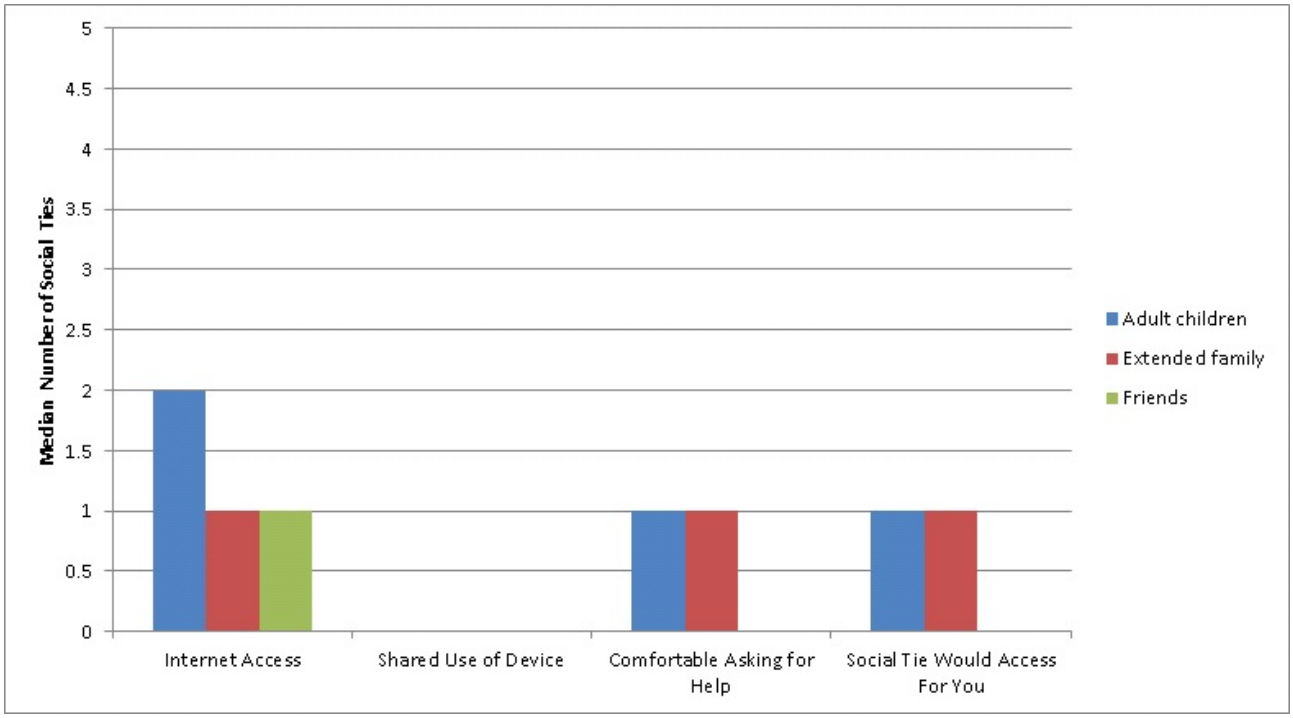


Figure 2. Perceived Internet access through specific types of social ties (adult children, extended family, or friends) among older Veterans without current Internet access (n=95).



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Discussion

Principal Results

Our study investigated a sample of older Veterans to understand their personal access to and use of technology as well as their reported ability to access technology through their social ties. We chose to examine a group of older Veterans because they represent an increasingly growing proportion of the US population [9,43,44], and present with complex health care needs [10-12] that could benefit from HIT support. In addition, the social and economic barriers to technology adoption are more common in Veterans. Thus, research conducted with Veterans can suggest solutions relevant to our more vulnerable patient subgroups. Our study provides a unique opportunity to examine the technology use and social relationships of a national cohort of vulnerable older adults. Among our sample, most of who were lower income, less educated, and managing multiple chronic conditions, we found that nearly half reported having no Internet access. Yet, these older Veterans without Internet access still reported a median of 5 (IQR 7) people in their lives with home Internet access, with more than four-fifths reporting two or more social ties with access.

The Reach of Technology Among Older Veterans

To place our sample in context, our respondents were similar in racial background, marital status, educational attainment, and income as compared to other studies of elderly Veterans [11,43] as well as the overall Veteran population [9]. Our entire sample of older Veteran respondents also had attained less education and earned less income than their civilian counterparts [45]. Thus, our study illustrates the technology use of a group typically at risk for digital disparities.

Recent surveys of civilian older adults from organizations such as the AARP and the Pew Research Center's Internet & American Life Project, have estimated that approximately half of older adults have access to and use the Internet, and most gain access through their home computer [6,40]. Our findings corroborate these estimates with 45% of our older Veteran respondents reporting Internet access through their home computer. Compared to Pew's estimation that 18% of older adults have adopted smartphones [6], we found similar rates of older Veterans reporting Internet access through a smartphone (18%), and that cellular phone use had been largely adopted by both older Veterans (~66%) and older civilians (77%, according to [6]). Older Veterans appear to adopt technological devices and use the Internet at similar rates as the older civilian population.

In our sample, older Veterans reporting current Internet access were younger, more educated, and wealthier than those Veterans reporting no access. These demographic predictors of Internet access (age, education, and income) are consistent with other studies of the digital divide in civilians [2,6,8,41], as well as other investigations of Veterans [46,47]. Because approximately two-thirds of our sample earned less than US $35,000 per year, it is possible that the patterns of use reported by older Veterans were driven by income rather than age. Nevertheless, recent Pew Research Center data report that among US adults who have yet to adopt the Internet, 41% are older than 65 years old, whereas 23% earn less than US $30,000 per year [48], which may indicate that age is still a strong predictor of technology adoption. Future work should attempt to disentangle the relationship between income and age within the digital divide among Veterans. Furthermore, we found that older Veterans without Internet access were more likely to report being very uncomfortable using the Internet, suggesting that a lack of computer literacy could also contribute to the lack of access. This parallels studies of older civilians that found that older adult technology adoption is moderated by computer anxiety and confidence in computer skills [49,50]. In fact, even among the older Veterans who reported current Internet access, only 37% (54/147) reported being "very comfortable" using the Internet. Although some older Veterans may be able to access the Internet at home, they may still lack the confidence or skills to fully engage with HIT tools. Therefore, the potential for supported use through social ties is great even among those older Veterans who have opted for home Internet.

The Potential For Social Access

We were particularly interested in the ability of older Veterans without Internet access to gain access through their social ties as this group exemplifies the "digital divide." Encouragingly, our study revealed that even among this group, the majority still reported two or more social ties with home Internet access. These respondents also reported at least one adult child or extended family member who would use the Internet for the older Veteran. Previous research on older British civilians has similarly found that older adults might gain Internet access by using the computer of a family member [7,51]. Our work, the first to quantify potential social use of technology among US Veterans, corroborates these findings and contributes to the body of literature by examining Internet use of a vulnerable US population within the context of health management. Similarly, "surrogate" health information seeking, in which a friend or family member conducts an online search for the benefit of another, has been documented [52-54] and is likely quite commonplace. Studies of this activity have predominantly focused on identifying the characteristics and behaviors of "surrogate seekers," who tend to be middle-aged, a spouse or parent, and serve as a caregiver [52-55]. Surrogate seekers also are more likely to engage in a variety of online content-generating activities, such as participating in online support groups or emailing health care providers [54]. Our study contributes to this literature by assessing the reported experiences and behaviors of older Veterans who may benefit from surrogate searches. Our older Veteran respondents appear to have multiple social ties who could perform a surrogate search for the benefit of health management, allowing the older adult to benefit from the Internet indirectly.

Those Veterans without Internet access also reported at least one adult child or extended family member that the older Veteran would feel comfortable asking for help to use the Internet. This corresponds with the concept of the "warm expert" whereby someone in a close relationship with the technology novice can serve as a mediator between the needs and skills of the novice and the technological system [56]. In other words, the family can provide instruction, assistance, and other instrumental support to the older adult for the purpose of direct

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technology access for health management. Recent polls suggest that 70% of older adults who currently use technology, and 87% of nonusers, say that they would need to ask someone for assistance to learn a new technology [6]. Thus, our finding that older Veterans report even a few social ties who could serve in this capacity suggests that older Veterans can identify the warm experts in their lives and may be willing to call on these social relationships for technology assistance. Interventions that educate families about the value of HIT for health management and promote skills for family technology collaboration may help to reduce the gap in older Veteran HIT use.

Implications for Technological Design and Health Care Policy

Our study finds that older Veterans are able and willing to call on social ties for both direct and indirect access to the Internet. This indicates that social relationships may represent a possible solution to ensuring that older Veterans benefit from HIT innovations. However, one practical challenge to collaborative use of health technology concerns information privacy. For example, the majority of Americans desire to be in control of their personal information, both online and offline [57]. Therefore, older Veterans may not want to share their health information with their family or friends via collaborative use of HIT tools. Nevertheless, most of our participants endorsed comfort with having a social tie assist with Internet use in the context of health management, where health information is likely be transmitted. If an older Veteran feels such comfort asking their social tie for assistance, it is likely that the older Veteran would feel similar comfort with this close tie having access to their personal health information.

As another challenge, current technological design typically does not allow for social means of access, limiting the potential for social ties to engage and assist older users. For example, a scan of five prominent health care systems revealed that only two currently allow patients to designate a family member as a caregiver who can access all their personal health information. Thus, for most older patients, social ties are unable to assist with access to personal health information or providers (through electronic messaging) in a secure, confidential way. We recommend that developers design HIT tools that are conducive to multiple log-ins across multiple platforms in order to facilitate and encourage surrogate use and family collaboration. Similarly, we suggest that health care systems allow patients to delegate a surrogate who gains equal access to the HIT tools provided to patients. This could have a two-fold effect of encouraging family involvement in the care of older patients as well as enhancing information sharing between informal caregivers and family members.

Limitations

Our study does have a few limitations. As noted, approximately 19% of our sampling cohort returned a completed survey, which is a lower response rate than we had targeted. As a result, we may be experiencing a nonresponse bias whereby those who returned the survey do not share the same characteristics as the entire sample. This may suggest that our findings do not represent most older Veterans. However, we found that our respondents are similar to the overall Veteran population across major demographic characteristics (ie, age, race, marital status, income, and education), and similar to those older adults most vulnerable to the digital divide: those with less education and income.

Additionally, our sample received the survey through the mail and could choose to participate by returning the completed survey. We may have experienced a participation bias, whereby those older Veterans who opted to return the survey were more comfortable with or interested in technology and more likely to have access. Yet, we found that almost half of our sample reported having no Internet access and that our sample reported engaging in technology at similar rates to the older civilian and overall Veteran populations. This could indicate that our findings accurately represent the wide spectrum of older Veteran use of technology and ability for access through social ties. In addition, we may have experienced an item nonresponse bias, whereby some older Veterans failed to respond to survey questions by mistake or purposefully. However, our study is not designed to represent a definitive scan of the population, but an initial inquiry in order to determine the feasibility of future social network interventions.

Finally, our study is not a traditional social network survey in that we investigate older Veteran reports of their social ties, but do not assess the social ties themselves. Although older Veterans may report the ability for direct and indirect Internet access through social ties, the social ties may account differently. Future work should examine the ability and willingness of family and friends to assist older adults with Internet access and use of HIT tools for a number of health management activities (eg, prescription requests vs bill payment vs access to clinical notes) in order to fully understand the experiences of all stakeholders.

Conclusions

The digital divide puts some older adults at a disadvantage, limiting their ability to benefit from technology innovations that support health management. This study found that older Veterans are surrounded by social ties that do have access and can likely assist the older Veteran to use these tools. These findings can be used to design family interventions, develop HIT tools, and inform health care policy. In short, the potential for older Veteran access to HIT through social ties is great, and may serve as a partial solution to the digital divide.

Acknowledgments

This work was funded as a locally initiated project by the eHealth Quality Enhancement Research Initiative of the Department of Veterans Affairs. The authors also want to acknowledge the assistance and support of Felicia Kleinberg in data collection and

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management, as well as Kathryn DeLaughter in preparation of the manuscript. The views expressed in this paper are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government.

Conflicts of Interest

None declared.

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Abbreviations

HIT: health information technology
VHA: Veteran’s Health Administration

Edited by G Eysenbach; submitted 28.07.16; peer-reviewed by K Jiggins Colorafi, C Brown-Johnson; comments to author 11.08.16; revised version received 20.09.16; accepted 07.10.16; published 23.11.16.

Please cite as:
Luger TM, Hogan TP, Richardson LM, Cioffari-Bailiff L, Harvey K, Houston TK
Older Veteran Digital Disparities: Examining the Potential for Solutions Within Social Networks
J Med Internet Res 2016;18(11):e296
URL: http://www.jmir.org/2016/11/e296/
doi:10.2196/jmir.6385
PMID:27881361

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Review

Preconception Care Education for Women With Diabetes: A Systematic Review of Conventional and Digital Health Interventions

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Abstract

Background: Worldwide, 199.5 million women have diabetes mellitus (DM). Preconception care (PCC) education starting from adolescence has been recommended as an effective strategy for safeguarding maternal and child health. However, traditional preconception care advice provided by health care professionals (HCPs) within clinic settings is hindered by inadequate resources, suboptimal coverage, and busy clinics. Electronic health (eHealth), which is instrumental in solving problems around scarce health resources, could be of value in overcoming these limitations and be used to improve preconception care and pregnancy outcomes for women with DM.

Objective: The objectives were to: (1) identify, summarize, and critically appraise the current methods of providing PCC education; (2) examine the relationship between PCC educational interventions (including use of technology as an intervention medium) on patient and behavioral outcomes; and (3) highlight limitations of current interventions and make recommendations for development of eHealth in this field.

Methods: Electronic databases were searched using predefined search terms for PCC education in women with type 1 or 2 DM for quantitative studies from 2003 until June 2016. Of the 1969 titles identified, 20 full papers were retrieved and 12 papers were included in this review.

Results: The reviewed studies consistently reported that women receiving educational interventions via health care professionals and eHealth had significantly improved levels of glycosylated hemoglobin (P<.001) with fewer preterm deliveries (P=.02) and adverse fetal outcomes (P=.03). Significant improvements in knowledge (P<.001) and attitudes toward seeking PCC (P=.003) were reported along with reduced barriers (P<.001).

Conclusions: PCC has a positive effect on pregnancy outcomes for women with DM. However, uptake of PCC is low and the use of eHealth applications for PCC of women with DM is still in its infancy. Initial results are promising; however, future research incorporating mobile phones and apps is needed. Clearly, there is much to be done if the full potential of eHealth PCC to improve obstetric outcomes for women with DM is to be realized.

(J Med Internet Res 2016;18(11):e291) doi:10.2196/jmir.5615

KEYWORDS

preconception care; education; diabetes mellitus; women; review; smartphone; mobile applications; technology

Introduction

Electronic health (eHealth) is transforming health care delivery [1-9] and increasingly being used to promote healthy behaviors in people with diabetes mellitus (DM) [10-17]. eHealth is the cost-effective and secure use of information and communication technologies (ICT) in support of health and health-related fields, including health education, knowledge, and research [1]. eHealth

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plays an instrumental role in improving access to health care, particularly where resources are scarce, and encourages individuals to actively connect with health care services [6,18]. eHealth technologies include consumer health informatics, the Internet, and mobile devices [19]. The Internet has emerged as a popular source of health care information that may replace face-to-face consultations, strengthen patient participation, and supplement health care [20].

A recent report on Internet use [21] identified that of the average 5.6 hours spent on the Internet per day, 51% of time was spent accessing it via mobile devices compared with computers or laptops (42%) and other connected devices (7%). By providing individuals with increased access to information anytime and anywhere, eHealth delivered via mobile phones has significant potential to transform health care delivery. Evidence suggests that 90% of the world's population own a mobile phone, and over a third of the 7.1 billion mobile devices in use are now smartphones [22,4,23-26] that run third-party apps. Apps are programs designed to enhance smartphone functionality and their increased popularity has resulted in proliferation of educational, decision support, and patient monitoring apps [24]. In 2010, over 200 million health apps were downloaded with estimates suggesting that this figure will have risen to 1.7 billion by 2017 [22].

eHealth technologies can be used to maximize preventative health care for people with chronic conditions such as DM. Worldwide 415 million people have DM, of which 199.5 million are women [27]. DM is now of increasing concern in the field of women's health and the most common preexisting medical condition complicating pregnancy [28,29]. Poorly-controlled DM at conception coupled with unplanned pregnancy is a major contributor to morbidity and mortality including miscarriages, maternal and perinatal death, and congenital malformations [29,30-36]. It is therefore recommended that women optimize their health via preconception care (PCC) [29,36-42]. Women are also encouraged to achieve a target glycosylated level of hemoglobin (HbA1c; average blood glucose level over the past 2-3 months) of <7% before and during the first trimester of pregnancy to reduce obstetric risks [29,36,38-41]. However, less than 50% of women with DM receive PCC advice [34,43,44] with fragmented and suboptimal services being reported [45-47]. As a result, women with DM have insufficient knowledge of the risks associated with pregnancy to themselves or their baby [12,48,49]. International clinical guidelines [29,38-41] recommend PCC education from adolescence for all women with DM as an effective strategy to facilitate behavior change and improve pregnancy outcomes. However, barriers such as inadequate resources, busy clinics, time, and distance to health facilities [48,50] can inhibit and restrict the extent to which women engage in PCC. Hence, eHealth could be of value in overcoming these limitations and extending the reach of health interventions.

While rapid advances in eHealth technology create a new opportunity to improve knowledge and health outcomes, to date there is no extant literature appraising and quantifying the impact of different methods of PCC provision for women with DM. Therefore, a systematic literature review was undertaken to (1) identify, summarize, and critically appraise the current methods of providing PCC education; (2) examine the relationship between PCC educational interventions (including use of technology as an intervention medium) on patient and behavioral outcomes; and (3) highlight limitations of current practice and make recommendations of eHealth in this field.

Methods

Search Strategy

A systematic approach was used to search the literature for relevant articles. The review was limited to human studies conducted between 2003 and June 2016 to reflect current and emerging trends in design and conduct of PCC interventions for women with DM. The reviewed literature drew on a wide range of evidence. The following databases were searched: Medline, Embase, Web of Science, Maternity and Infant Care, Cumulative Index to Nursing and Allied Health, CAB Abstract, British Nursing Index, PsycINFO, Scopus, Science Direct, and Google Scholar.

The keywords "preconception care," "education," "counseling," "diabetes," "pregnancy outcomes," "knowledge," "behavior change," "birth defects," and "women" were used in various combinations when searching the databases (see Multimedia Appendix 1 for full text of search string). Additionally, reference lists of retrieved articles, reviews, and related articles were hand-searched for potentially relevant papers. Emphasis was placed on primary research. No language restriction was applied to the search.

Study Selection

The titles, abstracts, and full papers were screened by CHN and checked by NC and JS. Articles were excluded if there was an agreement that the article met 1 or more of the following exclusion criteria: did not contain any human data; contained no original data (ie, was a commentary, meeting abstract, or editorial); population of interest was not women with DM; and did not assess impact of a PCC educational intervention. The search protocol included identification of potentially relevant articles, screening of identified papers based on their titles and abstracts, examination of full text of potentially relevant studies for eligibility, and application of the inclusion criteria to select the studies included in the review. For the study to be included in the literature review, the following inclusion criteria were applied.

- Women of reproductive age with preexisting type 1 diabetes mellitus (T1DM) or type 2 diabetes mellitus (T2DM) not pregnant at the time of the PCC intervention.
- PCC interventions including but not limited to education, advice, or counseling on use of folic acid, insulin therapy, glycemic control, screening for diabetes complications, contraception use, and blood glucose monitoring.
- Comparator was standard care in all studies except the one [12] in which the intervention group also served as the control.
- Studies reporting maternal and neonatal outcomes and knowledge and attitudes toward PCC.

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- Quantitative studies, that is randomized controlled trials, before and after studies, and observational (cohort, cross-sectional and case control) studies.

Data Abstraction

The data was subsequently extracted by CHN and checked by NC and JS for accuracy and completeness. The reviewers were not masked to the articles' authors, journals, or institutions.

Quality Assessment

Assessment was initially performed by CHN and results agreed by NC and JS. The quality of reviewed studies was assessed using a modified version of the EPHPP quality assessment tool for quantitative studies which was developed by the Effective Public Health Practice Project (EPHPP), Canada. It contains summary judgments and an accompanying dictionary that increases standardization of the study quality assessment [51,52]. This tool includes items on selection bias, study design, confounders, blinding, data collection, and withdrawals and dropouts. Each of these 6 aspects of quality received a score out of 3 to make up a total score of 18. The studies were given a rating out of 18, and the quality of the evidence was graded as strong (rating> 14), moderate (rating 7-13), or weak (rating 1-6).

Synthesis

Meta-analysis of the data was not appropriate because there was great diversity in the interventions, research designs (methodology), and outcome measures. In this review, the main focus was on extracting data on descriptions of interventions (study design, samples, and intervention overviews), outcome measures, and examinations of the effectiveness of interventions. The results are presented as a narrative summary.

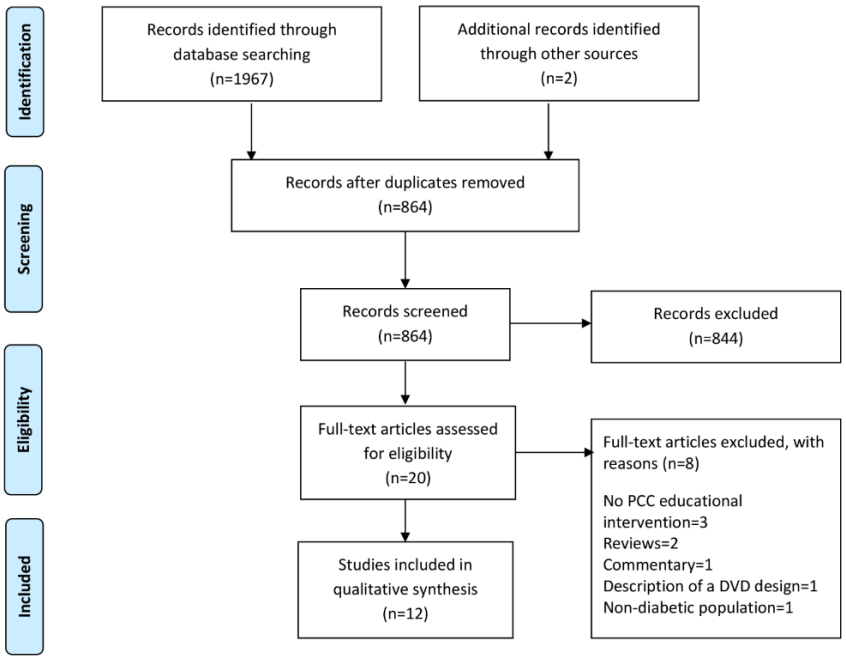
Results

Search Results

A total of 1969 articles were identified from the literature search and the titles and abstracts of 864 articles were screened for eligibility. After excluding 844 articles that did not meet the eligibility criteria, 20 full text articles were selected for detailed review, of which 12 met the eligibility criteria (Figure 1).

The 12 included studies evaluated 2 categories of PCC health education delivery in use for women with DM: health education provided by health care professionals (HCPs; n=8) and health education using eHealth technologies (CD-ROMs and DVDs; n=4). Of the included studies, 8 were found to investigate the effect of PCC education on maternal and child health outcomes, whereas 4 focused on use of eHealth technology for PCC of women with DM. Of the 12 included articles, 1 study discussed their findings in 2 articles [53,54]. Hence, 12 articles of 11 studies were included.

Figure 1. Preferred reporting items for systematic reviews and meta-analyses (PRISMA) flowchart of included studies. PCC: preconception care.



Study Characteristics

The summary characteristics of reviewed articles are given in Multimedia Appendix 2. All studies provided face-to-face or eHealth PCC education to women with DM. Women were recruited from specialist and primary care diabetes clinics. Of the included studies, 8 focused on the effect of a PCC intervention on maternal and child outcomes [43,44,53-58] and 4 on improving knowledge and changing attitudes toward PCC [10,11,12,13]. Timing and duration of intervention for some studies was not specified [12,44,55-58]. Follow-up periods ranged from 3 months to 12 years.

All studies were carried out in clinical settings, except one [12], undertaken in women's homes. Most of the studies were observational [43,44,53-58], with data collected from medical,

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pregnancy and birth records, or databases. Of the included studies, 4 [10-13] used previously validated and reliable questionnaires. Although data collection methods were different for the face-to-face and eHealth PCC studies, there was consistency in findings and methods of data collection used within each category. Sample sizes ranged from n=58 to n=680. All studies, except one [12], had a separate intervention and control group. All studies were carried out in developed country settings (United States, n=3; United Kingdom, n=5; France, n=1; Spain, n=1; Finland, n=1; and Republic of Ireland, n=1), highlighting increased prioritization of PCC for women with DM in these countries. Studies which adopted eHealth for PCC of women with DM were based in either United States (n=3) [10,11,13] or United Kingdom (n=1) [12], perhaps reflecting the increasing use of ICT to support PCC service provision in these countries.

Study Quality

Studies varied with respect to their quality (See Multimedia Appendix 2). Of the included studies, 3 had a rating above 14 [11,13,43] and 9 were rated between 7-13 [10,12,44,53-58]. All studies used appropriate study designs, namely, randomized controlled trials, before and after, and cohort studies but lacked details on blinding and allocation concealment. Although small sample sizes [10,11,12], selection bias [10,12,58], and confounding [12,56,57] were underlying issues of weakness within most studies, these were acknowledged and addressed by the authors.

Findings

Of the included articles, 12 of them reporting on 11 studies (n=12) were grouped into 2 main categories based on their mode of PCC health education delivery: (1) evaluation of PCC education provided by HCPs (n=8) and (2) evaluation of PCC education provided via eHealth technology (n=4).

Evaluation of PCC Education Provided by HCPs

PCC education traditionally provided in clinical settings by health care professionals is associated with positive maternal and child health outcomes. An overview of the interventions, outcome measures, and their effects are described in the following points.

Maternal Health Outcomes

Of the included studies, 2 [56,57] explored the effect of a PCC educational intervention on levels of glycosylated hemoglobin (HbA1c). Boulot et al [56] assigned women with T1DM and T2DM to either an intervention group (n=175) where they received the PCC education before conception, or to a control group (n=360) receiving standard care. Results showed that the educational intervention was effective in enabling more women in the intervention group attain HbA1c <8%. Intervention participants had improved HbA1c in the first trimester with a significantly lower number of women with T1DM (4.3% vs 55%) and T2DM (2.9% vs 27.9%) having HbA1c >8% compared with those in the control group (P<.001). A similar study by Galindo et al [57] in Spain included women with both T1DM and T2DM. The intervention group (n=15) received preconception counseling, whereas the control group (n=112) only presented to medical care when pregnant. Although Galindo et al [57] did not set out to measure the effect of a PCC intervention on maternal HbA1c, the intervention group had significantly improved HbA1c (<7%) compared with those in the control group (P=.02).

Another UK study [53,54] considered the effect of PCC education on maternal HbA1c, spontaneous abortion, preterm deliveries, and gestational age at presentation for prenatal care. Statistically significant differences were found in intervention participants who had improved and sustained HbA1c (6.5% vs 7.6%; P<.001) throughout pregnancy, presented earlier for prenatal care (6.6 vs 8.3 weeks; P<.001), less spontaneous abortions (P=.06), and preterm deliveries (P=.02).

Furthermore, 2 other studies [43,44] reported the effects of PCC education on HbA1c, gestational age at presentation for prenatal care, and folic acid intake in women with T1DM and T2DM. During the 3-year study period by Murphy et al [43], women who received a structured education program were assigned to the intervention group (n=181) and those who did not, to a control group (n=499). Women in the intervention group with increased intake of 5mg folic acid before conception (P<.001) had significantly improved HbA1c values (6.9% vs 7.6%; P<.001), and an earlier date of presentation for prenatal care compared with those in the control group (6.7 vs 7.7 weeks; P<.001). The role of PCC education in promoting healthy preconception behaviors and pregnancy planning was also explored by Tripathi et al [44] who assigned women receiving PCC counseling to the intervention group (n=240) and those who did not, to the control group (n=297). Results showed that participants receiving the intervention had significantly improved and sustained levels of HbA1c (≤7% vs >7%) 3 months before conception (P=.002) and during the first trimester of pregnancy (P<.001), higher rates of folic acid intake 3 months before pregnancy (P<.001), and presented earlier for prenatal care (≤8 weeks vs >8 weeks; P=.001).

Additionally, 2 recent studies [55,58] reinforced the benefits of PCC education on HbA1c and pregnancy outcomes. Neff et al [55] assigned women with T1DM to the intervention group where they received health education (n=70) while those in the control group received standard care (n=394). Intervention participants had significant improvements to HbA1c <7% (6.9% vs 7.8%; P<.001) and earlier prenatal care presentation (6±2 weeks vs 8±6 weeks; P<.001) compared with those who received standard care. However, the effect on rates of spontaneous abortion or preterm delivery was not found to be statistically significant (P=.12, P=.46 respectively). Kekalainen et al [58] also found statistically significant differences in the intervention group who had improved and sustained HbA1c (7.1% vs 9.1%; P<.001) and reduced adverse pregnancy outcomes (P=.06).

Child Health Outcomes

Boulot et al [56] demonstrated that women with T1DM who received PCC education had significantly lower rates of perinatal mortality and congenital malformation (P<.005) compared to those in the control group. Furthermore, women with DM whose HbA1c was > 8% in the first trimester had double the risk of developing adverse fetal outcomes such as perinatal mortality

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(*P*<.005), congenital malformation (*P*<.01), and preterm delivery (*P*<.005).

Additionally, 5 further studies [43,53,54,57,58] reported similar findings. Temple et al [53,54] found that women who received a PCC educational intervention had significantly reduced risk of adverse outcomes (including malformations, stillbirths, and neonatal death) compared with those receiving standard care (*P*=.03). Similarly, Murphy et al [43] and Kekalainen et al [58] found that the intervention group participants experienced a significant reduction in congenital malformations compared with those in the control group (*P*=.009; *P*=.001). Galindo et al [57] also found a positive relationship between increase in maternal HbA1c levels (>7%) and the occurrence of fetal malformations. Additionally, Tripathi et al [44] and Neff et al [55] found a significant association between lack of preconception care education and increased risk of adverse fetal outcomes (*P*=.03).

Most studies (n=7) reported low levels of PCC uptake, range 12% [57] to 48.5% [56], amongst women with DM.

Evaluation of PCC Education Provided via eHealth Technology

Low levels of PCC uptake among women with DM have elicited interest in use of multimedia technologies such as CD-ROMs and DVDs as an intervention tool for PCC education.

Four studies [10-13] investigated the effect of eHealth technology on knowledge and PCC behaviors. Charron-Prochownik et al [10] developed and used an interactive computer program (CD-ROM) to promote PCC knowledge. Adolescent girls with T1DM were randomized to receive the 3-month CD-ROM intervention (n=37) or standard care (n=16). Significant improvement in knowledge (*P*<.05), perceived benefits (*P*=.04), and reduced barriers to seeking PCC (*P*=.01) were reported in intervention participants. An RCT by Fischl et al [11], which lasted 9 months, similarly used an interactive CD-ROM to deliver PCC health education. Adolescent girls with T1DM were randomized to either the intervention group (n=43) where they watched 2 CD-ROMs, read a book, and met with a nurse for counseling or standard care (n=45). Compared with those receiving standard care, intervention participants had significantly improved knowledge and perceived benefits of PCC (*P*<.001), reduced barriers to seeking PCC (*P*<.001), and increased intention to initiate PCC discussion with health care professionals (*P*<.001). The effect on intention to use contraception was not significant (*P*=.10).

A UK study by Holmes et al [12] aimed to explore whether an educational DVD would improve PCC knowledge and behavior. Women with T1DM and T2DM (n=97) who viewed the contents of the DVD individually in their homes showed a significant increase in perceived benefits and attitudes to contraceptive use (*P*=.001), receiving PCC (*P*=.003), knowledge of pregnancy planning (*P*<.001), and pregnancy-related risks (*P*<.001). Finally, Charron-Prochownik et al [13] assessed the long-term effect (12 months) of an educational DVD on knowledge and attitudes to PCC in adolescent girls with T1DM and T2DM. Participants who were randomized to receive the intervention (n=51) demonstrated a significant increase in PCC knowledge (*P*=.001), and intention to discuss PCC and contraception with health care professionals (*P*=.03, *P*=.003), compared with those in the control group who received standard care (n=58).

Discussion

Principal Findings

The reviewed evidence suggests that educationally-based PCC (delivered by health care professionals) is effective in improving maternal and child health. The evidence is consistent across studies, but with few robust controlled studies of PCC educational interventions for women with DM. Studies are generally of moderate quality, with only one assessed as high quality [43]. The inadequacy in traditional PCC education in meeting the needs of women with DM has been widely recognized [43,44,48,56-58], but alternative means of providing PCC remains underresearched. This review highlights the potential capacity of eHealth technologies to help improve coverage and access to PCC.

PCC should ideally be provided to all women with DM [29,34]. However, evidence presented in this review confirms that PCC uptake is still <50% [44,55-57], in line with the low PCC uptake reported in the 2007 confidential enquiry into maternal and child health (CEMACH) in women with DM [34]. Women who do not receive PCC also have poor levels of glycemic control, higher rates of unplanned pregnancy, and adverse pregnancy outcomes [29,30,43,53,54,56-58]. It is therefore worrying that PCC service provision and uptake has not increased at the same rate as the prevalence of DM in women of reproductive age. PCC provided predominantly in a health care setting by a HCP also excludes the 55% (3.1 billion) of the developing world's population in rural areas who do not have adequate access to health care [59]. PCC provision is therefore almost nonexistent for many women in the developing world who have increased risk of adverse maternal and fetal outcomes [37]. This underlines the shortcoming of traditional PCC practice. We have reached the age of personalized medicine [23]. The growing popularity and effectiveness of eHealth technologies for health promotion in several areas including obesity and smoking cessation [4,15-17,60-62], makes its use in PCC of women with DM timely, warranting further exploration.

eHealth technologies hold great promise in terms of helping to deliver preconception health education that increases knowledge and supports behavior change [10-13]. This review highlights the potential of these technologies to empower women with DM to make informed reproductive health decisions. The ultimate goal is to prevent unplanned pregnancies and reduce adverse maternal and fetal outcomes. Behavioral interventions must reach the target population to achieve success [62]; in this lies a weakness of the reviewed eHealth intervention studies which have used technology that is now dated and offers limited scope to the many women who do not have access to computers and/or DVD players [10-13].

Challenges of eHealth PCC

This review highlights that adoption of eHealth in this field is slow and use of ICT for PCC is still very limited. For example, between 2008 and 2016, only 4 studies examined the effect of

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eHealth PCC using multimedia technology—CD-ROMs and DVDs, with none examining the use of the Internet or mobile phones. Computers or ICT has been used by some reviewed studies to provide health education within clinic settings [10,11,13]. However, people are now proactive in seeking health information and increasingly prefer to do things in the privacy of their homes and in their own time. Developments in technology mean that increasingly health programs can be delivered to people outside the traditional clinic setting, improving access for hard to reach populations across the world, as reflected in the recently agreed goals of the United Nations sustainable development plan [63].

The majority of studies (n=11) involved women traveling to clinics to physically receive the PCC educational intervention. However, constraints such as inadequate resources, time, and distance to health facilities have been shown to inhibit women's ability to adequately access such PCC interventions [48,50], and for many women around the world, this has negative implications for PCC uptake. Furthermore, no studies were carried out in developing countries; reflecting the existent inequality in PCC service provision. Mobile technologies can be used to extend the reach of PCC interventions given that 90% of the world's population now have access to a mobile phone [25]. Moreover, evidence of a reverse digital divide confirms that low income populations and those living in resource-poor settings are among the fastest growing users of mobile phones [64,65].

Bull [64] argues that if more people can be reached with health promotion interventions then even "modest" effects will translate into greater impact on morbidity and mortality. Contemporary eHealth technologies have the capacity to take an intervention that works on a small scale to a larger audience. From this review, which demonstrates the efficacy of PCC health education, it is apparent that the challenge lies in translating "what works" to a wider audience. We have a unique opportunity to overcome this challenge in eHealth PCC using mobile phones.

Way Forward for eHealth PCC

Mobile phones represent an underutilized resource that could be developed to support eHealth interventions for women with DM. Mobile phone ownership in developed countries has outstripped the population, with an average phone ownership of 1.16 mobile phones per person [25]. In developing countries, mobile communications technology is the fastest growing sector of the telecommunications industry with over a billion mobile phones [65,66]. Smartphones in particular, have the capacity of both computers and the Internet [24]. Their significant advantage over desktop computers, laptops, and DVD players make them a valuable tool for giving more women access to PCC [46]. They offer the opportunity to penetrate a larger population, are easily accessible, technologically advanced, utilize existing features (eg, geo-positioning technology; Internet access with photos, videos, and voice-recording capabilities), are mobile and convenient to use [4,22,23,67].

Many of the advanced functionalities of smartphones are aided by software applications or apps which hold great potential in helping to deliver cost-effective health interventions [4,16,17,22,23,67]. 90% of the time spent on mobile phones is spent on apps and in terms of usability, they are preferred over Web or computer-based applications [14,68]. Incorporating health education interventions into apps could help reduce barriers to adoption and facilitate increased acceptance of the intervention [4,24,69]. The innovative integration of smartphones or apps and PCC health education could help reduce the widespread burden caused by unplanned pregnancies in women with DM.

This is the first review to incorporate the use of eHealth technologies for PCC of women with DM into a discussion of PCC interventions. It highlights the benefits and limitations of each mode of delivery, and recommends use of smartphones and apps for maximizing the impact of future PCC interventions.

Limitations

A number of limitations should be noted. All reviewed studies were conducted in developed countries and their generalizability is limited to the geographical locations and health care settings in which the studies have been conducted. Various research methodologies were used in this review, and study quality was mainly moderate. Methodological weaknesses present in the study designs (small sample sizes, selection bias, confounding, and short follow-up periods) require caution in interpreting the results.

Conclusions

PCC education has a positive effect on pregnancy outcomes for women with DM. However, uptake of PCC is low and the use of eHealth apps for PCC of women with DM is still in its infancy. eHealth apps have the potential to improve access to PCC around the world, particularly in developing countries where women have increased risk of adverse maternal and fetal outcomes. Further research utilizing smartphones and apps is urgently needed as these technologies are increasingly being used around the world to provide health care information and support. Clearly, there is much to be done if full potential of eHealth PCC to improve obstetric outcomes for women with DM is to be realized.

Acknowledgments

The primary author (CHN) is supported by a grant from Funds for Women Graduates (FfWG).

Authors' Contributions

CHN was responsible for the conception and design, and writing of the manuscript. NC and JS assisted with study design and writing of the manuscript. All authors critically reviewed the manuscript and approved the final version submitted for publication.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Medline Strategy.

[PDF File (Adobe PDF File), 22KB - jmir_v18i11e291_app1.pdf]

Multimedia Appendix 2

Summary characteristics and quality assessment of reviewed articles.

[PDF File (Adobe PDF File), 206KB - jmir_v18i11e291_app2.pdf]

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Abbreviations

ACE: angiotensin-converting enzyme
CEMACH: confidential enquiry into maternal and child health
DM: diabetes mellitus
DSN: Diabetes specialist nurse
HbA1c: glycosylated haemoglobin
HCPs: Health care professionals
ICT: Information and communication technology
PCC: preconception care
PNC: prenatal care
RCT: randomized controlled trial
READY-Girls: reproductive-health education and awareness of diabetes in youth for girls
T1DM: type 1 diabetes mellitus
T2DM: type 2 diabetes mellitus

Edited by G Eysenbach; submitted 07.02.16; peer-reviewed by M Allman-Farinelli, A Georgiou; comments to author 18.04.16; revised version received 26.06.16; accepted 21.09.16; published 08.11.16.

Please cite as:
Nwolise CH, Carey N, Shawe J
Preconception Care Education for Women With Diabetes: A Systematic Review of Conventional and Digital Health Interventions
J Med Internet Res 2016;18(11):e291
URL: http://www.jmir.org/2016/11/e291/
doi:10.2196/jmir.5615
PMID:27826131

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Original Paper

Encouraging Patient Portal Use in the Patient-Centered Medical Home: Three Stakeholder Perspectives

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Abstract

Background: Health care organizations are increasingly offering patients access to their electronic medical record and the ability to communicate with their providers through Web-based patient portals, thus playing a prominent role within the patient-centered medical home (PCMH). However, despite enthusiasm, adoption remains low.

Objective: We examined factors in the PCMH context that may affect efforts to improve enrollment in a patient portal.

Methods: Using a sociotechnical approach, we conducted qualitative, semistructured interviews with patients and providers from 3 primary care clinics and with national leaders from across a large integrated health care system.

Results: We gathered perspectives and analyzed data from 4 patient focus groups and one-on-one interviews with 1 provider from each of 3 primary care clinics and 10 program leaders. We found that leaders were focused on marketing in primary care, whereas patients and providers were often already aware of the portal. In contrast, both patients and providers cited administrative and logistical barriers impeding enrollment. Further, although leadership saw the PCMH as the logical place to focus enrollment efforts, providers and patients were more circumspect and expressed concern about how the patient portal would affect their practice and experience of care. Further, some providers expressed ambivalence about patients using the portal. Despite absence of consensus on how and where to encourage portal adoption, there was wide agreement that promoting enrollment was a worthwhile goal.

Conclusions: Patients, clinicians, and national leaders agreed that efforts were needed to increase enrollment in the patient portal. Opinions diverged regarding the suitability of the PCMH and, specifically, the primary care clinic for promoting patient portal enrollment. Policymakers should consider diverse stakeholder perspectives in advance of interventions to increase technology adoption.

(J Med Internet Res 2016;18(11):e308) doi:10.2196/jmir.6488

KEYWORDS

personal health record; portal; enrollment; primary care; patient-centered medical home; qualitative

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Introduction

Background

Health care organizations are increasingly engaging patients in the management and coordination of their own care [1]. This patient-centered model of health care positions the patient as an integral member of the care team and allows for patients not only to receive information about their health, but also to contribute information that informs their care [2]. Information and communications technologies (ICTs) that facilitate the sharing and exchange of information between patients and their clinical teams' members are a key aspect of patient-centered care. One such technology that equips patients with tools to interact with their clinical teams is the Web-based patient portal. In recent years, patient portals have evolved from providing patients with a way to view information in their medical record to also encompass secure Web-based apps that offer various electronic tools to support health care system transactions, information tracking, and communication [3]. Health care systems have increasingly promoted the use of patient portals, motivated in part by a desire to satisfy "meaningful use" requirements of the Medicare and Medicaid Electronic Health Record (EHR) Incentive program [4]. Most large health care organizations [5-7], including the Veterans Health Administration (VHA) [8,9], offer patient portals. Although the functionality of patient portals varies, all strive to increase patient engagement.

The use of ICTs such as patient portals is often considered a critical component of a patient-centered medical home (PCMH). The PCMH has been described as a way of organizing primary care that emphasizes coordination and communication, and better aligns primary care with patients' goals [10]. As part of a broader transformational initiative to realize the principles of patient-centered care, the VHA broadly implemented a PCMH model beginning in 2010 [11,12]. In this model, every patient is assigned to a PCMH, which typically consists of a primary care provider, nurse, medical support assistant, and access to professional staff, such as clinical pharmacists, mental health specialists, social workers, or nutritionists, all who work collaboratively to care for a panel of patients [13]. Promoting patient engagement through the use of ICTs has been a key element in implementing the VHA's PCMH model [14,15]. VHA's patient portal, My Health*e*Vet, enables patients to view, print, and download information (eg, clinicians' notes, laboratory results) from their EHR, communicate electronically with their health care team using secure messaging, refill prescriptions, view wellness reminders, and access educational information. See Multimedia Appendix 1 for a summary of PCMH principles and exemplary features of the My Health*e*Vet patient portal.

Despite the potential benefits associated with patient portal use and the role that they are envisioned to play in PCMH, the actual enrollment of patients has remained low [16,17]. A number of possible reasons contribute to low enrollment, including limited awareness [18], lack of familiarity with computers and the Internet [19], low levels of health literacy [20], and lack of provider endorsement [14]. At the time of this study, less than 1 in 5 Veterans using VHA health care had enrolled in My Health*e*Vet. Currently, more than half of VHA patients now access My Health*e*Vet; however, challenges remain.

Study Goals

Given the central role of PCMH in many health care systems, including the VHA, PCMH settings may be an ideal place to reach patients and increase enrollment in patient portals. Understanding the potential of the PCMH setting to enroll patients in a patient portal requires an in-depth understanding of influential contextual factors [21]. Similarly, a sociotechnical perspective emphasizes the need to examine the interrelationship between technology and its social environment [22,23]. As such, our objective was to gather the perspectives of 3 different stakeholder groups to understand the range of sociotechnical factors affecting efforts to improve enrollment in the My Health*e*Vet patient portal.

Methods

Study Design, Setting, and Participants

Our qualitative study design used focus groups and semistructured interviews to ascertain 3 critical perspectives: patients, primary care team providers, and program leaders. The patient and provider components of the study took place in 3 primary care clinics at 2 VHA Medical Centers in the northeast United States in 2011 and 2012. Program leaders included VHA employees who served on national working groups that guided the development of and set policy for VHA patient portal use. Informed consent was obtained from all participants. VHA employees were not compensated; patients received US $20. Study procedures were approved by the appropriate VHA Institutional Review Boards.

At the time of the study, enrollment in My Health*e*Vet required multiple steps. First, patients needed to establish an account through an online registration process. Second, patients were required to visit a VHA facility to verify their identity; this process is known as in-person authentication. Third, patients wishing to use the secure messaging feature of My Health*e*Vet had to "opt in" in an additional step. Thus, we identified 4 classes of patients: (1) not registered for My Health*e*Vet, (2) registered but not yet have in-person authentication, (3) had in-person authentication but did not opt in for secure messaging, and (4) opted in to secure messaging. The first group was considered "not enrolled" for the purposes of this research; the 3 other classes were considered "enrolled."

Data Collection

We employed a convenience sampling strategy to recruit patients, providers, and leadership.

Patient Focus Groups

Patients were recruited using flyers posted and pamphlets handed out in primary care. VHA databases were used to identify participants to recruit by mail. We held focus groups for "enrolled" and "not enrolled" patients using the preceding criteria.

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We held 4 focus groups: 2 for enrolled patients, 2 for unenrolled patients. The focus group guides (see Multimedia Appendix 2) were similar, but tailored to enrollment status. All focus group participants were asked about familiarity with the patient portal, practices for managing health information, and computer familiarity and use. Participants were also asked about receptivity to learning about the My Health*e*Vet patient portal in the primary care setting and strategies to increase enrollment. For patients who had already enrolled in the portal, we also asked about their experience in enrolling. Data were analyzed according to enrollment status to discern if there were differences between these groups. Focus groups were held in private rooms near the primary care setting and were audio recorded. Each lasted approximately one hour.

Provider and Program Leader Interviews

Providers were identified by primary care clinic affiliation and recruited in person and via email. Program leaders were identified by their national, system-wide role in the My Health*e*Vet patient portal program and subsequently recruited by email and telephone. Participants included individuals who served on policy-making committees. Others were involved in the design and evaluation of the patient portal; some were active in clinical roles in their local VHA Medical Centers. For the provider interviews, we developed a semistructured interview guide to assess clinicians' familiarity with the My Health*e*Vet patient portal, experiences discussing the portal with patients, and their perceptions of patient interest and portal use among their patients. For the program leaders, we developed a semistructured interview guide to elicit the history of the My Health*e*Vet patient portal, understand existing efforts to improve enrollment practices in primary care as well as other settings, gain feedback on potential enrollment interventions, and understand the evolution of the portal. Interviews were conducted over the telephone or in person and audio recorded with permission. Each interview lasted approximately 30 minutes.

Both the focus group and interview guides were developed through iterative rounds of review by the team. They were designed to be used flexibly and tailored to the group or unique position of each interviewee.

Analysis

Focus group and interview data were transcribed verbatim. In an effort to maximize rigor and trustworthiness, we engaged multiple team members in our analysis who met regularly and coded the transcripts using emergent analytic techniques involving a grounded theory approach [24]. Initially, team members GF, DA, and TH each independently reviewed a transcript reflecting each of the 3 stakeholder groups in the study and then met to compare their respective findings. The outcome of this meeting was a codebook that was applied to all transcripts in iterative rounds of analysis. As coding proceeded, clinicians and program evaluators with deep knowledge of VHA's primary care context and the My Health*e*Vet patient portal were consulted and asked to provide feedback on the team's analytic interpretations. Coding was performed in Microsoft Word, using separate documents to capture text exemplifying codebook themes. This process was initially done separately for the different patient focus groups, and provider and leadership interviews. Subsequently, we synthesized themes across the groups.

Results

We conducted 4 patient focus groups and interviewed 1 primary care provider from each of the 3 clinics, along with 10 program leaders. 5 key themes that cut across the data were identified:

1. Disconnect over the role of marketing in primary care to increase enrollment;

2. Differing perspectives on where barriers to enrollment exist;

3. Divergence of opinions on the appropriateness of primary care for promoting personal health record (PHR) portal enrollment;

4. Provider ambivalence regarding the value of the My Health*e*Vet PHR portal; and

5. Lack of consensus over appropriate patients to target for My Health*e*Vet PHR portal enrollment.

Disconnect Over the Role of Marketing in Primary Care to Increase Enrollment

Leadership was focused on the potential of marketing to increase awareness and enrollment, whereas providers and patients felt saturated with information about the My Health*e*Vet PHR portal. The program leader interviews centered on ways to promote and market My Health*e*Vet:

> *If we start the marketing perspective I think there is a lot more that can get involved before getting to the registration piece. I think pharmacy techs, lab techs, volunteers at the front desk, they could all be involved in the marketing, handing out a flyer.* [Leader]

In contrast, the provider interviews did not emphasize patients' awareness, focusing instead on identifying which patients are most likely to be interested in My Health*e*Vet. In response to a question about raising My Health*e*Vet with his patients, one provider shifted the conversation to discuss which patients are appropriate for My Health*e*Vet:

> *We've been aggressively trying to engage our patients to sign up for My HealthVet and [secure messaging]; however, I do believe that difference in the demographics and patient population has its bearing on how well it happens. It happens still that this particular practice tends to be more geriatric with less computer savviness.* [Provider]

This same provider was asked if patients ever bring up My Health*e*Vet. He responded, " Usually by the time they get to my office, they are fully aware of the existence of this as an option, and they don't need me as an advisor for computer training options here."

The patients we spoke with, including those who were not yet enrolled in My Health*e*Vet, were aware of My Health*e*Vet. Patients described learning about My Health*e*Vet through a variety of sources including providers, other patients, and promotional materials such as online advertisements, posters,

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mailed materials, and brochures handed out during appointments. Not all patients viewed the brochures favorably:

> *I'm sure I have probably about 40 copies of this [My HealthVet brochure]...But because I have this [brochure], I have that [brochure], I have this, I have that...by the time I get home, it's like, "Take all this [VHA information] and chuck it. Put it in the recycle bin.*" [Unenrolled patient]

Similarly, a program leader lamented that marketing materials, such as water bottles and lanyards with the My Health*e*Vet logo, were not utilized at the anticipated rate. Further, he noted the importance of being persistent but also making sure not to tell the same patient repeatedly about My Health*e*Vet: "We have to be a little bit careful when a [patient] says, 'No, I'm not interested, don't ask me again,' we have to make sure that we don't ask them again."

Differing Perspectives on Where Barriers to Enrollment Exist

Discussions in patient focus groups repeatedly returned to issues about challenges to completing enrollment, which were less prominent in leadership interviews. The providers we spoke with recounted administrative and logistical problems with the My Health*e*Vet enrollment process that they encountered in their primary care practices. Likewise, much of the patient focus groups, both the enrolled and unenrolled, were spent discussing problems the participants encountered in trying to enroll. One unenrolled patient stated, "The steps we have to go through to register [are] just ridiculous." Notably, more than half (7/12) of the unenrolled focus group participants reported having tried to enroll in My Health*e*Vet. Several of these participants thought they had completed all the steps necessary to access the full range of My Health*e*Vet features. One was certain she was fully registered, despite the research team identifying her as unenrolled from verified databases. Another said her provider told her that she was registered, but she still reported that she could not access My Health*e*Vet.

Many of the patients in the "enrolled" focus groups had similar experiences to those in the "unenrolled" groups, especially when describing challenges in completing the enrollment process. In-person authentication was particularly problematic. At the medical centers where the study was conducted, in-person authentication was available in 1 location. Patients reported that the office was difficult to find and had limited hours (see Figure 1): "There is an office downstairs, they tell me to go into and sign up, every time I go to that office, it's closed" (Unenrolled patient).

Providers were aware of patients' logistical difficulties trying to enroll in My Health*e*Vet. One provider characterized the current enrollment process as "completely out of touch [with] reality" because patients—who may have taken time off of work to come to their clinical appointment—were expected to go to another location in the hospital, sometimes on a different day, to enroll in My Health*e*Vet. This physician described problems with the location and hours of the in-person authentication office:

> *The part that bums me is how many [patients] have gone to that office, saw it was closed and never let me know, and just months went by until the next visit, and they said, "yeah, you know, I've tried to go in there and it was closed.*" [Provider]

Of note, this clinician subsequently told her patients how to bypass the official enrollment office. She referred patients to a different office, which had more regular hours and staff willing to help patients complete the enrollment.

In contrast, in interviews with national program leaders, issues related to logistical barriers were not brought up, aside from one leader referring to a potential enrollment "glitch" that might prevent a patient from using My Health*e*Vet, during a larger discussion about the importance of getting providers to use secure messaging.

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Figure 1. Sign on door to My Health*e*Vet enrollment office at one of the study sites.



Divergence of Opinions on the Appropriateness of Primary Care for Promoting Personal Health Record Portal Enrollment

Leadership assumed primary care was the best and most logical location within the organization for promoting PHR portal enrollment; however, providers and patients preferred to focus on pressing clinical issues. Program leaders saw a role for primary care providers in the patient portal enrollment process. Although they did not feel that providers needed to be directly involved, they nonetheless felt that providers needed to play a strong supporting role by both encouraging their patients to enroll and supporting coworkers' efforts to enroll patients, in keeping with the PCMH model:

> *Physicians, they have to champion it. That is going to be a critical piece. If the physician doesn't champion it, then nobody else is going to get behind it.* [Leader]

The program leaders were aware of providers' concerns about the potential workload involved in promoting and enrolling one's patients in My Health*e*Vet. One noted the importance of ensuring that providers did not perceive My Health*e*Vet enrollment "as yet another thing to review with Veterans."

The program leaders uniformly acknowledged that primary care providers had limited time to personally enroll patients in My Health*e*Vet: "The clinicians, the health care team members play a role, and they play an important role, but the scope of that role needs to be limited...It's got to be a group effort."

Yet, the program leaders still felt the provider role was a critical part of the process: "It's fine to have the nurse do it, but I would also argue that the physician should also be the one saying [to their coworkers], 'You need to do this.'"

In contrast, providers viewed My Health*e*Vet promotion less as a shared responsibility and more as needing to be the responsibility of other team members.

At the time of our fieldwork, the 3 primary care clinics serving as study sites had instituted a My Health*e*Vet patient portal clinical reminder in the EHR. The reminder would appear for primary care patients, as part of a series of wellness reminders that primary care clinicians and staff were responsible for resolving in the EHR. Even though providers and support staff all saw the My Health*e*Vet clinical reminder, the providers we spoke with viewed the reminder as "something for the medical assistants, the [licensed practical nurses], whoever is doing the intake of the patient. I don't see that as my reminder, so I don't act on it." Another provider similarly stated, "I also don't think it should be a physician-driven reminder; it should be filled by someone else on the team." Moreover, one provider thought primary care should have a limited role in My Health*e*Vet enrollment, and that it should instead be a broader, system-level

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responsibility: "I think if [getting patients enrolled is] going to work it needs to—it's an institutional issue, it's not, I don't see it as necessarily as a primary care issue."

The providers we spoke with were largely uninterested in being involved in discussions with patients about My Health*e*Vet. One stated, "I do not have time in my practice to advocate for My Health*e*Vet use routinely."

Moreover, the patients we spoke with felt that the primary care setting was not the appropriate place for patients to learn about My Health*e*Vet. They felt their primary care team members—including not only their provider, but also the receptionist, medical support assistant, and nurse—were too busy to talk to patients about My Health*e*Vet. The focus group participants did not want to receive information about My Health*e*Vet during their clinical appointments. They already felt they received considerable informational materials while in the primary care clinic. For My Health*e*Vet materials in particular, they felt that it was incongruous to include this information along with brochures about cholesterol and influenza vaccines. Further, when providers brought My Health*e*Vet up in the context of other clinical discussions, patients were confused:

> *They gave me the My HealthVet paperwork...and just a brief overview, but then at the same time they're giving me information about cholesterol...I feel overwhelmed...I really kind of didn't get My HealthVet.* [Unenrolled patient]

Some patients felt uncomfortable with their primary care provider promoting My Health*e*Vet during an appointment. One participant thought her provider had been too assertive in saying, "This is the *only* way you can communicate with me!"

Providers, too, were generally unenthusiastic about the My Health*e*Vet clinical reminders:

> *We have so many reminders that just get read in a robotic way, that it may just be noise to the patient, and if the person delivering the information isn't excited or truly on board with the process, I don't think it's, it's going to be useful.* [Provider]

Another commented:

> *There are other times when half the reminders don't get done, and the ones that are done, the patient had no clue that they were done, so it raises some concern in my mind that the communication between the [medical assistant] and the patient is not very effective.* [Provider]

Beyond primary care and its PCMH model, the program leaders we spoke with felt that others in the medical center needed to be responsible for promoting My Health*e*Vet. They emphasized that leadership throughout each medical center should participate in My Health*e*Vet. In addition to local leadership support, the national program leaders felt other clinical services should share the responsibility with primary care for My Health*e*Vet enrollment: "We should also be having the lab[oratory employees] telling people that they can get the results of their blood tests [through My Health*e*Vet]."

Provider Ambivalence Regarding the Value of the My Health *e* Personal Health Record Portal

Although leadership saw clear value in the use of the My Health*e*Vet PHR portal, providers were less convinced of its utility in practice. National leaders felt provider buy-in was key to promoting My Health*e*Vet. One program leader stressed that local leaders need to "both model that I'm using My Health*e*Vet and demonstrate some basic knowledge of how to use it, really advocate for it" and "not be cynical." Yet all 3 participant groups—patients, providers, and program leaders—acknowledged that there was some provider ambivalence. Patients reported that although some providers aggressively encouraged enrollment, others seemed indifferent or even negative about My Health*e*Vet. Providers expressed mixed feelings. Some appreciated that My Health*e*Vet made medication refills easy for patients and subsequently reduced workload. However, other providers expressed concerns about My Health*e*Vet, from how it might affect patient-provider relationships to what information in the medical record their patients would be able to see. Others had concerns about enrolling patients in a system that they perceived as not fully functional. One of the providers was uneasy about the upcoming option for patients to view the clinician's progress notes, which VHA added in 2013:

> *I'm also concerned about the fact that patients will see full progress notes. To the extent that patients start reading their own medical record directly—I would say that there is nothing in my note that should be offensive to a patient. But if a patient has problems with compliance, if they have problems with substance abuse, if we feel they're manipulating and we need to communicate that to keep track of that ourselves, and communicate that to each other.* [Provider]

This provider went on to elaborate concerns about patients viewing documentation in the medical record that he viewed as primarily intended to communicate to other clinicians about sensitive matters, such as substance abuse or poor adherence.

In contrast, another provider, who had previously worked in a different health care system which had for several years been using a patient portal, said she promotes My Health*e*Vet use because of the ability to exchange secure messages with her patients. She saw the secure messaging feature as especially useful because the alternative was having patients use the telephone call center. She described the call center as unreliable; she did not consistently receive patients' messages. In contrast, when her patients used secure messaging, no communications were lost.

Lack of Consensus Over Appropriate Patients to Target for My Health *e* Personal Health Record Portal Enrollment

Primary care providers relied on their beliefs about who they thought might be appropriate for My Health*e*Vet use to guide conversations about enrollment, whereas leaders felt it should be targeted to all patients with computers. Providers did not think My Health*e*Vet was appropriate for all patients. One felt she had a good sense of her patients' receptivity to My

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Health*e*Vet. She demonstrated this to the interviewer by reviewing her patient list for the day and commenting on each patient's likelihood of using My Health*e*Vet. She cautioned that being older should not be seen as an exclusion criterion and went on to describe her octogenarian father's extensive computer use. This view was not shared by other providers. Another said that in addition to age, computer literacy was an issue:

> *The main barrier, at least in this practice, is the fact that it is geriatric population. Even if it wasn't a geriatric population, with my younger patients, it's a question of computer literacy.* [Provider]

Some providers promoted My Health*e*Vet to patients who were younger or showed interest in computers. Other providers were more passive, only bringing up My Health*e*Vet in response to patients who showed an interest in technology or inquired about My Health*e*Vet:

> *There have been a couple of times with younger patients who I know use computers that I may have mentioned it, and asked them if they got the My HealthVet information, and encourage them to sign on, but I don't do that with the majority of my patients.* [Provider]

This provider went on to say, "I wait for clues that the patient has some interest. My approach is to reinforce them, rather than be proactive, and saying, 'This is on my checklist to make sure [you enroll].'"

Even a provider who described himself as highly supportive of My Health*e*Vet responded: "I don't have really in-depth conversations with people who don't indicate with me that they would want to use it."

A focus group participant in his 80s noted that his providers had not mentioned My Health*e*Vet. Another described seeing My Health*e*Vet promotional materials, but initially thought My Health*e*Vet was for younger patients. He described how his clinician mentioned that My Health*e*Vet would allow him to have direct communication without using the telephone. This patient noted that as a result of this interaction, his perception changed—he realized that My Health*e*Vet was not limited to younger patients.

Instead of targeting My Health*e*Vet based on demographics, national leaders spoke of tailoring My Health*e*Vet promotion to patients with Internet access, such as having the clinical reminder begin by asking about access to the Internet. If the patient reported no access, they would no longer be targeted for enrollment.

Discussion

In this qualitative study, we sought to identify and understand factors in VHA's primary care context that might affect enrollment in the health care system's PHR portal. Through our discussions with 3 stakeholder groups—patients, providers, and leadership—we found differing views of both the value of the My Health*e*Vet PHR portal as well as whether primary care in its role as the medical home was an appropriate location to support portal enrollment. 5 salient themes representing these divergent views emerged from our analysis. We discuss each theme subsequently as well as the perspectives of stakeholders and how our findings align with, and add to, the existing literature.

Disconnect Over the Role of Marketing in Primary Care to Increase Enrollment

The program leaders we spoke with differed from patients and providers on their perspective about the role of marketing to increase awareness. Although program leaders perceived that lack of awareness was a significant issue, which additional marketing could address, findings from both patients and providers suggested otherwise. The providers felt their patients were aware of My Health*e*Vet and that any marketing efforts needed to be tailored specifically to patients who were most likely to enroll. The patients we spoke with were generally aware of My Health*e*Vet, with several noting the abundance of marketing materials being distributed in primary care. However, patients were less familiar with *how* to enroll in My Health*e*Vet. Although the program leaders were focused on marketing strategies, our patient data suggest that knowledge of My Health*e*Vet is not the prominent barrier to enrollment. Instead, patients encountered difficulty with enrollment procedures. An enrollment strategy where patients are automatically enrolled and would have to opt out if they were not interested could vastly reduce patient enrollment burden [25]. Additionally, VHA has updated its marketing and outreach strategy utilizing social media, online YouTube videos, and partnering with community organizations [26].

Differing Perspectives on Where Barriers to Enrollment Exist

The patient and provider interviews focused their discussions on their poor experiences with the My Health*e*Vet enrollment process. Patients in both the enrolled and unenrolled focus groups recounted similar barriers to enrolling, the notable difference being that the enrolled participants were ultimately successful. Moreover, it appeared that a number of patients who had begun the registration process had failed to complete all the necessary steps to gain access to valuable features of the portal, such as secure messaging and viewing laboratory results. Of those who were unenrolled, many were not aware they had not completed all the steps of the enrollment process. In contrast, this discussion of barriers was not a prominent theme in the leadership interviews. Instead, their focus was on marketing and increasing awareness at this early stage of the My Health*e*Vet initiative.

Since the completion of the study, PHR portals and strategies to engage patients to adopt and use them have continued to evolve. At VHA, several changes have occurred to improve awareness of and enrollment in My Health*e*Vet. Some VHA Medical Centers have established organizational structures outside of the primary care setting to support patients who are interested in learning more about My Health*e*Vet (eg, establishing a special group visit clinic). These settings also provide patients with assistance in completing the enrollment process and often offer educational opportunities to learn how to use the various portal tools effectively [27,28]. Other sites have successfully tested providing clinic clerks with prompts

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and resources to engage with patients about interest in completing My Health*e*Vet enrollment as part of the initial enrollment process for VHA services. This innovation is now being implemented within the EHR nationwide. Many VHA Medical Centers also offer My Health*e*Vet enrollment via point-of-service kiosks. In addition, authentication can now be completed online, obviating the need for patients to visit the facility to complete enrollment [29]. Veterans can also now use their [military service] Department of Defense-issued "DS Logon" credentials to log in to My Health*e*Vet and upgrade their account. These changes were made in local settings or by the national program office in response to Veteran and staff feedback about ways to improve enrollment processes obtained through focus groups, online surveys, and quality improvement initiatives. Additionally, strong collaboration between the national program office and VHA researchers continues to inform implementation strategies [9,14,30,31].

Divergence of Opinions on the Appropriateness of Primary Care for Promoting Personal Health Record Portal Enrollment

National leadership viewed primary care, in its role as the medical home, as the logical place to enroll patients in My Health*e*Vet, but this view differed from patients' and providers' perspectives. Both patients and providers stated that primary care should be focused on the already time-consuming demands of providing needed clinical services. Notably absent in our data were patient references to the reorganization of primary care into teams. This may be because the reorganization had occurred in advance of My Health*e*Vet or possibly because patients do not view issues surrounding the structure of their primary care teams as germane to My Health*e*Vet. However, patients found it incongruous to hear about My Health*e*Vet along with clinical issues or vaccines. Likewise, providers did not feel they had time to address issues outside of their clinical demands.

Providers are concerned about the added workload helping patients use patient portals [32]. They are feeling overwhelmed by clinical tasks, including responding to EHR clinical reminders [33], and may not have the capacity to add more to their clinical encounters.

Provider Ambivalence Regarding the Value of the My Health *e* Personal Health Record Portal

National leaders espoused the importance of primary care providers promoting My Health*e*Vet, but the providers we spoke with described mixed feelings about My Health*e*Vet. Some providers were concerned about what patients might learn by reading their medical record and, therefore, did not encourage enrollment. Yet, as the leaders knew, primary care support may be critical to patient enrollment.

These findings mirror those of others who found poor provider support of patient portals. Witry et al [34] found providers held a limited view of patient health record functions and benefits, whereas Kittler et al [35] found providers are hesitant to electronically communicate with patients. Although such views may be evolving with the spread of PHRs across health care organizations, providers not fully supporting PHRs can still undermine efforts to get providers to promote patient portals. It may be that providers do not see a role for patient portals or how they might fit into their own practice [36]. Provider education, such as an academic detailing approach, may be a way to increase familiarity and interest in My Health*e*Vet by providing tailored and feasible feedback on what My Health*e*Vet promotion could look like in primary care settings [37].

Lack of Consensus Over Appropriate Patients to Target for My Health *e* Personal Health Record Portal Enrollment

There was some agreement among program leaders and providers that My Health*e*Vet enrollment should be targeted. National leaders felt My Health*e*Vet should be promoted toward patients who had computer access, whereas providers thought about their patients in terms of demographic characteristics, such as age. Regardless of the population of focus, targeting specific populations and monitoring their uptake are effective at increasing patient portal adoption [38], although this may contribute to widening of the digital divide.

Conclusion

Our findings reveal the importance of seeking a multistakeholder perspective to identify and understand challenges to enrollment in patient portals. More broadly, our findings may have implications for adoption of new patient facing technologies in general. These lessons are important because of the continued trend toward making patient access to care broader (ie, accessible 24/7 asynchronously from any location), the resulting pressures that can surface in the clinical setting as roles shift and adaptation is required, and the implications for resources to support new processes. Implementation strategies will be needed to address these challenges. Additional technologies are being implemented, such as text messaging systems [39-42] and wearable devices [43], both of which will take the time of someone (providers, techs, clerks) to explain to patients what they are, how to use them, and to help them enroll. Similarly, it will be important to bring providers on board for these other technologies because they are likely to be at least partially affected either by the data they provide or patients asking about them.

Our study has several limitations. This work is a snapshot in time, representing the state of the VHA patient portal in 2011-2012. A variety of factors have subsequently influenced the evolution of policies and processes of My Health*e*Vet enrollment. Additionally, this study is limited to the experiences of patients and providers from 3 primary care clinics in the northeastern United States. Although the sites we visited had limited office hours to complete enrollment, this was not uniform across all VHA facilities nationally. Further, our lessons may not be uniformly relevant to other organizations.

Despite these limitations, our findings suggest several lessons for health care organizations seeking to increase enrollment in their patient portals. Although primary care may have seemed an ideal location to promote My Health*e*Vet, and this idea was supported by program leaders, the patients and providers we spoke with did not share this view. In their review of patient portals, Goldzweig et al [44] concluded that additional

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information about context is necessary to help policymakers better understand how successful portals have been implemented.

Further, our data underscores the importance of speaking to all invested parties. From these 3 critical stakeholder groups—patients, primary care clinicians, and national program leaders—we captured sometimes divergent perspectives regarding how efforts to improve enrollment in the PHR portal aligned with the primary care setting. Although primary care may have intuitively seemed like an ideal setting to improve enrollment, providers and patients offered some cogent reasons that refute this intuitive choice. It was only through our discussions with patients and providers that we learned of their familiarity and existing ambivalence about VHA's PHR. The state of enrollment was not a reflection of not knowing about My Health*e*Vet, but was instead symptomatic of a system with some obstacles to enrollment and concerns about the role of My Health*e*Vet in primary care. As previously noted, since the time of the study several improvements have been implemented both in marketing strategy and methods, and in the actual enrollment process.

From a sociotechnical perspective, our study raises important questions regarding the relative fit of efforts to increase enrollment in PHR portals within primary care contexts [45]. Primary care providers may not feel it is their responsibility to focus on enrollment and patients may be wary of detracting from issues directly related to their health that are seen as more pressing. Based on our analysis, we recommend that PHR portal enrollment processes be creatively reimagined and streamlined. Patients could, for example, be automatically enrolled unless they opt out, similar to how some organizations structure retirement plans [25]. Proactive, customized implementation strategies, such as those described in the literature, may be considerably effective [46]. Understanding the perspectives that diverse stakeholders may have of such strategies could make all the difference in their success.

Acknowledgments

This study was funded by the Department of Veteran Affairs, Health Services Research and Development, Quality Enhancement Research Initiative, Project #RRP 11-241. This material is based on work supported by the Department of Veterans Affairs, Veterans Health Administration, Office of Research and Development, Health Services Research and Development. The views expressed in this paper are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government. An earlier version of this work was presented at the Department of Veterans Affairs Health Services Research & Development 2012 Annual Meeting. The authors thank Dr Thomas K Houston and Stephanie L Shimada for their advice at various stages of the project.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Table 1. Principles of Patient-Centered Medical Homes and Exemplary My Health*e*Vet Patient Portal Features.

[PDF File (Adobe PDF File), 16KB - jmir_v18i11e308_app1.pdf]

Multimedia Appendix 2

Focus group and interview guides.

[PDF File (Adobe PDF File), 29KB - jmir_v18i11e308_app2.pdf]

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Abbreviations

EHR: electronic health record
ICT: information and communications technology
PCMH: patient-centered medical home
PHR: personal health record
VHA: Veterans Health Administration

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Edited by CL Parra-Calderón; submitted 15.08.16; peer-reviewed by L Green, C Lyles PhD; comments to author 12.09.16; revised version received 23.10.16; accepted 29.10.16; published 22.11.16.

Please cite as:
Fix GM, Hogan TP, Amante DJ, McInnes DK, Nazi KM, Simon SR
Encouraging Patient Portal Use in the Patient-Centered Medical Home: Three Stakeholder Perspectives
J Med Internet Res 2016;18(11):e308
URL: http://www.jmir.org/2016/11/e308/
doi:10.2196/jmir.6488
PMID:27876686

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Original Paper

Test-Enhanced E-Learning Strategies in Postgraduate Medical Education: A Randomized Cohort Study

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Abstract

Background: The optimal design of pedagogical strategies for e-learning in graduate and postgraduate medical education remains to be determined. Video-based e-learning use is increasing, with initial research suggesting that taking short breaks while watching videos (independent of answering test questions) may improve learning by focusing attention on the content presented. Interspersed test questions may also improve knowledge acquisition and retention.

Objective: To examine the effect of interspersed test questions and periodic breaks on immediate knowledge acquisition and retention at 6 months by pediatric residents engaged in video-based e-learning.

Methods: First- and second-year pediatric residents were randomized to 1 of the following 3 groups: viewing the complete video uninterrupted (full video), viewing the video interrupted with unrelated logic puzzles (logic puzzles), or viewing the video interrupted with brief comprehension test questions (short answer questions). Residents answered pre- and post-tests before and after video viewing, followed by a retention test at 6 months. Primary outcome included comparison of the change in test scores between groups.

Results: A total of 49 residents completed the initial testing session. All 3 learning groups had comparable mean increases in immediate knowledge gain, but with no significant differences between groups ($F_{2,46}$=0.35, P=.71). Thirty-five residents completed retention testing with comparable degrees of knowledge retention in the full video and short answer test questions groups (P<.001), but no significant change in the logic puzzles group ($F_{1,32}$=2.44, P=.13).

Conclusions: Improved knowledge gain was not demonstrated among residents answering interspersed questions or completing logic puzzles during interrupted online video viewing when compared with residents viewing uninterrupted video content. However, residents who either participated in uninterrupted video viewing or answered interspersed questions during interrupted video viewing demonstrated significant knowledge retention at 6 months.

(J Med Internet Res 2016;18(11):e299) doi:10.2196/jmir.6199

KEYWORDS

distance learning; computer-assisted instruction; medical education; educational measurement; retention

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Introduction

The recent introduction of e-learning initiatives in postgraduate medical education has been heralded as a disruptive change to efficiently scale knowledge and promote more effective learning. Although e-learning can deliver knowledge, research to inform the optimal learning design and teaching practices in this environment remains in its infancy [1-4]. Research in the cognitive psychology literature demonstrates that test-enhanced learning, that is, answering test questions at repeated intervals during an educational activity, improves knowledge gain in both classroom [5,6] and e-learning settings by encouraging active information retrieval, focusing attention on the content presented, promoting task-relevant behaviors such as note-taking, and reducing overall cognitive demand [7].

Using interspersed test questions as an educational learning tool also allows for superior knowledge retention relative to passively restudying the same material when students are tested at extended intervals after the initial learning activity [8,9]. Tests that stimulate deeper retrieval of information, such as short answer or essay, have the potential to achieve better knowledge gains than recall tests such as simple multiple choice questions [10,11]. Multiple choice questions can further be classified as those that require clinical knowledge application, or context-rich questions, versus those that require simple factual recall, or context-free questions [11].

Despite the increased use of e-learning platforms to educate postgraduate medical trainees, we were unable to identify any studies investigating the implementation of test-enhanced learning strategies in an e-learning platform for postgraduate medical education. Yet, many e-learning platforms and massive open online courses (MOOCs) utilize uninterrupted instructional videos as a means of learning, with or without pre- and post-tests for knowledge assessment [12-14].

The purpose of this study was to evaluate the extent to which the use of interspersed test questions or taking periodic breaks while watching an online video would impact knowledge gain as compared with watching the same video without any breaks. As a proxy for knowledge gain, the primary study outcome was the difference between pre- and post-test scores between groups. Secondary outcomes included the difference between pre- and post-test scores within each group and the difference in retention test scores at 6 months compared with pretest scores between groups.

Methods

Recruitment and Study Design

We conducted a randomized, prospective, cohort study in 3 academic medical centers in Boston, Massachusetts between June 2014 and March 2016. Pediatric residents in their first or second year of postgraduate training were eligible to participate. Participation was completely voluntary, as this educational initiative was independent from educational obligations during their clinical pediatric intensive care unit (PICU) rotations. Residents were ineligible if they had previously completed a 4-week PICU rotation during residency because the study intervention assessed knowledge acquisition and retention of mechanical ventilation concepts that would have been encountered by residents on their first PICU rotation. Email invitations were sent to all eligible residents enrolled in the following pediatric residency programs: Boston Combined Pediatric Residency Program, Massachusetts General Hospital, and Tufts Floating Hospital for Children. Residents provided voluntary written consent for study inclusion. No residents who volunteered to participate actively refused participation at a subsequent time point during the study. Residents received a US $50 Amazon gift card and the chance to receive an iPad via random selection upon completion of 6-month retention testing. The Boston Children's Hospital's Institutional Review Board deemed this study exempt from informed consent, given no identifying data on study participants were collected. Affiliated institutions honored the exempt status. Initial testing was conducted at each of the 3 institutions with all sessions monitored by 1 of 2 study facilitators who were available to troubleshoot technical difficulties and monitor for dishonest behavior. Retention tests were administered via email. Residents were asked to abide by the honor code when completing the retention test.

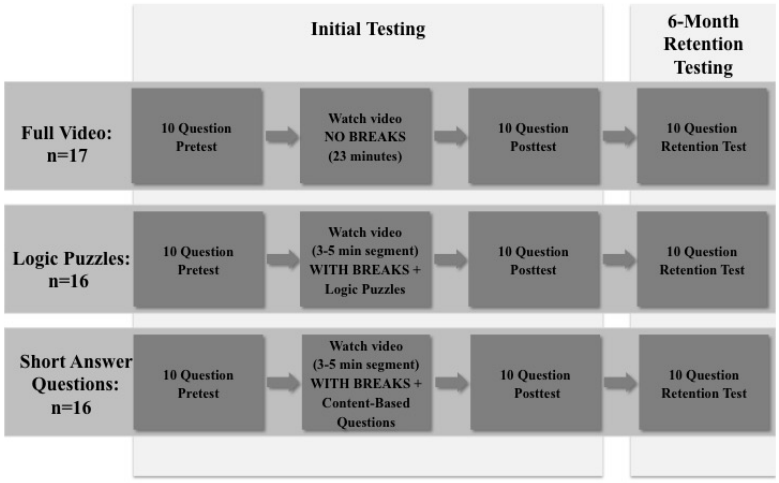
Pediatric residents were blindly randomized via concealed envelopes to 1 of the following 3 groups: full video, logic puzzles, or short answer questions (Figure 1). Residents in the full video group watched the video uninterrupted (without breaks), representing the "control" group as this is the typical e-learning video format. Residents in the logic puzzles and short answer questions groups watched the same video with interspersed breaks during which they either completed noncontextual logic puzzles or content-based test questions.

Study Materials

Residents completed all computer-based elements of this study via a single lesson plan created on the commercial e-learning platform Softchalk (Softchalk LLC, Richmond, VA). All residents watched a peer-reviewed video about the basic principles of high frequency oscillatory ventilation (HFOV), assuming that pediatric residents would have limited baseline knowledge of this content as clinical exposure to ICUs is low early in residency training. In addition, this specific topic was chosen for educational use because although HFOV is an important mode of mechanical ventilation for advanced, refractory pediatric respiratory failure and requires basic conceptual understanding by residents, the use of this type of mechanical ventilation is an overall low-frequency event in most PICUs. The video was written and presented by a Harvard Professor who conducts research on HFOV, as part of an existing curriculum on OPENPediatrics, an open access, e-learning platform [12]. This video was peer-reviewed by mechanical ventilation content experts. OPENPediatrics has been integrated into the Boston Combined Residency Program curriculum such that residents rotating through the PICU must complete video-based lessons on OPENPediatrics, including those related to HFOV. Thus, survey data collected the information whether the residents had ever logged into OPENPediatrics and watched HFOV-related videos. OPENPediatrics verified whether study participants viewed the HFOV video on OPENPediatrics during the study timeline.

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Figure 1. Schematic design of randomized study protocol for the 3 learning groups.



Three content experts from the Division of Critical Care at Boston Children's Hospital developed test questions and acceptable answers. All experts utilized the same content validity scoring system to evaluate questions. Questions scored as highly relevant (ie, score of 3 or 4) were included. All questions required free text answers. During the initial testing session, all residents completed a 10-question pretest prior to video watching and a 10-question posttest immediately afterwards. Six months after initial testing session completion, all residents were asked to complete a 10-question retention test. Different questions were included on pre-, post-, and retention tests, but all tested similar concepts. Three independent graders scored all test questions upon participant completion. Free text responses were scored on a binary scale (0 points=incorrect, 1 point=correct). Scores were reported as percent correct, out of a possible 100% (ie, 10 points out of 10 questions=100%). No partial credit was given.

Statistical Analysis

A biostatistician with several decades of experience in the field reviewed and approved the analytic plan used to evaluate the data. Pearson chi-square tests and one-way analysis of variance (ANOVA) were used to compare baseline demographic characteristics between groups. One-way ANOVA was used with *F*-tests to compare differences in the change in pre- and post-test scores among the 3 groups immediately and at 6-month follow-up [15]. Repeated measures mixed-model ANOVA was used to compare the changes in test scores within each group [15]. Statistical analysis reported results as mean percent correct test scores with associated 95% CIs. ANOVA analyses were performed using SPSS statistical software version 23.0 (IBM Corporation). Two-tailed values of $P<.05$ were considered statistically significant.

Sample Size Calculations

Power calculations indicated that 16 residents randomized to each of the 3 learning groups would provide 80% statistical power (two-tailed alpha=.05, beta=.20) to detect a 20% mean difference at immediate posttest evaluation and 6-month retention test evaluation, assuming a pooled standard deviation of 18-20% (approximate effect size=1.1) (version 7.0, nQuery Advisors, Statistical Solutions, Cork, Ireland).

Results

Descriptive Characteristics

A total of 49 pediatric residents completed the initial testing session. Table 1 reports the baseline characteristics of each group prior to initial pretest. The majority of residents in all groups had little exposure to ICU rotations, both as residents and medical students. Residents self-reported a wide exposure range in caring for ventilated patients with 94% (46/49) reporting limited exposure in caring for patients ventilated by HFOV (<5 patients). Residents in all groups reported no prior exposure to HFOV-related video content on OPENPediatrics. Review of each participant's video viewing activity within OPENPediatrics verified residents' self-reported lack of prior video content exposure.

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Table 1. Residents' baseline demographic characteristics (overall and by group). Previous ICU experiences represent each individual's combined experiences as a medical student and resident.

Baseline characteristics	All groups (N=49)	Full video (n=17)	Logic puzzles (n=16)	Short answer questions (n=16)	*P* value
Age in years (Mean)	25-36 (28)	25-32 (27.6)	25-35 (27.8)	25-36 (29.6)	.57
Gender, n (%)					.19
Male	17 (35%)	3 (18%)	7 (44%)	7 (44%)	
Female	32 (65%)	14 (82%)	9 (56%)	9 (56%)	
Degree, n (%)					.31
MD	41 (84%)	15 (88%)	15 (94%)	11 (69%)	
MD-PhD	7 (14%)	2 (12%)	1 (6%)	4 (25%)	
Other	1 (2%)	-	-	1 (6%)	
Field of residency training, n (%)					.38
Pediatrics	41 (84%)	16 (94%)	14 (88%)	11 (69%)	
Internal medicine-pediatrics	4 (8%)	-	1 (6%)	3 (19%)	
Combined pediatrics-neurology	2 (4%)	1 (6%)	-	1 (6%)	
Combined pediatrics-anesthesia	2 (4%)	-	1 (6%)	1 (6%)	
Current year of residency training, n (%)					.99
PGY[a]-1	31 (63%)	11 (65%)	10 (63%)	10 (63%)	
PGY-2	18 (37%)	6 (35%)	6 (37%)	6 (37%)	
Combined previous intensive care unit experience					
PICU[b], n (%)					.89
0 Months	33 (67%)	13 (76%)	10 (63%)	10 (63%)	
1 Month	13 (27%)	3 (18%)	5 (31%)	5 (31%)	
≥2 Months	3 (6%)	1 (6%)	1 (6%)	1 (6%)	
NICU[c], n (%)					.44
0 Months	12 (24%)	3 (18%)	3 (19%)	6 (38%)	
1 Month	13 (27%)	5 (29%)	6 (37%)	2 (12%)	
≥2 Months	24 (49%)	9 (53%)	7 (44%)	8 (50%)	
MICU[d] (adult), n (%)					.08
0 Months	41 (84%)	17 (100%)	12 (75%)	12 (75%)	
1 Month	8 (16%)	-	4 (25%)	4 (25%)	
SICU[e] (adult), n (%)					.60
0 Months	47 (96%)	16 (94%)	16 (100%)	15 (94%)	
1 Month	2 (4%)	-	-	2 (12%)	
CICU[f] (adult), n (%)					.12
0 Months	47 (96%)	17 (100%)	16 (100%)	15 (94%)	
≥2 Months	2 (4%)	-	2 (12%)	-	
Burn ICU, n (%)					.12
0 Months	47 (96%)	17 (100%)	14 (88%)	16 (100%)	
1 Month	2 (4%)	-	2 (12%)	-	
Previous experience in care of ventilated patients					

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Baseline characteristics	All groups (N=49)	Full video (n=17)	Logic puzzles (n=16)	Short answer questions (n=16)	*P* value
Conventional mechanical ventilation, n (%)					.62
0-5 patients	13 (27%)	4 (23%)	5 (31%)	4 (25%)	
6-10 patients	16 (33%)	8 (47%)	5 (31%)	3 (19%)	
11-15 patients	11 (22%)	2 (12%)	4 (25%)	5 (31%)	
>16 patients	9 (18%)	3 (18%)	2 (13%)	4 (25%)	
High frequency oscillatory ventilation, n (%)					.72
0-2 patients	33 (67%)	11 (65%)	11 (69%)	11 (69%)	
3-5 patients	13 (27%)	4 (23%)	5 (31%)	4 (25%)	
6-8 patients	3 (6%)	2 (12%)	-	1 (6%)	
Previous experience with OPENPediatrics					
Personal log-in attempts, n (%)					.99
0	33 (68%)	12 (70%)	11 (69%)	10 (63%)	
1	5 (10%)	1 (6%)	2 (12%)	2 (12%)	
2	6 (12%)	2 (12%)	2 (12%)	2 (12%)	
≥3	5 (10%)	2 (12%)	1 (6%)	2 (12%)	

[a]PGY: postgraduate year.

[b]PICU: pediatric intensive care unit.

[c]NICU: neonatal intensive care unit.

[d]MICU: medical intensive care unit.

[e]SICU: adult surgical intensive care unit.

[f]CICU: cardiac intensive care unit.

Initial Testing Session Analysis

Pediatric residents were randomized to the following groups: full video (n=17), logic puzzles (n=16), and short answer questions (n=16). Mean initial pre- and post-test percent correct scores and 95% CIs for each group are reported in Tables 2 and 3 and represented in Figure 2. Mixed-model ANOVA showed significant improvement in knowledge gain between pre- and post-test scores in each of the 3 groups during the initial testing session (full video: $F_{1,46}$=80.52, P<.001; logic puzzle: $F_{1,46}$=67.36, P<.001; short answer questions: $F_{1,46}$=87.98, P<.001). One-way ANOVA revealed comparable mean improvement in the change in the test score from pre- to post-test in all 3 groups during the initial testing session ($F_{2,46}$=0.35, P=.71). Adjustment for gender and postgraduate training year did not alter the overall results, although second-year residents randomized to the short answer questions group had greater percent improvement in posttest scores compared with first-year residents (63% [SD 13] vs 39% [SD 16] vs P=.02).

Table 2. Residents' mean percent correct test scores by group for initial testing. Mean difference in test score at 6-months follow-up represents the difference between initial pretest and 6-month follow-up test.

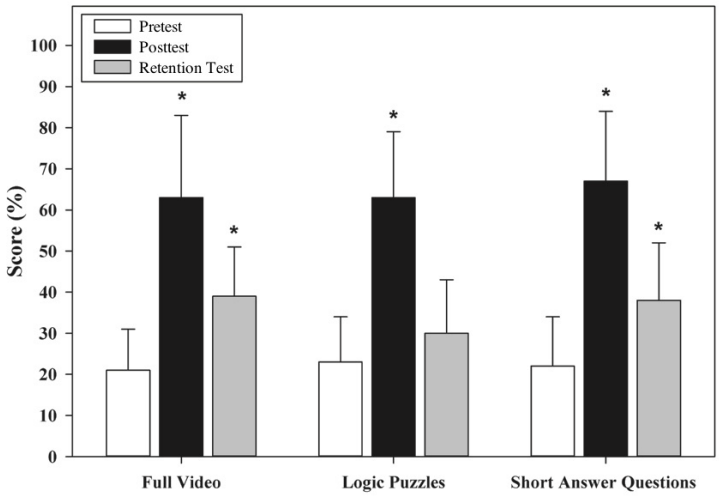
Group	Mean percent correct pretest score % (95% CI)	Mean percent correct posttest score % (95% CI)	Mean difference in percent correct test score % (95% CI)	*P* value
Full video (n=17)	21 (14-28)	63 (56-70)	42 (32-52)	<.001
Logic puzzle (n=16)	23 (16-31)	63 (55-70)	39 (29-50)	<.001
Short answer questions (n=16)	22 (14-29)	67 (60-74)	45 (35-55)	<.001

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Table 3. Residents' mean percent correct test scores by group for 6-month retention testing. Mean difference in test score at 6-months follow-up represents the difference between initial pretest and 6-month follow-up test.

Group	Mean percent correct retention test score % (95% CI)	Mean difference in percent correct test score % (95% CI)	*P* value
Full video (n=12)	39 (31-47)	18 (8-28)	<.001
Logic puzzle (n=11)	30 (21-38)	7 (-3-17)	<.001
Short answer questions (n=11)	39 (31-47)	17 (7-27)	<.001

Figure 2. Residents' mean percent correct pretest, posttest, and 6-month retention scores according to group. Error bars represent standard deviation in each group. Asterisks represent statistical significance (P<.001) in scores when compared with pretest scores.



Six-Month Retention Test Analysis

Thirty-five residents (71%; 35/49) completed the 6-month retention test with similar numbers in each group (full video: n=12; logic puzzles: n=11; short answer questions: n=12). During this 6-month interval, 10 residents overall rotated through the PICU (full video: n=5; logic puzzles: n=3; short answer questions: n=2; P=.80), all reporting caring for at least 3 patients receiving HFOV. No residents cared for more than 5 patients receiving HFOV (P=.67). Five residents reported repeated viewing of the HFOV video on OPENPediatrics prior to the 6-month posttest (full video: n=1, logic puzzles: n=3, short answer questions: n=1). Cross-reference of OPENPediatrics data verified that only 2 participants had actually watched the video in between the initial and 6-month retention testing. Mean retention test scores for each group are reported in 3.

One-way ANOVA revealed that all 3 groups had comparable degrees of mean knowledge retention between the initial pretest and retention test ($F_{2,32}$=2.77, P=.08). Repeated measures mixed-model ANOVA demonstrated that the full video and short answer questions groups had a significant degree of knowledge retention at 6 months, although to a lesser degree than knowledge gained on initial mean posttest scores (full video: $F_{1,32}$=22.08, P<.001; short answer questions: $F_{1,32}$=20.12, P<.001). The logic puzzle group did not demonstrate statistically significant knowledge retention at 6 months ($F_{1,32}$=2.44, P=.13).

Discussion

Principal Findings

This study did not demonstrate a significant difference related to overall initial knowledge gain when pediatric residents watched a video without structured breaks compared with those with interspersed breaks and completion of either logic puzzles or short answer questions. Despite this finding, we demonstrate that irrespective of group assignment, all groups had significantly higher mean percent correct test scores on initial posttests compared with pretests. This suggests that the online video itself is an effective teaching modality. Six-month retention analysis reveals a continued lack of statistical significance when comparing residents' change in test scores between groups. However, there is an overall significant increase in the change in test scores between initial pretests and 6-month retention tests in the full video and short answer groups (P<.001), although to a lesser degree compared with the change in test scores between initial pre- and post-testing.

Although not statistically significant, the short answer questions group's mean change in test score demonstrates the largest percentage point difference in comparison of pre- to post-test score, consistent with previous literature supporting improved knowledge gain via the use of interspersed short answer test questions [3,5-11]. It is not surprising that our 6-month retention analysis demonstrates a lesser degree of knowledge gain compared with initial pre- and post-testing within each group, especially as there were no additional testing intervals prior to the 6-month retention test. This is consistent with the cognitive

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psychology theory of spaced learning, suggesting the need for more frequent testing intervals to improve ongoing knowledge retention at 6 months [16-21]. What remains curious is why pediatric residents in the logic puzzles group did not retain as significant knowledge between the initial pretest and retention test as the other 2 groups, despite demonstrating a knowledge gain between initial pre- and post-testing. This is most likely attributable to small sample size, but raises the question of whether this type of mind-engagement, although active, negatively affects long-term knowledge transfer by increasing cognitive load.

Comparison With Prior Work

We are unaware of any prior studies similar to our study design and findings; however, in recent years, test-enhanced learning has been studied in various online educational settings [3,5,10,22]. Szpunar et al (2013) studied undergraduates taking an online statistics course and found that interspersing test questions while watching an online lecture not only improved overall learning, but also encouraged task-relevant note-taking activities and discouraged mind-wandering activities when compared with students passively reviewing the lecture content [3]. A few questions arise from this study including the specific timing and frequency of interspersed test questions, the type and format of questions used (content-relevant or not), and whether just taking periodic breaks with mind activation during an educational activity can improve knowledge gain. Cook et al (2014) investigated what may represent the optimal number of interspersed questions in the context of e-learning, suggesting that there may be a critical number of questions ideal for enhancing learning, above which no additional learning benefit is acquired [21]. McConnell et al (2015) demonstrated equivalence between short answer questions and context-rich multiple choice questions in mock licensure exam score improvement among Canadian medical students; yet, both of these educational strategies remained superior to restudying and context-free multiple choice questions [11]. Finally, if just taking breaks during an educational activity improves knowledge gain, then it would be important to understand how the specific activity one performs during those breaks affects knowledge gain.

Strengths and Limitations

The strengths of this study include the overall design involving 3 independent groups with comparison of 2 active interventions, the quality of educational material used, and the high follow-up rate for 6-month retention evaluation. The exact reason for residents who were lost to follow-up at 6 months is unknown (n=15), but possibly due to time constraints related to clinical rotations or time away from residency during which they were unresponsive to email.

We acknowledge several limitations to this study. First, the sample size reported here was designed to power to an 80% level, yet it is still possible that our sample size was too small to detect significant differences between groups. Second, the lack of a statistically significant difference in knowledge gain between groups may be related to several factors, including overall video duration, timing of when residents completed this study in the context of their clinical rotations, emotional state of residents during study completion (ie, level of fatigue, anxiety, distraction), and their overall content interest. Third, this study may have some methodological insufficiency regarding the use of spaced learning for evaluation of knowledge retention, and we believe that this would be an interesting hypothesis to incorporate in a future study.

The overall duration of the video used in this study was relatively short (23 min) such that this may have contributed to not finding a meaningful effect size difference between groups who were taking breaks while watching the video. Yet, data regarding the optimal video length for learner engagement are conflicting. Research in disciplines other than medicine suggests that shorter duration is generally better and that including breaks within longer videos helps reduce cognitive load. Data from TED talks suggests that the optimal video length is around 18 min, which is short enough to hold attention, yet long enough to succinctly communicate complex topics, both of which decreases cognitive overload by limiting the amount of time of active brain engagement, and forces the speaker to be clear and concise [22]. Data from EdX blog, an open-source e-learning platform and MOOC provider, support that longer videos should be divided into smaller segments, with preliminary evidence demonstrating that for students enrolled in various math and science courses, the optimal video length for engagement was between 6 and 9 min [23]. More rigorous study of the optimal timing for video-based e-learning in the context of medical education is warranted to determine and reinforce these concepts.

In addition, inattentiveness and mind-wandering have been linked to poor knowledge gain, and these behaviors occur more frequently when students are experiencing an underlying negative emotional state, lack engagement, or experience stress related to learning [24]. These are all prominent factors encountered in postgraduate medical training, and as such may have affected some residents in this study. Moreover, residents did not receive immediate feedback after answering test questions during this study to avoid confounding 6-month retention test results by restudying material. This lack of immediate feedback could have negatively affected long-term learning in this context.

Finally, several limitations must be considered when reviewing our secondary outcome of retention test score analysis. First, residents were not directly observed for dishonest behavior on retention test completion, which could potentially falsely elevate test scores. Second, we did not specifically control for “on-the-job” training. However, given the overall small exposure to patients ventilated by HFOV as self-reported by residents across all groups between the initial testing and the 6-month follow-up, we do not believe this has greatly impacted our findings as differences in exposure between groups lacked statistical significance (P=.67). If this were clinically significant, we would have expected to observe a greater increase in knowledge retention within all groups at 6 months’ follow-up. Similarly, numbers of residents rotating through the PICU between initial testing and 6-month follow-up were low and not statistically different between groups (P=.80). We continue to acknowledge the overall small sample size in interpretation of our 6-month follow-up analysis.

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Conclusions

In summary, this cohort study of pediatric residents did not demonstrate similar findings to those reported by Szpunar (2013), in which interspersed test questions and periodic breaks integrated into an online statistics lecture improved knowledge gain among undergraduate students. However, when our findings are viewed together with other previous studies [3,7,10,21], we find there is a continued need to investigate optimal strategies for augmenting learning and retention in video-based e-learning, with ongoing consideration of the need to integrate periodic breaks, interspersed test questions, and spaced learning intervals, in addition to determining optimal video length. Future e-learning platforms will also need to support robust analytics for data collection of privacy-protected, deidentified data that will better inform research on optimal learning strategies and technologies going forward.

Acknowledgments

The authors thank Nicole Stenquist and Kevin Hughes for their assistance in data collection and test scoring; Tanya Logvinenko for additional statistical support; and also consultants Dr Karl Szpunar, Professor Chris Dede, and Dr David Cook for their thoughtful advice with regard to the study design.

Conflicts of Interest

None declared.

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Abbreviations

HFOV: High frequency oscillatory ventilation
MOOC: Massive open online courses
NICU: Neonatal intensive care unit
PICU: Pediatric intensive care unit

Edited by G Eysenbach; submitted 14.06.16; peer-reviewed by M Hoy, DP Larsen, H Johnson, T Getchius; comments to author 04.10.16; revised version received 27.10.16; accepted 29.10.16; published 21.11.16.

Please cite as:
DelSignore LA, Wolbrink TA, Zurakowski D, Burns JP
Test-Enhanced E-Learning Strategies in Postgraduate Medical Education: A Randomized Cohort Study
J Med Internet Res 2016;18(11):e299
URL: http://www.jmir.org/2016/11/e299/
doi:10.2196/jmir.6199
PMID:27872034

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Original Paper

"How Did We Get Here?": Topic Drift in Online Health Discussions

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Abstract

Background: Patients increasingly use online health communities to exchange health information and peer support. During the progression of health discussions, a change of topic—topic drift—can occur. Topic drift is a frequent phenomenon linked to incoherence and frustration in online communities and other forms of computer-mediated communication. For sensitive topics, such as health, such drift could have life-altering repercussions, yet topic drift has not been studied in these contexts.

Objective: Our goals were to understand topic drift in online health communities and then to develop and evaluate an automated approach to detect both topic drift and efforts of community members to counteract such drift.

Methods: We manually analyzed 721 posts from 184 threads from 7 online health communities within WebMD to understand topic drift, members' reaction towards topic drift, and their efforts to counteract topic drift. Then, we developed an automated approach to detect topic drift and counteraction efforts. We detected topic drift by calculating cosine similarity between 229,156 posts from 37,805 threads and measuring change of cosine similarity scores from the threads' first posts to their sequential posts. Using a similar approach, we detected counteractions to topic drift in threads by focusing on the irregular increase of similarity scores compared to the previous post in threads. Finally, we evaluated the performance of our automated approaches to detect topic drift and counteracting efforts by using a manually developed gold standard.

Results: Our qualitative analyses revealed that in threads of online health communities, topics change gradually, but usually stay within the global frame of topics for the specific community. Members showed frustration when topic drift occurred in the middle of threads but reacted positively to off-topic stories shared as separate threads. Although all types of members helped to counteract topic drift, original posters provided the most effort to keep threads on topic. Cosine similarity scores show promise for automatically detecting topical changes in online health discussions. In our manual evaluation, we achieved an F1 score of .71 and .73 for detecting topic drift and counteracting efforts to stay on topic, respectively.

Conclusions: Our analyses expand our understanding of topic drift in a health context and highlight practical implications, such as promoting off-topic discussions as a function of building rapport in online health communities. Furthermore, the quantitative findings suggest that an automated tool could help detect topic drift, support counteraction efforts to bring the conversation back on topic, and improve communication in these important communities. Findings from this study have the potential to reduce topic drift and improve online health community members' experience of computer-mediated communication. Improved communication could enhance the personal health management of members who seek essential information and support during times of difficulty.

(J Med Internet Res 2016;18(11):e284) doi:10.2196/jmir.6297

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KEYWORDS

consumer health; health informatics; health care information systems; similarity measures; Internet communications tools; Web-based interaction; collaborative and social computing systems and tools

Introduction

To illustrate the importance of addressing topic drift in online health communities, consider the case of Anne who was curious about a side effect she was experiencing with a newly prescribed medication for attention deficit hyperactivity disorder (ADHD). She was worried that the side effect would get worse and wanted to hear about other people's experiences. She started a discussion regarding the drug and side effects in an online discussion group. Other online community members joined the discussion and shared their experiences as ADHD patients. When someone mentioned taking medication to prevent being fired from work, the topic of conversation changed to ADHD and work performance, including a discussion of the Americans with Disabilities Act (ADA) and legal advice. Ultimately, the conversation ended when one member repeatedly posted about his negative experience obtaining ADA assistance. Anne's specific question regarding her medication side effect was never answered, and she decided to stop taking the drug. If she had learned how others dealt with the side effect and that it did not get worse, she might have continued the treatment. What could Anne, moderators, or the online community have done to get Anne's questions answered?

Anne experienced topic drift [1], where the focus of conversation changes as a discussion progresses. In a conversation, topics naturally and continuously change [2]. However, topic drift occurs frequently in computer-mediated communication (CMC) and can be a source of incoherence [3] and frustration. Moreover, topic drift can hinder meaningful social interaction [4] and knowledge construction [4,5]. Despite the importance of maintaining the goal (eg, acquiring information or support on the initiating topic) and topic of discussion, drift can still occur. For example, in a previous study of social-oriented chat on the Internet, nearly half (47%) of conversation was considered off-topic [6]. Additionally, keeping conversation on topic has been shown to be difficult even for highly focused discussion groups, such as those that discuss the Oklahoma City bombing [7] or health and fitness [8].

Previous studies on topic drift have focused on different domains and CMC methods, including email-based newsgroups [7], online discussion about open source software design via mailing lists [9], chats about classical music [10], and pharmacy class meeting chats [11]. Although for some domains, topic drift can be inconsequential or even a natural course of conversation, for other sensitive domains, such as health, topic drift can pose serious consequences—as Anne's case demonstrates. Online health communities allow patients to cope and manage their illnesses through social interactions while providing means to overcome barriers, such as geographical isolation or stigma from certain diseases. Previous studies have shown a correlation between participating in online health communities and improvement of depression [12-16], anxiety [14,16,17], stress [14,15], negative mood [18], and health outcomes [19,20]. Although topic drift can hinder obtaining these benefits, in-depth analyses of topic drift in health discussions have yet to be reported, and thus it is not well understood.

Analyzing topic drift can shed light on the overall community experience. For example, Lambiase found that emotionally aggressive postings led discussion away from the original topic and led participants to unsubscribe or remain inactive [7]. Similarly, Selfe and Meyer found that participants who used powerful and persistent language controlled the topic of conversation while limiting the opinions of others [21]. Few online communities employ moderators to govern discussion and create an engaging and respectful community culture [22]. In a moderated community, it is reasonable to assume that moderators will provide a structure to keep topics relevant to the goal of the thread and community as well as counteract aggressive and persistent postings. Whether moderators or other members provide effort to counteract topic drift—returning back to the original goals and topics of the discussion—is an unanswered research question.

According to Hobbs, 3 conversational devices attributed to topic drift in dialogues are semantic parallelism, chained explanation, and metatalk [1]. Semantic parallelism occurs when a small portion of a topic gradually changes to other topics with similar and relevant properties. Chained explanation occurs when an explanation seems more interesting than the current topic and becomes the new topic. Metatalk occurs when participants evaluate the drifted topic and change it back to the original topic of conversation. The first 2 devices are cases of gradual topic drift, whereas metatalk opposes the drift by explicitly encouraging a return to the main topic.

Many manual analyses of topic drift [3,7,11] have used Hobbs' theoretical conversational devices of topic drift to explain how topics change in both synchronous (eg, chat) [3,11] and asynchronous (eg, email, forums) [7] CMC. Other topic drift studies that did not employ Hobbs' theory also manually assessed topic drift [9,10]. One limitation of manual assessment is the inherently subjective nature of determining topic drift [11]. Moreover, such analyses require tremendous effort and time.

Returning to our motivating scenario, people like Anne openly discuss and seek information and support in online health communities, such as WebMD [23,24]. These online health communities provide psychosocial benefits (eg, adaptive coping) [25] as well as useful health information [26,27]. Although topic drift can hinder these benefits, the effects of and members' reactions toward topic drift in online health communities have not been studied. Despite the importance of staying on topic, counteracting efforts to topic drift have received limited attention. *Who* provides this counteracting effort to topic drift in topically focused communities is unknown. Furthermore, automated techniques have the potential to detect both topic drift and counteracting efforts but are unexplored in online health communities. Answering these open issues is important

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to inform support that helps valuable online health communities thrive.

Methods

Data

The data for this study consist of posts from moderated, disease-specific WebMD communities. WebMD is one of the most popular health information sources for health consumers [28], thus we examined posts from WebMD communities. We selected specific communities that vary with respect to disease and illness characteristics to cover wide aspects of health (ie, biological, psychological, and sociological) and representative demographics (ie, age and gender). WebMD communities also employ staff moderators and medical doctors (MDs) who have clearly defined community roles compared with regular members (ie, "users"), which allowed us to analyze the relationship between community member role and both topic drift and counteraction to topic drift. To understand how staff moderators and MDs influence topic drift, we considered the total number of available staff moderators and MDs as well as their total number of posts in community selection.

We selected 7 WebMD communities: (1) attention deficit hyperactivity disorder (ADHD), (2) breast cancer, (3) diabetes, (4) heart disease, (5) multiple sclerosis (MS), (6) pain management, and (7) sexual health (Table 1). We downloaded all publicly available posts from these seven communities. Then, we removed threads without posts replying to the initial post. Communities averaged between 2.86 and 7.78 posts per thread, and across all communities the average thread length (TL) was 6.76 posts.

The University of Washington Institutional Review Board determined this study exempt from review.

Research Questions and Topic Drift Analysis

To understand topic drift in online health communities, we characterized the severity of topic drift as either *gradual* or *abrupt topic drift*, determined by the degree of topical change from the previous post to the current post in a thread (RQ1). Gradual topic drift refers to small degrees of topical change in which the current topic is related to the previous topic. We considered a complete change of topic as well as topic domination as abrupt topic drift. Topic domination was measured through previously identified tactics—using a high volume of messages [29] and ignoring conventional conversational rules [30] (eg, disrupting the conversation or ignoring the main goals of the thread).

Table 1. Characteristics of 7 WebMD communities studied. ADHD: attention deficit hyperactivity disorder; MS: Multiple Sclerosis.

	ADHD	Breast cancer	Diabetes	Heart disease	MS	Pain management	Sexual health
Dates data were collected	7/2005 to 6/2012	8/2007 to 5/2012	6/2007 to 5/2012	3/2008 to 5/2012	11/2007 to 1/2013	9/2007 to 6/2012	9/2007 to 1/2013
Posts, n	8704	21,612	64,085	11,874	27,412	27,333	68,136
Threads, n	2313	3227	8242	4146	4943	4656	10,278
MDs and staff, n	13	13	16	10	11	12	11
Users, n	2984	2147	4385	3815	2710	5843	13,624
Power users, n	5	17	36	8	16	17	32
Mean thread length (TL)	3.76	6.70	7.78	2.86	5.55	5.87	6.63
Median TL	3	5	5	2	4	4	4
Max TL	85	88	97	71	68	97	99

Table 2. WebMD datasets used to answer research questions.

		Dataset analyzed	Gold standard used for evaluation
Qualitative and systematic analyses	RQ1	416 posts from 50 randomly selected threads with minimum of 6 posts	N/A
	RQ2	185 posts from 168 unique threads selected with key words: "hijack" and "off topic"	N/A
	RQ3a	50 randomly selected threads from RQ1 and an additional 20 purposively selected threads with 187 posts	N/A
Quantitative analyses	RQ3b	229,156 posts from 37,805 threads	N/A
	RQ4	229,156 posts from 37,805 threads	77 posts were assigned using key words and 70 posts were manually evaluated to create a gold standard
	RQ5	229,156 posts from 37,805 threads	50 randomly selected posts from 50 threads were manually evaluated to create a gold standard

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We also categorized the types of topic drift as either *global* or *local topic drift*, based on the characteristics of topic drift [7,31]. Local topic drift refers to initiating a new topic unrelated to the current topic of conversation (ie, when someone brings up a new topic within a thread that does not relate to the original post but stays within respective communities' goals). In contrast, global topic drift refers to discussions outside of the respective communities' goals (ie, when someone starts a new thread that does not relate to the focal topic for that community).

To understand topic drift in a health context, we manually analyzed topic drift in online health communities to answer 3 initial research questions:

RQ1: How does local topic drift occur in threads?

RQ2: What are members' reactions and meta-discussions towards topic drift in explicitly identified topic drift threads?

RQ3: Who brings the topic back to the original topic of threads (ie, counteraction effort)?

Based on results from RQ1-RQ3, we developed an automated approach to identify both topic drift and efforts by members to prevent or counteract such drift. Many of the studies on topic drift manually analyzed conversations [3,7,9-11]. The manual method is accurate but is labor intensive and limited to small datasets. However, in the field of information retrieval, researchers have long used automated methods to cluster similar topics [32] as well as to detect and track topic changes on various streams of text from newswire, television, radio, and Web broadcast news shows [33]. One of the more widely used methods is similarity measurement of terms in text segments using thresholds based on term frequency-inverse document frequency (tf-idf)—a statistical representation of importance of a word to a document in a collection of documents [34]. Likewise, we applied a cosine-similarity metric and vector space model to assess similarity between posts within the same thread to detect both gradual and abrupt local topic drift.

We chose to use cosine similarity because it is one of the most widely used and thoroughly studied measures [35]. One advantage of cosine similarity for analyzing various types of consumer-generated text is that the measurement normalizes the text length during the comparison. Thus, longer replies would not necessarily be considered to have a higher number of shared words and appear to be more on topic. To measure topic drift by cosine similarity between posts, we first represented each post as a vector in N-dimensional vector space, where N is the number of unique terms across all posts and the value is the frequency with which terms occur in that post. Cosine similarity measures the cosine of the angle between 2 vectors representing the posts. The resulting cosine similarity score ranges from 0 to 1. A score of 0 indicates no shared terms between the 2 posts, whereas a score of 1 indicates all terms and the relative proportion of the terms used are exactly equal. We calculated tf-idf at the community level to reflect important terms discussed across each of the 7 communities. Then, we automatically measured the general trend of topic drift in the 7 online health communities.

To examine the application of our automated approach, we answered the following research questions:

RQ4: How accurately can local topic drift be detected automatically?

RQ5: How accurately can counteraction effort be detected automatically?

In the following section, we present a summary table of datasets that we used and delineate methods for each research question. Table 2 overviews the WebMD datasets used to answer each research question, including gold standards used for evaluations.

RQ1. How Does Local Topic Drift Occur in Threads?

We first manually analyzed 50 randomly selected threads with at least 6 posts, which was the average number of posts in all 7 WebMD communities and provided enough posts per thread to perform an in-depth, manual analysis of topic drift. The heart disease community was randomly selected to have 8 threads, whereas the other communities had 7 threads to make up our randomly selected 50 threads for this analysis. We systematically identified a number of main topics in each of the posts and examined whether and how many of those main topics changed as threads evolved. Using this information, we categorized topical changes into gradual (ie, at least one previous topic remained) or abrupt topic drift (ie, no previous topic remained). We also qualitatively analyzed and identified possible sources and the general trend of topic drift following an open coding process [36].

RQ2. What Are Members' Reactions and Meta-Discussions on Topic Drift in Explicitly Identified Topic Drift Threads?

We began this analysis using self-identified topic drifted threads. We analyzed member-identified threads where topic drift occurred. We analyzed reactions and meta-discussions when topic drift was apparent to members to understand the consequences of topic drift in overall community experience. Terms such as "anyway," "speaking of X" [37], "so," and "oh" [38,39] were identified as markers that initiate topic drift in a face-to-face conversation. Similarly, we used a lexicon-based extraction approach to extract threads containing explicit expressions of topic drift with the variations of the key terms "hijack" or "off topic," which are known markers for local and global topic drift in CMC. "Hijack" or "hijacking" a thread is a colloquial term in CMC denoting changes in topic from original posts [40] (ie, local topic drift). This term was also used and well understood in the communities we analyzed. "Off topic" is another term that was used to describe topics irrelevant to the main discussion in CMC [7,41]. "Off topic" can indicate either local or global topic drift. We extracted posts that contained either key terms in the body of the posts (ie, not the title). Then we manually referred back to the preceding posts and reviewed the context of the conversation to ensure that the key terms were used for rhetorical strategies to change topic, gain control over the topic, or indicate off-topic content in the post. In other words, the key terms had to be used to indicate or relate to either global or local topic drift. We then qualitatively analyzed these threads with respect to meta-discussion and members' emotional reaction towards topic drift. We then applied a Mann-Whitney U test (U) [42] to statistically compare the length of off-topic threads to the rest

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of the threads to further investigate members' usage of these off-topic threads. We applied nonparametric tests because our data were not normally distributed. Given the large sample of threads, we report effect sizes (*r*) using rank-biserial correlation [43].

RQ3. Who Counteracts Topic Drift?

To understand who brought the topic back to the original topic of a thread, we examined counteraction in 2 phases using (1) manual and (2) automated methods. First, we manually analyzed threads to determine who counteracts (RQ3a). The concept of staying on topic is related to one of Hobbs' conversational devices, metatalk [1]. Metatalk also can be about a discussion regarding their conversation. Therefore, for clarity, we did not use the term metatalk. Instead, we defined a community member's effort to stay on topic as the *counteraction* to topic drift.

In addition to the 50 randomly selected threads in RQ1, we purposely sampled an additional 20 threads with at least 6 posts, in which members with defined roles (ie, MDs and staff moderators) participated to understand how these members impact or counteract topic drift. We chose a purposive sampling strategy because participation of members with defined roles was relatively limited, and we were not able to sample enough threads with their participation using random selection. For posts in each of the 70 threads, we de-identified the community member identification (ID) and manually examined the role of the community member who made the effort to counteract topic drift (ie, users vs MD or staff moderators).

In the manual analysis, first we systematically identified main topics in each of the posts and noted neglected topics in subsequent posts. Second, we looked for any rhetorical cues to previously neglected topics. For example, we observed statements like "to answer your question on" that were often used when counteracting topic drift. Third, we noted posts discussing previously neglected topics without any rhetorical cues for counteraction. Fourth, based on this information, we categorized each post as counteracting or not counteracting.

In the second phase (RQ3b), we automatically detected counteraction efforts and noted the role of the member who made that effort. According to Dorval, the topic of conversation is not static but a constantly changing feature [2]. Furthermore, Lambiase showed that the topic of conversation slowly drifted from the original topics as conversation progressed in CMC [7]. Assuming the same natural deviation happens in the online health discussions, we focused on the irregular increase of cosine similarity scores to detect counteractions to topic drift in threads. The irregular increase of similarity score could indicate that the current post contained more relevant topics to the initial post compared to the previous post (ie, threshold), a sign of a counteraction to topic drift.

As with our approach to detect topic drift, we applied the cosine-similarity metric and vector space model with tf-idf to detect counteraction efforts. We automatically measured who (ie, which type of member) made counteractions. To understand how people in defined roles provide counteractions, we categorized the members as moderators (ie, staff/MD) or users according to their community member identification (ID). We categorized users further as *original posters*, *power users*, and *regular users*, which were mutually exclusive roles for individual threads. We defined original posters as users who initiated a thread, power users as users who posted more than the average number of posts by moderators, and remaining users as regular users.

For each role, we estimated average counteraction effort. The unit of analysis was a role within a thread (ie, original posters, staff/MD moderator, power user, regular user). Even though a given member can play more than one role, for purposes of this analysis, we assumed that members' counteracting behavior was independent if they played different roles in different threads. To estimate average counteraction effort, we counted the number of occurrences of counteraction each member made in each thread. Because the most active members have a greater chance of providing such effort, we normalized each member's total counteraction occurrences divided by the total number of replying posts they made in the thread (ie, excludes the original post), thus converting the occurrences into percentages (ie, "counteraction effort"). We averaged the mean counteraction effort for each member when acting in the same role. Then we averaged the mean counteraction effort for each role.

To compare counteraction effort among roles, we applied a Kruskal-Wallis H-test (X^2) [42]. We then conducted post-hoc pairwise comparisons of counteraction effort between roles using Mann-Whitney U tests (U) [42] with a Holm -Bonferroni correction to *P* values. Given the large sample of members, we report effect sizes (*r*) for the pairwise comparisons using rank-biserial correlation [43]. Finally, we compared results from automated measurement (RQ3b) with results from the manual measurement (RQ3a).

RQ4. How Accurately Can Local Topic Drift Be Detected Automatically?

We evaluated our automated topic drift detection technique with self-identified topic drift and "on-topic" posts. First, we used posts from RQ2 that contained key terms: "hijack" or "off topic" as positive cases that our detection system should recognize as low in similarity measurement, given that members explicitly indicated the off-topic nature of the post. Because the interpretation of topic drift can be subjective [11], we relied on members' explicit indication of topic drift as the gold standard for positive cases. To ensure quality, we manually examined and removed posts from this analysis if (1) the keyword hijack literally meant illegally seize or steal (a few posts were about the 9-11 tragedy), (2) the keywords were used to describe the definition of an acronym (eg, *"OT means [...]"*) or community nomenclature (eg, *"hijacking a thread means […]"*), (3) the keywords had a modifier to indicate lesser degree (eg, *"may be slightly off topic"*), (4) the keywords were used in meta-discussion about off-topic discussions, or (5) the keywords were used to start new off-topic threads (eg, *"OFF TOPIC BUT […]"*). These were stricter criteria than RQ2 because this also removed global topic drifts along with the posts that described OT and lesser degreed local topic drifts.

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To identify negative cases, we first used posts from RQ2 if (1) the posts negated the keyword (eg, *"this is not off topic"*) or (2) community members had shown intention to bring topics back to the original post (eg, *"your question got hijacked, I'll try to get it back on track"*). Because there were only a few negative cases, we added 70 manually selected "on-topic" posts with little or no topic drift that the detection system should recognize as high in topical similarity from the RQ3a qualitative analyses. We made these selections and adjustments prior to the evaluation process without any information on their similarity scores.

Using these positive and negative cases as a gold standard, we calculated the precision, recall, accuracy, and F1 score of the automated topic drift detection system compared to the average score of posts in the same position of all threads. The position of the post was important because we expected the topic of conversation to naturally change [2,7] and the cosine similarity scores to decrease accordingly as conversation progresses. Precision measures the proportion of predicted positive instances that are correct. Recall measures the proportion of positive instances that are predicted. Accuracy measures the percentages of correctly predicted instances among the total number of instances examined. F1 score is the weighted harmonic mean—reflecting both performance and balance—of precision and recall. In all measures, higher scores reflect better performance.

RQ5. How Accurately Can Counteraction Effort Be Detected Automatically?

To evaluate our approach to automatically detect counteraction efforts, we used 50 new, randomly selected posts from 50 threads: 25 posts with a natural decrease in similarity score and 25 counteracting posts with an increase in similarity score. We de-identified the origin of the 50 posts then manually categorized as natural topic drift or counteraction to topic drift, while referring back to initiating and other previous posts to understand the context. Using manual assessment of 50 posts as a gold standard, we then calculated the precision, recall, accuracy, and F1 score of the automated topic drift detection system.

Results

In this section, we present the results of 3 manual analyses (RQ1-RQ3a) and then the results of quantitative analyses (RQ3b-RQ5) for the 7 moderated online health communities.

RQ1. How Does Local Topic Drift Occur in Threads?

We manually analyzed 416 posts from 50 threads. Our systematic analysis showed that in most threads, the topic changed gradually— *gradual topic drift* —in which topics remained in the discussion while few topics were newly introduced or neglected (ie, semantic parallelism). This gradual change occurred among posts in nearly every thread. However, threads generally (46/50, 92%) stayed within the global frame of community topics, including symptoms, treatments, side effects, insurance issues, and emotional support for the specific community. On average, threads started with 3.44 topics and 1.05 topics were carried from post to post, while 1.58 topics were newly introduced. The following are themes associated with the severity and sources of topic drift.

Severity and Sources of Topic Drift

Abrupt topic drift occurred in 22% (11/50) of manually examined threads. The following is an example thread (Example Thread 1) from the Heart Disease community that showed abrupt topic drift, in which Poster_C controlled and changed the topic to their personal experience—topic domination. The thread ends as Poster_C repeatedly posted about their personal experience to control the topic and caused abrupt topic drift.

Poster_A: *I have heard that minutes makes a difference concerning a stroke, could seven hours make a difference with a blood clot beginining in the uppper leg traveling down?*

Poster_B: *I don't know how long it takes for tissue to die, but I would not wait 7 hours. But more important the clot can breakup and go to the lungs.*

Poster_C: *My mother died waiting for 7 hours, before she was taken to hospital. She was refused transport by ambulance service, because of misdiagnosed by Paramedic.*

MD_Poster_D: *It could - the longer tissues are deprived of blood and oxygen, the greater the risk of having permanent damage. Always better to seek medical attention earlier when there are concerns of a stroke or of other similar types of issues.*

Poster_C: *Thanks Dr. [Name], I feel she could have been saved, if she had gotten treatment sooner. The doctors will not say one way or the other, they afraid of being ask to testify in court.*

MD_Poster_D: *I'm so sorry to hear about your loss – it's really helpful for other people in this forum to hear about your experiences - so thank you for sharing them with us.*

Poster_C: *Dr. [Name], Thanks for your welcome response. You seem like a caring and knowledgeable Doctor. I would like to talk to you further about this situation, My email address is [email address]* (Example Thread 1 from Heart Disease community)

We observed that sharing personal experience pertaining to the main thread topic was commonly practiced. Although personal narratives can provide powerful information [27], they can also prompt topic drift when shared in the middle of threads as shown in Example Thread 1 above.

Another source of abrupt topic drift was requests to MD moderators. Many community members asked MDs personal questions in the middle of the threads, similar to Poster_C in Example Thread 1 above. Other causes of abrupt topic drift included jokes or the inability of community members to use the online interface. For example, members started new conversations or sent personal messages from within the thread, then excused themselves for changing the topic:

> *"Hi guys, it maybe kinda off topic. I actually don't know how to post my own topic (I'm new here, sorry.) […]"*. [Sexual Health Community]

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Table 3. Usages of the key terms.

	Local only	Global only	Both	Total
Hijack	34	0	7	41
Off topic	33	23	21	77

Abrupt topic drift occurred from multiple sources, including members' desire to joke, share personal stories, or interact with MD members as well their inability to use the interface. Although complete prevention of abrupt topic drift may not be possible, some can be addressed through better design (see Discussion).

RQ2. What Are the Reactions and Meta-Discussions on Topic Drift in Explicitly Identified Topic Drift Threads?

We found 185 posts from 168 unique threads: 53 posts in which community members used the key term "hijack" and 132 posts in which community members used the key term "off topic". We also found 2894 posts from 373 threads that contained either key term in the title. However, we did exclude the latter from analysis. Both members and moderators used the terms. After applying these criteria, only 118 posts from 114 unique threads were considered in this analysis.

"Hijack" was associated with local topic drift whereas "off topic" was used to indicate both local and global topic drift. The types of topic drift were not mutually exclusive (Table 3).

Two major themes emerged from qualitative analysis and are presented below. First, we found evidence of a posting culture in members' reactions towards abrupt topic drift (ie, hijacking and off-topic discussions). Second, contrary to previous research, we found that members supported having off-topic discussions (ie, global topic drift).

Posting Culture With Respect to Abrupt Topic Drift

The following was a canonical example of how a community member believes threads should start and unfold in WebMD communities.

> *It is usually best to start your own discussion if you have questions or are seeking support. Certainly, you can share your own experiences and that is encouraged here. […] Elaborating too much is sometimes considered "hijacking a thread" in internet message board lingo. Many times this happens in these discussions - they take many tangents with different twists and turns. […] Regardless of how a discussion evolves, I always pray that we all can find the answers and relief we need.* [Pain Management community]

As shown in the example post above, the community member was aware of topic drift and described it with the term "hijacking." According to the member, hijacking could occur when a member elaborates too much or otherwise dominates a thread. Dominating the conversation has been associated with topic control and topic drift in previous studies [7,21,29] because the dominant participant frequently changes the current topic to their own areas of interest. In the last sentence of the example post above, the member indicated how topic drift could affect the original poster in obtaining desired help. Furthermore, the member showed an intuitive understanding that the main purpose of a thread is to answer or give support to the original poster. To illustrate, the original posters shows frustration when the topic drifts:

> *"Why do my post always get treated as if I am posting something none [no one, sic] needs to know I do not think I will post here anymore, :angry: [name]".* [Diabetes community]

According to Lambiase [7], off-topic discussions are associated with discontinuation or inactivity by community members. Similarly, we observed frustration of original posters when the topic drifted in the middle of threads as shown in the example above. Furthermore, we found apologetic behavior shown by community members who caused the topic to drift. The following example post is a response to the example post above in which the member apologizes to the original poster for changing the topic after being confronted:

> *"I am sorry I hijacked your thread, [name]. That is a bad habit of mine. Your post IS valuable. […] Truly, [name], I didn't mean to hurt your feelings. I am sorry."* [Diabetes community]

Because WebMD members showed an intuitive understanding of the thread's main goals, members worked to counteract topic drift by bringing the conversation back to the original purpose of the thread as shown in the following example post:

> *"Since your question seems to have gotten hijacked by a debate about the economy and the merits of various forms of education, I'll try to get it back on track […]".* [Sexual Health community]

Moreover, experienced community members knew the sensitivity of certain topics, such as religion, that could easily become the main topics of the conversation through *chained explanation* (ie, explanation that seems more interesting than the current topic and becomes the new topic) [1]:

> *"As for the Christian aspect, I hesitate to go there at all because in my observation of past threads, this tends to hijack the main topic completely […]".* [Sexual Health community]

The posts above show how community members reacted negatively to local topic drift and its negative effect on the main topic. These examples of topic drift often occurred in the middle of threads as conversations evolved. In contrast, members described starting off-topic discussions with regard to goals of the specific community (ie, global topic drift) positively, which we describe next.

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Useful Purposes of Sharing Off-Topic Discussions

Although members reacted negatively towards local topic drift in the middle of the thread, they reacted positively to off-topic stories (ie, global topic drift) when shared separately in new threads. The following posts show the reaction of moderator and user member towards global topic drift.

> *To all re your comments about staying on point....if this community were being taken over with off-topic and/or "fun" discussions, that would be one thing. But that's not the case in this community or even on this thread. Yes, on any board there are newcomers and lurkers. They get good information and support here. But, to me, a bit of fun can also add to creating a community where someone would like to stay for a while.* [Diabetes community moderator]

> *Personally, if all that was discussed in any community on WebMD was the main topic, I would cease to be involved. I enjoy sharing with others and getting to know them by discussing what is happening in their lives other than the main health concern.* [Diabetes community member]

Members showed support for having off-topic discussion because it could build rapport and bring members closer. However, members also suggested ways to indicate that the topic of the thread was unrelated to the health condition of the specific community. For example, adding either *OT* or *off topic* in the title was suggested or practiced in 5 communities (ie, ADHD, Breast Cancer, Diabetes, MS, and Sexual Health) as shown in the quote: "'OT' means 'off topic.'

> *It lets people know the subject won't be MS. Otherwise, someone will click on it expecting to find MS info, then they may get upset when they find that it's not what they wanted.*" [MS community]

Moreover, we found that off-topic threads were significantly longer (mean 7.76 posts) than on-topic threads, with an average 6.76 posts (U=5456222, *P*=2.69e-05, *r*=.13). Our findings suggest that members reacted negatively towards local abrupt topic drift and topic control similar to previous studies [7,21,29]. However, we extend the literature by identifying novel benefits of global topic drift in online health communities.

RQ3a. Manual Analysis: Who Counteracts Topic Drift?

For the first phase, we examined counteraction to topic drift through manual analysis of 70 threads, including 416 posts from 50 threads used in RQ1 with an additional 187 posts from 20 new threads. We found counteraction in 13 of the 70 threads (19%). Of the 13 threads with counteraction, 6 were made by original posters, 5 were made by other users, and MDs and moderators made the remaining 2 counteractions to topic drift. Next, we present qualitative themes that emerged from our analysis of counteracting topic drift.

Original Posters Put the Most Effort Into Counteracting

Threads with highly active original posters tended to stay on topic better than threads with fewer active original posters. Original posters reposted to their own threads in 37 out of 70 threads (53%). Below is an example thread (Example Thread 2) from the Heart Disease community in which the original poster provided counteraction to topic drift:

Poster_A: *My roommate is not yet 40 and has had to have 3 stints in the last year. Now the Cardiaologists are saying that he needs a pacemaker and most likely was born with Bradycardia. What exactly is Bradycardia and are we looking at a not so good prognosis for his future? Isn't he somewhat young to be needing a pacemaker and what if the pacemaker does not have the expected result? What is the next step?*

Poster_B: *Bradycardia just means a heart rate of less than 60. That in itself is not a problem. The problem is when it is not beat fast enough to keep up with demand. Here is some information on the causes and treatment.* [URLs]

MD_Poster_C: *Bradycardia means a low heart rate, usually less than 60 beats per minute. A pacemaker can be recommended when bradycardia is symptomatic, or if there is another underlying electrical problem with the heart that increases the risk of the heart slowing even more or even stopping. Pacemakers work very well […]*

Poster_D: *Dear Dr. [Name], My mother is 73 years old, and had a pacemaker placed 2 years ago at the, Mayo Clinic. She is doctoring in her home town now. They are having trouble contoling her comidon levels, it has been 2 weeks now, and still do not have the levels controled. Is this unusual to have it take so long to adjust her levels?*

Poster_A: *Thanks for your reply. One more question. How does all of this associate with the stints and I forgot to mention that my friend has had two heart attacks this past year. Can we possibly look forward to my friend having a long and somewhat healthy life if the pacemaker and his new medication, Coreg, do what they are supposed to do? I realize that I am asking you to look into a crystal ball, but surely you have an educated guess?* (Example Thread 2 from Heart Disease community)

In Example Thread 2, Poster_A is the original poster who started the thread with multiple questions including (1) bradycardia and (2) possible outcomes and expectations. Both Poster_B and MD_Poster_C focused on bradycardia and treatment options (eg, uniform resource locators [URLs] and pacemakers). Poster_D, however, changed the topic to Poster_D's personal question and attempted to engage in a side discussion with the MD_Poster_C. The original poster, Poster_A, counteracted this drift by bringing the topic back to the unanswered question by elaborating on their situation. The 2 most common ways original posters counteracted topic drift were (1) focusing the discussion to the remaining unaddressed issues and (2) correcting the discussion trajectory (eg, "this is about X not about Y").

In our manual analysis, we found that original posters put in the most counteraction effort. Other users and members with defined roles (ie, MD and staff moderators) also counteracted topic drift. However, they also went along with the current topic of conversation at times. Similar to original posters, MDs, moderators, and other users counteracted topic drift by (1) addressing unanswered questions after topic drift had occurred or (2) discouraging abrupt topic drift (eg, *"I urge you to start another discussion"*).

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Table 4. Mean counteraction effort, standard deviation, and 95% confidence interval for different roles of members.

Role	Counteraction effort (SD)	95% CI
Original posters (n=6233)	0.61 (0.42)	0.60 to 0.62
Staff/MD (n=33)	0.46 (0.26)	0.36 to 0.55
Power user (n=94)	0.53 (0.13)	0.50 to 0.56
Regular user (n=33,469)	0.35 (0.46)	0.34 to 0.35

Table 5. A pairwise comparison of counteraction by role.

First role	Second role	U	Difference of means (Second – First)	Adjusted *P* value	95% CI	*r*
Original posters	Power user	358,110	-0.08	<.001	0.11 to 0.28	.22
Staff/MD	Original posters	75,350.5	0.15	.01	-0.33 to -0.04	.27
Staff/MD	Power user	1194	0.07	.05	-0.16 to 3.35e-06	.23
Power user	Regular user	227,792	-0.18	<.001	0.36 to 0.47	.86
Regular user	Original posters	1,087,761	0.26	<.001	-0.14 to -3.68e-05	.99
Regular user	Staff/MD	412,935	0.11	.01	-0.33 to -0.04	.25

Table 6. Confusion matrix of automated topic drift detection technique.

		Gold standard	
		Positive	Negative
Similarity score	Positive	53	23
	Negative	21	50

RQ3b. Automatic Analysis: Who Counteracts Topic Drift?

For the second phase, we automatically measured who counteracts topic drift most, using cosine similarity. Table 4 summarizes counteraction effort for each community member role. In total, 6233 original posters reposted to threads they initiated. On average, those original posters counteracted topic drift 61% of the time. Their effort to stay on topic exceeded that of any other role, similar to our finding in the qualitative analysis of RQ3a.

When we compared counteraction effort among roles, we found a significant difference (X^2_3=1715.70, *P*<.001). Table 5 shows post-hoc comparisons between specific roles. Original posters provided significantly more counteraction than other roles. In contrast, regular users provided significantly less counteraction effort compared to other roles. The effect sizes between power users and regular users as well as between regular users and original posters were considered large (>.50), while the effect sizes were small (<.30) for the other 4 pairwise comparisons. Findings indicate that original posters contribute most to counteraction effort and that this effect is large compared with regular users.

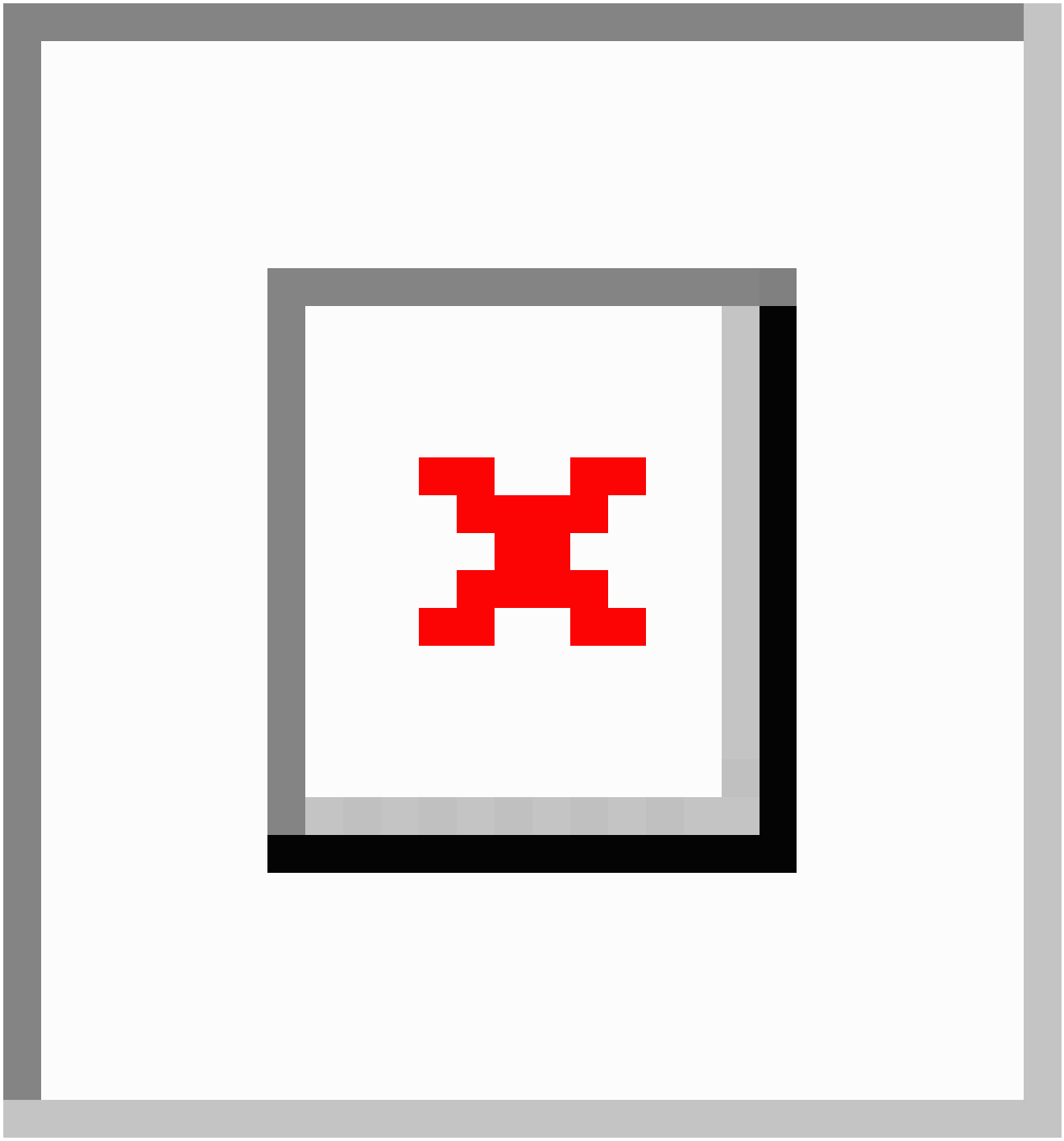
RQ4. How Accurately Can Topic Drift Be Detected Automatically?

We automatically measured local topic drift using a cosine similarity. Figure 1 shows topic drift as threads evolved across all 7 communities. The x-axis indicates position of the posts in threads, and the y-axis indicates average similarity scores for posts in that position compared with the original post across the 7 communities. We captured the average similarity scores for positions with 50 or more posts. We applied logarithmic regression (y=-0.017ln(x) +0.1296), which resulted in a relatively high r-squared value of .93. Individual WebMD communities showed a similar trend in which the topic gradually drifted as conversation progressed. Thus, our automatic measurement of topic drift showed a pattern of gradual topic drift in which some topics carried to the next posts. This pattern aligns well with our manual analysis in RQ1 as well as findings from an existing manually assessed topic drift study [7].

Next, we evaluated our automated technique for detecting topic drift. Our evaluation against the gold standard (ie, 74 positive cases and 73 negative cases) showed promising results as an application to track topic drift. Table 6 shows that the automated topic drift detection technique correctly predicted 53 out of 74 cases of topic drift and 50 out of 73 “on-topic” cases with little or no topic drift. Automatically detecting topic drift through similarity measurement achieved a precision of .70, recall of .72, accuracy of .70, and F1 score of .71.

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Figure 1. The general trend of topic drift in seven WebMD communities.



RQ5. How Accurately Can Topic Drift Counteraction Efforts Be Detected Automatically?

Next, we evaluated our automated technique for detecting counteraction to topic drift using our manual assessment of 50 posts as the gold standard. Table 7 shows results from blinded evaluation on 50 cases of automated classification against our manual judgement. The automated technique correctly predicted 18 out of 24 cases of counteraction and 19 out of 26 cases of topic drift, which achieved a precision of .72, recall of .75, accuracy of .74, and F1 score of .73.

Table 7. Confusion matrix of automatically detecting counteraction to topic drift.

		Gold standard	
		Counteraction	Topic drift
Similarity score	Counteraction	18	7
	Topic drift	6	19

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Discussion

Principal Findings on Topic Drift in Online Health Communities

Our findings shed light on how topic drift unfolds in online health communities, how members of these communities react to topic drift, and who brings topics back to the original intent of threads through counteraction. We also address gaps in previous literature by illustrating possible benefits of having off-topic discussions, highlighting counteraction provided by different types of community members, and applying an automated method to detect topic changes at the thread level.

Topic drift occurred in our online community data at 2 levels: global (ie, community-level) and local (ie, thread-level). Previous studies associated topic drift from global goals with incoherence [3] and described enforcing conversational participants to stay on global topics as difficult [44]. Moreover, off-topic discussion at a global level can lead members to unsubscribe or remain inactive [7].

However, in the online health communities we analyzed, we found topics generally stayed within the global level (ie, topics related to the intent of a specific community) with the exception of *OT* or *off topic* titled threads that purposely discussed off-topic issues. Both power users and moderators supported these off-topic discussions representing global topic drift. The off-topic discussion supporters, however, advocated that the off-topic nature of threads be indicated in the title so that the threads would not interfere with other discussions that pertained to the global goals of the community. The supporters voiced the opinion that off-topic discussions could build rapport and bring members closer. Such support might not be representative of reactions towards topic drift more generally because we focused only on self-identified topic drift threads.

We found that having off-topic discussions, as indicated by global topic drift, positively affected online health communities. For instance, many off-topic discussions were lively and humorous, which was in direct contrast to the melancholy and serious tone of many on-topic discussions. Moreover, off-topic discussion threads (ie, threads with OT in the title) had higher levels of participation. However, we did not find evidence that regular users supported off-topic discussions in our manual assessment. We suspect that either our sample size was not large enough or that only experienced members (eg, high level of active participation or defined community roles) were aware of the culture of sharing off-topic discussions. We reached this conclusion because we observed posts that asked about the meaning of *OT* in the title. Given this confusion, we suggest that designers and administrators of online health communities consider other structured ways to have off-topic discussions (see further discussion below).

Although power users and moderators supported off-topic discussions at the global level, most members reacted negatively towards abrupt local topic drift. We observed 2 types of local topic drift: gradual topic drift and abrupt topic drift. Gradual topic drift, in which only a fraction of topics changed through a semantic parallel, occurred most frequently. This change is common and expected in any conversation [2] including CMC [7]. Members typically seemed to tolerate such gradual topic drift. However, members reacted negatively towards abrupt topic drift—when previous topics were completely replaced with different topics. When abrupt topic drift occurred, original posters showed frustration, and some community members even attempted to revert the topic back to the original topic. Although complete elimination of abrupt topic drifts could be difficult, some abrupt topic drift is likely preventable with improved design.

Practical Implication for Online Community Use, Research, and Design

Many online communities use moderators and even community members to regulate the content of posts. Manual efforts of monitoring posts have been shown to miss or misjudge important posts [45]. Our automated method could be utilized to expand these efforts. For example, an automated method could be used to alert community members when topics of their posts are entirely different from the topic of the thread. Raising self-awareness could help to control topic drift.

Moreover, moderators could use automated methods as a supplement to reduce the burden of keeping discussions on track. Automated methods could alert moderators of abrupt topic drift occurring in the middle of threads. An immediate alert could allow moderators to provide timely support and minimize negative impacts. As for the community, similar automated methods could provide the basis for filtering spam or abusive content, while keeping relevant on-topic content available to the community.

Expanding these topic-oriented automated methods could further enhance online health communities by (1) locating topically relevant posts [46] in threads even if topic drift occurs and (2) identifying peers with shared circumstances [47]. Locating relevant information in large volumes of text can be daunting. An automated method could automatically locate previously written posts on a similar topic without delay. Moreover, such a system could provide opportunities to connect with members who previously discussed topics that reflect similar interests and experiences. Studies have consistently shown that patients find peer support more helpful when provided by fellow patients with similar experiences [48,49].

We also offer design considerations based on our findings. Our findings suggest that facilitating off-topic discussions could benefit members who desire emotional connection and lighten the mood of the community. The popularity of off-topic discussion threads also suggests that support for limited off-topic discussions could contribute to sustained participation, which is a prominent challenge for online communities [50,51].

We discovered that some members expressed a reluctance to change topics completely but did so anyway because starting a new thread or sending a private message was not an intuitive process. An intuitive interface supporting the creation of new topics or branching off a new side conversation might reduce abrupt topic drift.

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Limitation and Future Directions

One limitation in our qualitative analyses was that we had a single analyst and a dataset with 7 communities within the WebMD platform. Therefore results may not be generalizable to other communities. We recognize the limitation of using a single analyst. However, a previous study illustrated that the interpretation of topic drift can be subjective [11], thus we employed a systematic approach. We acknowledge that our large sample size could have inflated the statistical significance levels and raises questions about the practical significance of our quantitative findings. We completed effect size estimates to aid our interpretation of results.

We also considered observations within the unit of analysis (ie, role within a thread) as independent; nevertheless, correlation could exist in the counteraction effort a member provides when acting in different roles. However, both qualitative and quantitative analyses showed consistent results in a diverse group of online health communities in WebMD. Findings could indicate that original posters have a higher stake in keeping the thread on topic than other members. This finding, however, could also be due to differences in the responsibilities of moderators and other types of community members.

From previous research, we expect moderators to recruit new members, temper discussions, and create an engaging and respectful community culture [22]. Although we are uncertain of the specific obligations of WebMD moderators and MDs, it is reasonable to assume that they attend to many threads to create an engaging and respectful community culture. Due to their demanding responsibilities, moderators and MDs could miss topic drift in threads. Conversely, original posters might be more invested in their own threads, thus providing substantial effort to keep thread topics aligned with their interests to obtain desired support. Future work using mixed methods, such as surveys and interviews, could ask original posters about effects of topic drift or ask about responsibilities of the moderators to gain a deeper understanding.

Our findings suggest that topic drift occurs despite apparent differences in health aspects (ie, biological, psychological, and sociological) and representative demographics (ie, age and gender) of different communities. Understanding how these differences affect topic drift could deepen our understanding in future work. Although our term-based similarity metric was not developed to analyze conversations, our study showed its practical application for analyzing CMC through consistent results across the seven diverse WebMD communities. An extended evaluation using a large gold-standard dataset could investigate the effectiveness of this as well as other sophisticated similarity measurements, such as knowledge-based [52] and corpus-based [53] approaches to automated detection of topic drift. These sophisticated similarity measurements that consider semantic meaning or syntactic organizations of the words could improve the performance of topic drift and members' counteraction detection.

Conclusion

We provide new insights into topic drift by illustrating possible benefits of having global topic drift in online health communities, identifying sources of abrupt local topic drift, highlighting considerable counteraction provided by original posters, and creating automated methods to detect topic drift and counteraction at the thread level. Our findings suggest that members react negatively towards local topic drift in the middle of the thread but advocate sharing globally off-topic stories to build rapport and bring members closer. Although many members counteract topic drift, original posters appear to provide the most effort to keep their threads on topic. Finally, we demonstrated automated techniques to detect both topic drift and counteraction. Based on these findings, we have contributed practical suggestions for designing online health communities to better facilitate online discussions. Findings from this study have the potential to reduce topic drift and improve online health community members' experience. Such experiences could improve the personal health management of members who seek essential information and support during times of difficulty.

Acknowledgments

This work was funded by National Science Foundation Smart Health and Wellbeing (NSF SHB) 1117187 and National Institutes of Health - National Library of Medicine (NIH-NLM) #5T15LM007442-10 Biomedical and Health Informatics (BHI) Training Program.

Conflicts of Interest

None declared.

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Abbreviations

CMC: computer-mediated communication
ADHD: attention deficit hyperactivity disorder
ADA: Americans with Disabilities Act

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tf-idf: term frequency-inverse document frequency
MS: multiple sclerosis
MD: medical doctor
TL: thread length
OT: off topic
URL: uniform resource locator

Edited by G Eysenbach; submitted 30.06.16; peer-reviewed by S Herring, S Paige; comments to author 04.08.16; revised version received 15.09.16; accepted 20.09.16; published 02.11.16.

Please cite as:
Park A, Hartzler AL, Huh J, Hsieh G, McDonald DW, Pratt W
"How Did We Get Here?": Topic Drift in Online Health Discussions
J Med Internet Res 2016;18(11):e284
URL: http://www.jmir.org/2016/11/e284/
doi:10.2196/jmir.6297
PMID:27806924

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Original Paper

Assessing the Viability of Social Media for Disseminating Evidence-Based Nutrition Practice Guideline Through Content Analysis of Twitter Messages and Health Professional Interviews: An Observational Study

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Abstract

Background: Given the high penetration of social media use, social media has been proposed as a method for the dissemination of information to health professionals and patients. This study explored the potential for social media dissemination of the Academy of Nutrition and Dietetics Evidence-Based Nutrition Practice Guideline (EBNPG) for Heart Failure (HF).

Objectives: The objectives were to (1) describe the existing social media content on HF, including message content, source, and target audience, and (2) describe the attitude of physicians and registered dietitian nutritionists (RDNs) who care for outpatient HF patients toward the use of social media as a method to obtain information for themselves and to share this information with patients.

Methods: The methods were divided into 2 parts. Part 1 involved conducting a content analysis of tweets related to HF, which were downloaded from Twitonomy and assigned codes for message content (19 codes), source (9 codes), and target audience (9 codes); code frequency was described. A comparison in the popularity of tweets (those marked as favorites or retweeted) based on applied codes was made using *t* tests. Part 2 involved conducting phone interviews with RDNs and physicians to describe health professionals' attitude toward the use of social media to communicate general health information and information specifically related to the HF EBNPG. Interviews were transcribed and coded; exemplar quotes representing frequent themes are presented.

Results: The sample included 294 original tweets with the hashtag "#heartfailure." The most frequent message content codes were "HF awareness" (166/294, 56.5%) and "patient support" (97/294, 33.0%). The most frequent source codes were "professional, government, patient advocacy organization, or charity" (112/277, 40.4%) and "patient or family" (105/277, 37.9%). The most frequent target audience codes were "unable to identify" (111/277, 40.1%) and "other" (55/277, 19.9%). Significant differences were found in the popularity of tweets with (mean 1, SD 1.3 favorites) or without (mean 0.7, SD 1.3 favorites), the content code being "HF research" (P=.049). Tweets with the source code "professional, government, patient advocacy organizations, or charities" were significantly more likely to be marked as a favorite and retweeted than those without this source code (mean 1.2, SD 1.4 vs mean 0.8, SD 1.2, P=.03) and (mean 1.5, SD 1.8 vs mean 0.9, SD 2.0, P=.03). Interview participants believed that social media was a useful way to gather professional information. They did not believe that social media was useful for communicating with patients due to privacy concerns and the fact that the information had to be kept general rather than be tailored for a specific patient and the belief that their patients did not use social media or technology.

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Conclusions: Existing Twitter content related to HF comes from a combination of patients and evidence-based organizations; however, there is little nutrition content. That gap may present an opportunity for EBNPG dissemination. Health professionals use social media to gather information for themselves but are skeptical of its value when communicating with patients, particularly due to privacy concerns and misconceptions about the characteristics of social media users.

(J Med Internet Res 2016;18(11):e295) doi:10.2196/jmir.5811

KEYWORDS

social media; information dissemination; medical nutrition therapy; evidence-based medicine; heart failure

Introduction

The Academy of Nutrition and Dietetics published an Evidence-Based Nutrition Practice Guideline (EBNPG) for Heart Failure (HF) in 2008 [1]. Evidence supports the use of nutrition to manage the symptoms of HF and improve quality of life [1]. With these outcomes in mind, the EBNPG for HF provides recommendations on the use of medical nutrition therapy, sodium and fluid restriction, energy and protein needs, and dietary supplements [1]. These recommendations, along with all Academy of Nutrition and Dietetics (Academy) EBNPGs, are available on a website for Academy members and subscribers. Dissemination efforts focus on raising awareness of new guidelines among Academy members through email blasts and inclusion in newsletters to relevant subgroups of the organization. When the EBNPG for HF was developed in 2008, social media in its current form was relatively new (tracking by the Pew Research Center began in 2005), and therefore social media was not used for initial EBNPG for HF dissemination efforts [2]. More recent Academy EBNPGs are promoted through the Academy's professional social media channels. Whereas the primary audience for Academy EBNPGs is registered dietitian nutritionists (RDNs), increasing knowledge of the EBNPG among physicians and patients may help to increase the implementation by increasing RDN consultations for HF.

The use of the HF EBNPG, which has 11 specific recommendations on HF and medical nutrition therapy, protein needs, energy needs, fluid intake, sodium intake, alcohol, and dietary supplements, including folate, vitamin B12, thiamine, L-Arginine, Carnitine, Coenzyme Q10, and Hawthorne, has been limited relative to the use of other Academy ENBPGs. For example, 29 HF EBNPG toolkits (a supplemental product to assist in implementing an EBNPG) were purchased in 2015, which is 62% of the average sales for each of the other toolkits during the same period (unpublished data). Similarly, the digital EBNPG for HF received 2425 page views (1040 unique visitors) in 2015 when compared with an average of 4841 total annual page views for other individual Academy EBNPGs. The EBNPG for HF was also available through the National Guideline Clearing house for the first 5 years after publication and received 5049 page views through guideline.gov during this time. The causes or reasons for low utilization of the EBNPG for HF are unclear but may include lack of awareness or the small volume of HF patients referred to RDNs. The age of the specific EBNPG may also be a reason for low utilization; its content is undergoing revision currently and an update will be published soon. One proposed strategy for increasing referrals is raising awareness among physicians, RDNs, and patients about the availability of the EBNPG for HF and its content through the use of social media.

Social media is widely used in the United States, which shows its potential value as a dissemination tool. The Pew Research Center reports that 90% of all young adults and 35% of adults aged 65 years and above use social media in the United States [2]. Although there are disparities based on income and educational achievement, a large number of sociodemographic groups are connected to social media, and thus disparities are decreasing [2]. The Internet, including social media sites, are frequent sources of health information and support. One in 3 Americans has gone to the Web to attempt to diagnose a medical problem and a quarter have read about another individual's health condition or sought support on the Web from individuals with a similar condition [3]. Therefore, providing health information through social media may be a viable strategy for dissemination of evidence-based health care information to patients and professionals. This may be particularly important for breaking through the "noise" of nonevidence-based information available on social media. In a study of Web postings by Italians, Mazzocut et al [4] showed that patients frequently search for and post items related to alternative therapies for cancer treatment, many of which involve nutrition, showing that nutrition therapies are a topic of conversation on social media.

However, less is known about health care providers' use of social media to gather or distribute information. Other authors have reported that, in general, physicians' willingness to use social media for professional development is based on ease of use and attitude toward social media (ie, for nonprofessional development activities) [5]. Previous research has identified 6 benefits and 12 limitations for the use of social media in health communication with benefits that include reducing stigma and collecting data on patient experiences and opinions and limitations, which include lack of reliability, quality concerns, and lack of privacy and confidentiality [6]. Most of the work in understanding health care providers' use of social media is related to the privacy and ethical concerns that surround its use [7].

Social media is characterized by interactivity and user-generated content [8]. Therefore, the content is driven by those who choose to participate in social media and does not include content from those who are reluctant to engage, potentially impacting health care professional voices on social media. Popular social media channels include Facebook and Twitter, which is a micro-blogging platform with a limit of 140 characters per message (tweet). Twitter encourages content classification and

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interactivity through a variety of features, including hashtags (#) and addressing public tweets to specific user(s) (@). Hashtags are user-generated meta-data that allow a searchable grouping of related tweets. Use of the "@" symbol plus a username provides the ability to specifically target a message to a specific user(s). Finally, retweeting or reposting another user's tweet to one's own followers and marking as a favorite, indicating appreciation of a tweet, allow for further interaction between users and promotion of content.

Previous research has successfully used social media meta-data to describe the use and perceptions of health topics such as the use of little cigars and cigarillos [9], breast cancer [10], and pediatric obesity [11]. One of the characteristics of social media is its interactivity and the potential to engage a broad range of users in a dynamic conversation [8]. Previous health care–related social media research suggests that as recently as 2012, tweets made by state health departments lack the user engagement component, decreasing content impressions and potentially interest and dissemination power [12]. Number of retweets and followers on Twitter have been used previously as a proxy for interactivity [13].

The purpose of this study was to (1) identify the existing consumer and professional information about HF on social media and (2) identify RDNs' and physicians' attitude toward the use of social media to gather professional information and disseminate that to patients. Whereas other authors have suggested using mixed methods within Twitter content analysis, our study was primarily quantitative in the methods related to aim 1 and primarily qualitative in the methods related to aim 2 [14]. By using this approach, we were able to establish in aim 2 why we observed few health care professional voices discussing HF on Twitter in aim 1.

Methods

Design and Ethical Approvals

The methods were divided into two parts. Part 1 (Twitter content analysis) involved conducting content analysis of tweets related to HF. Part 2 (Health care provider interviews) involved conducting phone interviews with RDNs and physicians to identify health professionals' attitude toward the use of social media for the communication of general health information and information specifically related to the EBNPG for HF. Both parts were reviewed and approved by the American Academy of Family Physicians Institutional Review Board. Part 1 was approved as an exempt project and follows the guidelines set forth by the European Society for Opinion and Marketing Research (ESOMAR) stating that public postings on social media sites may be used for research when identifiable information is protected and is consistent with the Twitter Terms of Service [15,16]. Part 2 was approved as human subjects research utilizing a verbal consent process. The 2 methods were designed in tandem but completed sequentially—the interview questions were written prior to the content analysis, but not conducted until after the Twitter analysis. Care was taken to keep the Part 2 interviewers blinded to the results of Part 1. The codes used in Part 1 were considered for Part 2 interview coding but mostly were not found to be relevant.

Part 1: Twitter Content Analysis

Our method was loosely based on the one described by Step et al and similar to that described by Harris et al, particularly in the use of tracking a single hashtag [9,11]. Tweets that included "#heartfailure" were downloaded from Twittonomy. Twittonomy is a subscription Twitter aggregation service that allows the purchase of tweets and their associated metadata including username, hashtags, date posted, number of favorites and retweets. The download for this project was created on Tuesday, May 5, 2015 and included data from the previous 9 days, which included HF Awareness Day. "#Heartfailure" was selected for analysis based on surveillance of Twitter and use of analytics website (symplur.com) demonstrating that this was the most frequent hashtag applied to relevant messages. #HF, #CHF, #congestiveheartfailure, and #LVHF were also included in the surveillance but were not selected for download and analysis due to infrequent use.

Using a directed content analysis approach, one investigator (RKH) created a codebook with proposed codes and definitions (Table 1) before examining the tweets [14]. A second investigator (TMW) reviewed the codebook and suggested changes and additions that were made based on consensus among the 2 investigators. Once the codebook was edited, reviewed, and approved, both investigators individually coded the first 10% (29/294) of the downloaded tweets identified as original (excluding retweets). Their answers were compared and the final codes for each tweet were determined based on consensus. They also discussed and agreed upon whether new codes were needed, and changes to definitions of the existing codes. Tweets were viewed on the Twitter platform, which allowed viewing of any pictures that were included in the tweet (pictures were not included in the Twittonomy download), as well as profile information about the user who posted the tweet. Information about the user was used to determine the source and audience. If a tweet included a link to content, the initial posted link was opened and assessed as part of the content; however, coders did not open additional links from that page. A third investigator (JKA) who was trained to use the revised codebook, coded the first 10% (29/294) of tweets, and compared answers with the key created by RKH and TMW. The remaining 90% (265/294) of tweets were coded individually by an investigator (JKA). A 10% (29/294) random sample of these tweets was assessed by RKH and compared with the assessments of JKA. Discrepancies were noted and discussed. Of the 180 codes applied to the random sample of 29 tweets, 5 (2.8%) were removed after discussion and 12 (6.66%) were added, which was considered adequate agreement. The retweets were not coded. Codes were not mutually exclusive. The Twittonomy data indicated that how many times an original tweet had been retweeted or marked as a favorite as well as the number of followers a user had; these metrics were used to assess interest in a tweet.

If a user handle was listed at the beginning of a tweet, this was considered to be directed to that specific user. If a user handle was used at the end of the tweet, the named individual was considered to be a user who was related to the tweet. If a tweet varied only in the user handles listed, then it was coded identically to the original tweet. The recipients of these

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user-directed messages were considered in the audience assessment; the author's profile was also used for assessment of the audience. Messages that were coded as irrelevant content did not have source or audience codes applied; therefore the N for these analyses is lower.

Once the codes were applied, the number of original tweets with each code was quantified. Since more than one code could be applied to a tweet, frequencies exceed 100. Because one individual's posts (hereafter, frequent user) represented 84 of the tweets (28%), a post-hoc sensitivity analysis was performed to determine whether the proportion of tweets with each code varied when the frequent user's tweets were excluded from the entire sample. The next most frequent user only posted 14 messages, making the frequent user a clear outlier. The sensitivity analysis was performed using one sample *t*-tests comparing the frequency of each code with and without the frequent user's tweets.

Using the entire sample of tweets (N=294), differences in mean retweets and favorites for each message were compared using independent sample *t*-tests, based on whether each content code was applied. In addition to the number of times a specific tweet was marked as a favorite or retweeted, the mean number of followers for the user who had posted the message was compared for each tweet based on the source and audience codes using independent sample *t*-tests. In both cases, Levene's test for equality of variance was used and if it was statistically significant, a *t*-test that did not assume equality of variance was used. The number of retweets, favorites, and followers were considered as a measure of interactivity [13].

Analysis was performed in SPSS version 20.0 (IBM Inc) and significance was set as $P<.05$.

Part 2: Health Care Provider Interviews

Interview participants were recruited via emails to the Academy's Dietetics Practice Based Research Network (n=1815) and the American Academy of Family Physicians' (AAFP) Research Committee (n=10), AAFP Foundation grant reviewers (n=30), Commission on Health of the Public and Sciences (n=22). Participants were required to be physicians or RDNs and see outpatients with HF. Forty-two RDNs replied to the email and indicated they were interested in participating, and the first 10 who were eligible were selected. A total of 7 physicians, 3 physician assistants or nurse practitioners, and 2 family medicine researchers (PhDs) replied to the email and indicated they were interested in participating—only the 7 physicians were eligible and were scheduled.

Sixteen individuals (6 physicians, 10 RDNs) participated in an interview. One eligible physician did not attend the scheduled interview and opted not to reschedule. After obtaining verbal consent to participate in the study, participants were individually interviewed by trained interviewers via telephone using a semistructured interview protocol developed to assess knowledge, use, importance, and accuracy or validity of the Academy's HF EBNPG. The interview also explored provider and health care system, use of technology, and social media with HF patients to communicate general health or nutrition information. Questions about personal use of technology and social media were included in an effort to understand health care providers' familiarity and comfort level with these communication methods and to determine whether professional attitudes were shaped by personal use patterns. Interview participants were compensated US $150 for participating in the study. Interviews were recorded and transcribed verbatim, although filler words (eg, umm) were removed in the exemplar quotes presented here. In an effort to increase accuracy of transcriptions and thus reduce error, each interviewer transcribed only the interviews that he or she conducted. Transcripts were analyzed ethnographically using MaxQDA version 11 (VERBI GmbH) to identify themes in participants' responses to each set of questions presented in the interview. The unit of analysis was each participant's response to a specific question. Question responses could have more than one theme applied.

Results

Part 1: Twitter Content Analysis

The Twittonomy download included 298 original and 324 retweets that included #heartfailure. Between downloading and coding, 4 tweets had been deleted. Thirty-seven tweets were identical to previously coded tweets; these were included in the sample and received the same codes as the original tweets. A total of 728 content, 365 source, and 287 audience codes were applied, representing 2.47 (SD 1.61), 1.24 (SD 0.66), and 1 (SD 0.59) codes in each category per tweet, respectively.

The most frequent content code was "HF awareness" (166/294, 56.5%), followed by "patient support" (97/294, 33.0%; Table 1). However, the frequency of these content codes was strongly influenced by the content of the frequent user. The frequency decreased to 45.5% (95/209) and 10% (21/209), respectively when the frequent user's tweets were removed ($P=.001$). The second most frequent code without the frequent user's tweets was "HF research" (81/209, 38.8%). The most frequent source code among all tweets when the the frequent user was included in the sample was "professional, government, patient advocacy organization, or charity" (112/277, 40.4%), followed by "patient/family" (105/277, 37.9%). Without the frequent user's tweets the most frequent source code was "other" followed by "professional, government, patient advocacy organization, or charity" (81/192, 42.2% and 70/192, 36.5%, respectively) (Table 1). Users coded with the "other" source code included medical journals, health news services, and health websites like WebMD. The frequency of the source codes "patient and family" and "other" were statistically different based on the inclusion or exclusion of the frequent user's tweets. The most frequent target audience codes were "unable to identify" (111/277, 40.1%) and "other" (55/277, 19.9%). "HF nutrition" was rarely a theme of the messages (<10%) and RDNs were infrequent tweeters (1 message). "Other" target audiences included political figures and health advocates.

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Table 1. Codes applied to tweets with the hashtag "#heartfailure" in a landscape analysis of social media content related to nutrition and heart failure.

Category	Code	Definition	Number of tweets (%) with code n (%)	Number of tweets (%) with code except frequent user's tweets n (%)	*P* value of one sample *t*-test by comparing frequency with and without frequent user's tweets
Message content –What is the tweet discussing?			N=294	N=209	
	Awareness	Raising awareness of heart failure including its prevalence and/or risk factors	166 (56.5%)	95 (45.5%)	.002
	Patient support	Messages of support for patients with heart failure or support systems	97 (33.0%)	21 (10.0%)	<.001
	HF[b] research	Research related to HF	81 (27.6%)	81 (38.8%)	.001
	HF symptoms	Symptoms of HF such as fluid overload and shortness of breath. Also includes side effects and related conditions	79 (26.9%)	51 (24.4%)	.40
	HF outcomes	Outcomes of HF or HF treatments or research, may include mention of hospital re-admissions	68 (23.1%)	68 (32.5%)	.004
	HF management	Standard strategies for management of heart failure not specific to nutrition or exercise or medication. Novel strategies will more often fall under research.	58 (19.7%)	58 (27.8%)	.01
	Event	Advertising a specific event either for fundraising or a course opportunity	47 (16.0%)	28 (13.4%)	.27
	HF medication	Medications used to treat HF	34 (11.6%)	34 (16.3%)	.07
	Exercise	Exercise for HF including cardiac rehab programs	30 (10.2%)	14 (6.7%)	.045
	Fundraising	Raising money for heart failure research or charity	23 (7.8%)	6 (2.9%)	<.001
	Not relevant	Message is not relevant to HF	17 (5.8%)	17 (8.1%)	.22
	Other	Other message content related to HF	15 (5.1%)	15 (7.2%)	.25
	HF nutrition (general or other)	Nutrition requirements or restrictions for HF or mention of a dietitian in relation to HF. Use only if the subsequent specific codes cannot be used.	12 (4.1%)	12 (5.7%)	.31
	HF sodium restriction[a]	Sodium restrictions for patients with HF	10 (3.4%)	10 (4.8%)	.35
	HF fluid restriction[a]	Fluid restriction for patients with HF	6 (2.0%)	6 (2.9%)	.71
	HF energy needs[a]	Energy need for patients with HF	1 (0.3%)	1 (0.5%)	.71
	HF dietary supplements[a]	Dietary supplement products for patients with HF	1 (0.3%)	1 (0.5%)	.71
	HF alcohol[a]	Use or misuse of alcohol in the context of HF	0	0	
	HF protein needs[a]	Protein needs for patients with HF	0	0	

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Category	Code	Definition	Number of tweets (%) with code n (%)	Number of tweets (%) with code except frequent user's tweets n (%)	*P* value of one sample *t*-test by comparing frequency with and without frequent user's tweets
Source–who posted the tweet? Identified using information in the tweet or the author's profile			n=277	n=192	
	Professional, government, patient advocacy organization, or charity	Non-profit, charity, government organization, dedicated to a disease or condition or professionals related to that condition. Generally but not always specific to HF.	112 (40.4%)	70 (36.5%)	.26
	Patient or family	Patient with HF or family member of a patient with HF, or someone who identifies as being at risk of HF	105 (37.9%)	28 (14.6%)	<.001
	Other	A poster who has identifiable characteristics that are not described above	81 (29.2%)	81 (42.2%)	<.001
	Provider or hospital group	A hospital or medical care organization that includes more than one practitioner	25 (9.0%)	25 (13.0%)	.10
	Individual physician	A physician who is posting on his own rather than as part of an organization	16 (5.8%)	16 (8.3%)	.21
	Industry	Entity selling a product relevant to HF	14 (5.1%)	14 (7.3%)	.25
	Other individual provider	Another health care professional who is posting on his own rather than as part of an organization	8 (2.9%)	8 (4.2%)	.38
	Unable to identify	The characteristics of the poster cannot be determined	3 (1.1%)	3 (1.6%)	.53
	Individual RDN	A dietitian who is posting on their own rather than as part of an organization	1 (0.4%)	1 (0.5%)	.82
Target audience–who is the message's intended reader? Identified using information in the tweet or hashtags			n=277	n=192	
	Unable to identify	The characteristics of the audience cannot be determined	111 (40.1%)	81 (42.2%)	.64
	Other	Audience who has identifiable characteristics that are not described above	55 (19.9%)	25(13.0%)	.004
	Patient or family	Patient with HF or family member of a patient with HF, or someone who identifies as being at risk of HF	49 (17.7%)	44 (22.9%)	.10
	Other individual provider	Another health care professional who is posting on his own rather than as part of an organization	23 (8.3%)	10 (5.2%)	.05
	Professional, government, patient advocacy organization, or charity	Nonprofit or government organization dedicated to a disease or condition or professionals related to that condition. Generally but not always specific to HF.	18 (6.5%)	14 (7.3%)	.70
	Individual physician	A physician who is posting on his own rather than as part of an organization	21 (7.6%)	15 (7.8%)	.95
	Provider or hospital group	A hospital or medical care organization that includes more than one practitioner	7 (2.5 %)	7 (3.6%)	.41
	Industry	Entity selling a product relevant to heart failure	2 (0.7%)	2 (1.0%)	.65
	Individual RDN	A dietitian who is posting on his own rather than as part of an organization	1 (0.4%)	1 (0.5%)	.82

[a]Indicates the recommendations from the Academy's EBNPG for HF on that topic

[b]HF: heart failure.

Codes applied to tweets with the hashtag "#heartfailure" in a landscape analysis of social media content related to nutrition and heart failure are presented in Table 1. Codes were applied for tweet content, source, and audience. Themes are presented in descending order of frequency. To test the effect of one very active patient tweeter on the frequency of codes (frequent user),

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one-sample *t*-tests were used to compare the frequency of each code in the sample of tweets that did and did not include his posts.

Number of followers varied widely and no statistically significant patterns were discerned based on source or target audience (data not shown). Significant differences were found in the popularity of tweets with or without the content code of "HF research."(Table 2) Tweets with the code had more favorites (1 [SD 1.3] vs 0.7 [SD 1.3], *P*=.049), but fewer retweets (0.7 [SD 1.2] vs 1.3 [SD 2.0], *P*=.003). Tweets with the content code of "HF outcomes" were also less likely to be retweeted than tweets without this content code (0.6 [SD 1.6] vs 1.2 [SD 1.9], *P*=.023). Tweets with the content code "not relevant" were also less likely to be marked as a favorite. Tweets with the source code "professional, government, patient advocacy organizations, or charities" were significantly more likely to be marked as a favorite and retweeted than those without this source code (1.2 [SD 1.4] vs 0.8 [SD 1.2], *P*=.026), (1.5 [SD 1.8] vs 0.9 [SD 2.0], *P*=.026). No statistically significant differences were found for the target audience codes.

Part 2: Health Care Provider Interviews

Demographic characteristics of interview participants are shown in Table 3. Physician participants were somewhat older (mean 47.8 years) and reported more experience (mean 19.6 years) than RDNs (mean 40.2 years and 13.5 years, respectively). The overall sample were predominately white and female. The physician sample was somewhat more diverse than the RDNs.

Awareness of the Academy's HF EBNPG was low among both physician and RDN interview participants. RDNs were more likely to report being somewhat or fairly familiar with the Academy's HF EBNPG; one was very familiar. RDNs were also more likely to report being familiar with and using guidelines from the American Heart Association (AHA). Participants from both professions indicated that they believe guidelines are useful in caring for HF patients. They focused on the sodium and fluid restriction components of nutrition guidelines.

> *If it (Academy HF EBNPG) has anything to do with salt, but I don't know about any other nutritional guidelines so if it has to do with salt intake and so forth then yes, I would assume it would be helpful.* [Physician]

Two RDN participants were able to identify that the Academy's HF EBNPG recommends a stricter sodium restriction (2000 mg/day) [1] when compared to the AHA guideline, which simply states that for stage C class 3A HF, "sodium restriction is reasonable for patients with symptomatic HF to reduce congestive symptoms," without specifying a target intake [17].

Interview participants from both the professions reported the difficultly of behavior change for their patients. Physicians were likely to report not having time to review detailed diet information during office visits or their lack of nutrition-specific training. Although this might be expected to be associated with RDN referrals, physicians also identified many barriers to RDN referrals for patients including inability to pay and the high cost due to lack of insurance coverage for nutrition counseling. While both professions agreed on the need for an inter-professional team approach to HF, many reported that patient care was in fact disjointed:

> *I'm in one area, cardiology is in another separate building...some of our other HF areas are in whole other areas. So that's where some of that disjointedness comes together, and so having that continuity, and then if you look at across system you have different recommendations coming about...then I finally see the patient and I'm re-educating the patient, that is then totally confused on what they should or should not do.* [RDN]

RDNs were more likely to report using Facebook as a personal past-time as compared with physicians. RDNs were also more likely to report personal use of other social media channels such as Instagram and Pinterest. Personal use of Twitter was reported more commonly by physicians. Most interview participants reported professional use of technology such as email, the Internet, Web conferencing, listservs, electronic medical records (EMR) and patient portals. Participants described their use of social media and technologies to network with other professionals and stay up to date with new information:

> *Twitter is a really good useful tool in keeping up with medical literature, because if you follow the right people, both sort of journalists, and medical professionals, you can often get very good information or links to very good information. So that's, that's something I use quite frequently, probably daily. At least I'm checking Twitter to see what new developments there are.* [Physician]

When deciding what information to read online, participants cited credibility of the source and interest in the topic as the most important factors. One RDN identified that the host suffix was important in determining credibility, for example the ".edu" domain may be more credible than ".com". Another RDN reported that she often accesses information if the title "sparks" her interest:

> *(I am more likely to click on...)Something that just might be a little bit different or be controversial or something different from mainstream that might be said that might get, you know, I'd, I'd be more interested in that.* [RDN]

Participants were adamant about not using or not being permitted to use social media or certain other technologies to communicate with patients, citing legal, and ethical considerations related to the Health Insurance Portability and Accountability Act (HIPAA) and privacy:

> *From the patient's side...I feel like they give their implied consent if they're going to post their personal health information on social media. From the medical professional side, I feel like the appropriate thing is sort of, not to, sort of, if somebody wants to engage in a conversation about their personal health issues, you should guide them to another channel, instead of over tweets and replies or Facebook posts; things that are open. Because then, that does create potential*

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> *ethical issues about sharing that private information.* [Physician]

Most patient communication (eg, lab results), was handled through patient portals. Many participants reported that their institution communicated general medical information to patients through social media channels, including Facebook and Twitter, and other digital communications channels such as texting:

> *So, both the institution, the university has, you know, an account that posts health information now and then. And then our department also has a Facebook account and a Twitter account that occasionally will post links to articles or things with health information.* [Physician]

Some participants described how they used technologies during office visits to steer patients toward credible information. One RDN commented that she shared recipes, products, and "tips and tricks" with patients via Pinterest. A physician described using social media to communicate general health information to patients, but that this was not targeted to his patients specifically. Interview participants also noted that Facebook, Twitter, and other digital communications were often used to promote or advertise educational opportunities for patients. Interview participants were concerned about the credibility of information posted on social media, including in some cases the credibility of information posted by their own institutions when the social media managers were not medical professionals:

> *My only concerns are sometimes the person who is in charge of posting to those (social media) accounts does not have actually a medical background, at least at our department level. I'm not sure who does it at the university level, but there are occasionally things, posted or shared that I feel like are maybe not the most evidence based, or the most accurate, and so I do have concerns from that stand point.* [Physician]

Interview participants believed that social media could be effective channels to communicate health information to HF patients but were concerned about patient access to the Internet and use of technology. RDN interview participants reported that their HF patients tended to be older adults. Consequently, RDN interview participants believed patients were unlikely to be utilizing technology or social media:

> *Most heart failure patients are in their late 60's, 70's and above...A lot of those folks don't, you know, it's not their generation (to use social media).* [RDN]

Two RDNs discussed how social media might be used to provide support groups and disseminate health information to their patients with heart failure. One RDN suggested an "online community" that would be moderated by a health professional or other expert might be useful approach to engage patients with heart failure. Likewise, another RDN suggested that a private Facebook group might be utilized to support and educate HF patients.

To ensure patient privacy, interview participants believed that social media can only be used to provide general health information. However, participants pointed out that patients are more likely to respond to information that is individualized to them:

> *They're less likely to respond to things that aren't specifically directed to them, you know, like I said, so, so putting things out on Twitter is probably less effective than say emailing to them, or you know having, having like an App that they can download. I feel like that might be...a good way is if there was an App that the patients could access you know directly on their own device that sort of integrated recommendations and things like that with how they're tracking their own health information. That might be helpful, but I feel like things that aren't personalized are less helpful.* [Physician]

Similarly, interview participants recognized that general information on social media might help to raise awareness of guidelines among patients but that this would not necessarily translate into action or behavior change, which probably requires more personalized information:

> *So, if the idea is to get patients to recognize the guidelines exist, and perhaps get them to look at it, then whether it be Twitter or Facebook or something like that, I think you can make people aware. However, to actually get people to adopt those lifestyle choices, then I think it works better to come electronically, from their provider through the electronic portals most of us have with their electronic health records.* [Physician]

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Table 2. Comparison of mean favorites and retweets for messages with each content, source, and audience code versus messages without these codes in a sample of tweets using the hashtag "heartfailure" compared with independent samples *t*-tests.

Category	Code	Favorites			Retweets		
Message content		Mean (SD) with code	Mean (SD) without code	*P* value for independent samples using *t*-test	Mean (SD) with code	Mean (SD) without code	*P* value for independent samples using *t*-test
	HF[b] symptoms	0.8 (1.4)	1.0 (1.3)	.234	0.8 (1.7)	1.2 (2.0)	.13
	HF management	0.1 (1.6)	0.9 (1.2)	.92	0.9 (1.7)	1.1 (1.9)	.48
	Exercise	0.8 (1.0)	0.9 (1.3)	.66	1.1 (1.3)	1.1 (2.0)	.44
	Awareness	1.0 (1.2)	0.8 (1.4)	.30	1.1 (1.6)	1.0 (2.2)	.61
	Fundraising	1.4 (1.0)	0.9 (1.3)	.11	1.3 (1.2)	1.1 (1.9)	.57
	Event	1.2 (1.2)	0.9 (1.3)	.08	1.2 (1.4)	1.1 (2.0)	.69
	Patientsupport	1.0 (1.1)	0.9 (1.4)	.43[a]	1.1 (1.5)	1.1 (2.1)	.82
	HF medication	0.7 (1.3)	1 (1.3)	.22	0.7 (1.5)	1.2 (1.9)	.15
	HF research	1 (1.3)	0.7 (1.3)	.049	0.7 (1.2)	1.3 (2.0)	.003[a]
	HF outcomes	0.71 (1.2)	0.7 (1.4)	.10	0.6 (1.6)	1.2 (1.9)	.023
	HF nutrition (general or other)	0.5 (1.2)	0.1 (1.3)	.24	0.4 (1.1)	1.1 (1.9)	.21
	HF energy needs	0	0.9 (1.3)	.47	0	1.1 (1.9)	.57
	HF fluid restriction	1.0 (2.0)	0.9 (1.3)	.90	1.2 (2.9)	1.2 (1.9)	.92
	HF sodium restrictions	1.0 (2.2)	0.9 (1.3)	.87	1.0 (2.2)	1.1 (1.9)	.88
	HF dietary supplements	6.0	0.9 (1.3)	<.001	2	1.1 (1.9)	.63
	Other	1.1 (1.8)	0.92 (1.3)	.68	1.2 (2.1)	1.1 (1.9)	.93
	Not relevant	0.4 (0.6)	1.0 (1.3)	<.001[a]	0.4 (0.8)	1.1 (1.9)	.10
Source	Patient or family	1.1 (1.2)	0.9 (1.4)	.33	1.1 (1.2)	1.2 (2.3)	.61[a]
	Industry	1.1 (1.9)	0.96 (1.3)	.73[a]	1.1 (2.4)	1.1 (1.9)	.90
	Professional, government, patient advocacy organization, or charity	1.2 (1.4)	0.8 (1.2)	.026[a]	1.5 (1.8)	0.9 (2.0)	.026
	Provider or hospital group	0.9 (1.4)	1.0 (1.3)	.85	0.8 (1.5)	1.2 (2.0)	.43
	Individual physician	1.2 (1.5)	1.0 (1.3)	.49	2.0 (4.7)	1.1 (1.6)	.44[a]
	Individual RDN	0	1.0 (1.3)	.46	0	1.1 (1.9)	.56
	Other individual provider	0.6 (0.7)	1.0 (1.3)	.46	0.8 (1.2)	1.1 (2.0)	.57
	Other	0.7 (1.4)	1.1 (1.3)	.05	0.9 (2.4)	1.3 (1.7)	.12
	Unable to identify	0.7 (1.2)	1.0 (1.3)	.69	0	1.2 (1.9)	.31
Target audience	Patient or family	1.2 (1.9)	0.93 (1.2)	.40[a]	1.53 (2.1)	1.1 (1.9)	.15[a]
	Industry	2.0 (1.4)	1.0 (1.3)	.27	2.0 (1.4)	1.1 (1.9)	.52
	Professional, government, patient advocacy organization, or charity	1.3 (1.0)	0.9 (1.3)	.22	1.4 (2.4)	1.1 (1.9)	.56
	Provider or hospital group	1.7 (1.8)	1.0 (1.3)	.31	2.0 (2.6)	1.1 (1.9)	.13
	Individual physician	1.2 (1.3)	1.0 (1.3)	.33	0.9 (1.6)	1.2 (2.0)	.57
	Individual RDN	5	1.0 (1.3)	.002	7	1.1 (1.9)	.002
	Other individual provider	0.5 (0.7)	1.0 (1.3)	.09	0.5 (1.0)	1.2 (2.0)	.09
	Other	0.8 (1.1)	1.0 (1.4)	.35	0.8 (1.1)	1.2 (2.1)	.05[a]
	Unable to identify	0.9 (1.1)	1.02 (1.0)	.61	1.1 (1.6)	1.2 (2.1)	.43

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[a]Indicates that Levene's test for equality of means was statistically significant at $P<.05$ and so the *t*-test did not assume equality of variance.
[b]HF: heart failure.

Table 3. Demographic characteristics of interview participants. Age and experience are reported as mean and standard deviation; other characteristics are n and %.

Demographic characteristics	Physician (N=6)	Registered dietitian nutritionist (RDN) (N=10)	Combined (N=16)
Gender, n (%)			
Male	4 (67%)	0 (0.0%)	4 (25%)
Female	2 (33%)	10 (100%)	12 (75%)
Ethnicity or race, n (%)			
White	5 (83%)	9 (90%)	14 (88%)
Black	0 (0.0%)	0 (0.0%)	0 (0.0%)
Asian	1 (17%)	1 (10%)	2 (13%)
Hispanic or Latino	0 (0.0%)	0 (0.0%)	0 (0.0%)
Other	0 (0.0%)	0 (0.0%)	0 (0.0%)
Age[a] , mean (SD)	47.8 (10.8)	40.2 (8.6)	42.4 (9.9)
Years of experience[b] , mean (SD)	19.6 (8.6)	13.5 (10.5)	15.5 (10.3)

[a]Two physicians declined to report age.
[b]One physician declined to report years of experience.

Discussion

Principal Findings

Together, these findings support a role for health providers and organizations to use interactive social media —such as Twitter — to complement patient voices and provide important information to increase knowledge (dissemination) on focused health topics. This study shows that individual users are critical in shaping the content of social media, so if health care providers and their professional organizations are not active on social media, patient voices or nonexpert sources may dominate. Both individuals and organizations should attempt to provide evidence-based information to patients and colleagues, but with clear differentiation of the target audience. When a frequent user's tweets were included in analysis, the "patient support" and "fundraising" content codes and the "patient" source code were most frequent. Without this frequent user's tweets, "HF awareness" and "HF research" became the most frequent content codes. These data support Moorhead's uses of social media for providing health information on a range of conditions, for health intervention, promotion, and education [6]. Using social media to facilitate dialogue between patients to health professionals was a limited use in both our quantitative and qualitative datasets, but patient to patient dialogue was seen more frequently.

Different types of organizations use social media channels to varying degrees and it is likely that the preference for different channels varies over time as social media trends change [8]. For example, many hospitals use Facebook to provide health education information, recognize staff, and share hospital news, such as awards [18]. In our Twitter sample, journals and professional organizations were well represented and had success in interactivity as measured by favorites and retweets, indicating that social media users are interested in HF content from these resources. It is unclear whether journals are targeting the public or medical professionals. Our findings are similar to those in childhood obesity, which suggest that there is room for increased credible, evidence-based information from health organizations on Twitter [11].

Recent research examining guidelines from the American Academy of Neurology (AAN) indicated that social media dissemination did not supplement knowledge gains seen with traditional dissemination methods among physicians or patients [19]. This research used paid advertisements on social media sites, so it is unclear whether the results would be different if social media messages were used directly instead of using advertising placed on the sites [19]. The AAN study authors propose that their results are explained by a ceiling effect, in which individuals who already feel they know the information, perhaps from traditional dissemination methods, will not make any effort to learn more [19]. Sense of competence (the belief that one is already an expert in the content) frequently impedes dissemination of new information and may contribute to this ceiling effect [20]. Similarly, interview participants in our study indicated that they were much more likely to investigate or read more about content that was new, controversial, or different. Framing information in these ways may represent an opportunity to break through the "noise" of information overload. It is possible that the existing information on social media from professional organizations is adequate and that more information would meet this ceiling. However, much of the professional

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organization content was directed at patients or families; so directing this content to health care providers may be a new opportunity. Our interviews showed the participants willingness to use social media to obtain information for themselves.

Limitations

One theme that was unique to interviews and did not appear in the content analysis was participants' belief that age or socioeconomic status limited access to and use of social media. Given that the Pew Internet Report demonstrated widespread use of the Internet and social media across age and class groups, health professionals may need to be reeducated about who could benefit from social media [2]. Although social media use was lower among those aged 65 years and older, more than one in 3 of these individuals were using social media [2]. Assessing Internet availability and literacy as a component of health literacy may become necessary in order to customize educational materials and other resources for patients' needs. In addition, it was clear from our interviews that health professionals have significant concerns about privacy and social media, many of which have trickled down from their employers. Whereas there are privacy concerns, previous research has demonstrated that these may be overblown [18]. These incorrect assumptions about who uses social media and how it can be used while protecting patient privacy could prevent valuable information from reaching patients who need it. This is a challenge that was pointed out by Gholami-Kordkheili et al in their review of social media and medical professionalism—while social media has the potential to improve access to care by decreasing geographical barriers, access to the technology is required in order to reap these benefits [7]. Professional organizations may have a role in providing continuing education on the topic of social media use in order to overcome this misperception and provide guidance on using social media while protecting privacy.

We had previously demonstrated that RDNs are willing to take surveys about Academy EBNPG even when they are not familiar with the content; this is a method of learning new information, suggesting that surveys and quizzes may be novel dissemination strategies [21]. These strategies offer an element of interactivity and could be linked to social media posts. Thus far, attempts to use social media as a health information dissemination strategy have not used interactive components but rather use social media as an extension of traditional information sharing strategies. This failure to capitalize on the true Web 2.0 nature of social media could be the reason for poor uptake from social media dissemination strategies tested in the past and should be a focus of future work.

The Twitter analysis is limited by the use of a single hashtag to identify relevant tweets. Kim et al have suggested that keyword searches be used instead of hashtags, which may lead to a more sensitive and specific search [22]. Our use of surveillance to identify the hashtag on which we focused overcomes this to some extent, but we did not assess the sensitivity and specificity of our search results. Retweets, favorites, and number of followers were stand-ins for the interactivity of Twitter on the level of individual message themes, posters and audiences; however, it may be more appropriate to measure the interactivity of a specific user [13].

In many cases, it was challenging to identify the target audience of a specific tweet or a user in the content analysis. We used only profile information of the user posting the message to define the (intended) audience; however, methods have been developed to use the recent tweets from followers to define the interests of the actual audience [23]. We were also unable to use the data-mining techniques developed by Xu et al to describe the race and ethnicity of users and further describe both the posters and their audience [24]. Organizations or individuals using Twitter to disseminate evidence-based information should be mindful of cultivating a clear intended audience, as messages will likely differ when directed toward professionals versus patients. Some organizations have different accounts to disseminate their professional-oriented content versus patient-oriented content, which is one strategy to clarify the intended audience. In creating a social media strategy and evaluation plan, organizations should clarify whether their goal is dissemination (knowledge) or implementation (execution) of information. As expressed in the interviews, dissemination may be a reasonable goal for social media campaigns, while implementation may not be.

Despite the findings that most state health departments were using social media for one-way information sharing, the audience for these messages were unclear, similar to our findings in the content analysis [12]. Posting done by hospitals on Facebook were also found to share information more than interaction, with only 27% responding to comments posted on their page [18]. Together, these results lend validity to the concept, reflected in interviews, that social media was used as a dissemination rather than an implementation or engagement tool. However, Cameron et al were able to use Facebook to change actions, with their novel intervention to increase the registry of organ donors [25]. This was a one-time action rather than a behavior or lifestyle change, but it demonstrates that the interactivity of social media can be used to go beyond dissemination to implementation [25].

The frequent user clearly modified frequency of themes in the sample tweets; therefore, the content analysis may not be representative. It is unclear whether the inclusion of HF awareness day in our sample influenced the results. The timeframe for our gathering of Tweets was short because this was an initial exploration of the research question. The small sample size of Tweets limits generalizability and future research should use a longer collection period to ensure a larger number of messages are collected. Previous research indicates that there is a spike in the related Internet searches during breast cancer awareness month, but a smaller or no spike during lung or prostate cancer awareness events [24]. Given the media publicity for breast cancer awareness month, for which there is no HF equivalent, we would anticipate that HF awareness would be more similar to lung or prostate cancer, and therefore the influence on Twitter activity is likely to be low. Fundraising was a frequent topic in breast cancer awareness month tweets, similar to our sample [10]. It is interesting that the breast cancer analysis did not focus on the outcomes of research, but rather on fundraising for research [10].

The qualitative portion of this study built on the content analysis to understand how health professional attitude toward social

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media might explain the gaps in information identified in the content analysis, but is limited by the small sample of interview participants. The sample of RDNs and physicians who were interviewed may not be representative of all practitioners in their profession, in particular because we focused on a specific group—those who provide primary care to outpatients with HF. In addition, nurses and physician extenders may have an expanding role in taking care of patients with HF, and we did not interview any of these professionals because at the time of our initial grant application, this shift had not yet occurred. Because of the limited demographics collected from the interview participants, we are unable to compare them with their professions as a whole. The RDNs may be more representative than the physicians because of the use of a large Practice Based Research Network for recruiting [26,27]. In addition, more RDNs were interested in participating than were needed, leading to semirandom selection of the participants. We did not attempt to validate the interview responses through methods such as member checking. We were unable to determine whether the use of social media or knowledge of the EBNPG varied based on demographic or practice characteristics of the interview participants.

Conclusions

This study adds to a growing body of literature on the use of social media to disseminate health information. There are clear gaps in the current HF content on social media, which health organizations can fill, using information in evidence-based practice guidelines and targeting both patients and providers, although under separate cover. Health care providers have adopted social media as a way to gather information but are more skeptical of its use in their own communications with patients, which may be the reason that content from health care providers and their organizations are limited. Because the literature on the effectiveness of social media as a tool for health information dissemination is mixed, any social media campaigns should have a rigorous evaluation plan to continually assess this evolving digital communications strategy. The effectiveness of social media for dissemination of information to the public must also be demonstrated to show whether there is value to the provider in assuming the legal or liability risks of these communication strategies.

Acknowledgments

This project was funded by AHRQ grant 5-R18-HS-021953-03 (PI Hand). The views presented here are those of the authors and not necessarily AHRQ. The authors acknowledge the input of an expert advisory group for this project consisting of: Phyllis Naragon, MA; Toni Kuehneman, RD, LDN; Kimberly Stitzel; Deirdra Breakenridge; Linda Snetselaar, PhD, RD, LD, FAND; Esther Myers, PhD, RDN, FADA; Paula Ziegler, PhD, RDN; Neil Stone, MD; and Robert Gordon, MD. The authors also thank the members of DPBRN Oversight Committee Ellen J Anderson, MS, RD, and Jimin Yang, PhD, RD; and Academy staff member Constantina Papoutsakis, PhD, RD, for reviewing this manuscript prior to submission.

Conflicts of Interest

Rosa K Hand, Taylor M Wolfram, and Jenica K Abram work for the Academy of Nutrition and Dietetics, which may have a financial interest in the Evidence Analysis Library discussed here.

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Abbreviations

AHA: American Heart Association
AAFP: American Academy of Family Physicians
CHF: congestive heart failure
EBNPG: Evidence-Based Nutrition Practice Guideline
EMR: electronic medical record
HF: heart failure
LVHF: Health Insurance Portability and Accountability Act
HIPAA: left ventricular heart failure
RDN: registered dietitian nutritionist

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Edited by G Eysenbach; submitted 28.03.16; peer-reviewed by T Getchius, N Allen, A Roundtree; comments to author 05.07.16; revised version received 11.08.16; accepted 24.10.16; published 15.11.16.

Please cite as:
Hand RK, Kenne D, Wolfram TM, Abram JK, Fleming M
Assessing the Viability of Social Media for Disseminating Evidence-Based Nutrition Practice Guideline Through Content Analysis of Twitter Messages and Health Professional Interviews: An Observational Study
J Med Internet Res 2016;18(11):e295
URL: http://www.jmir.org/2016/11/e295/
doi:10.2196/jmir.5811
PMID:27847349

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Original Paper

Patients' Need for Tailored Comparative Health Care Information: A Qualitative Study on Choosing a Hospital

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Abstract

Background: The Internet is increasingly being used to provide patients with information about the quality of care of different health care providers. Although online comparative health care information is widely available internationally, and patients have been shown to be interested in this information, its effect on patients' decision making is still limited.

Objective: This study aimed to explore patients' preferences regarding information presentation and their values concerning tailored comparative health care information. Meeting patients' information presentation needs might increase the perceived relevance and use of the information.

Methods: A total of 38 people participated in 4 focus groups. Comparative health care information about hip and knee replacement surgery was used as a case example. One part of the interview focused on patients' information presentation preferences, whereas the other part focused on patients' values of tailored information (ie, showing reviews of patients with comparable demographics). The qualitative data were transcribed verbatim and analyzed using the constant comparative method.

Results: The following themes were deduced from the transcripts: number of health care providers to be presented, order in which providers are presented, relevancy of tailoring patient reviews, and concerns about tailoring. Participants' preferences differed concerning how many and in which order health care providers must be presented. Most participants had no interest in patient reviews that were shown for specific subgroups based on age, gender, or ethnicity. Concerns of tailoring were related to the representativeness of results and the complexity of information. A need for information about the medical specialist when choosing a hospital was stressed by several participants.

Conclusions: The preferences for how comparative health care information should be presented differ between people. "Information on demand" and information about the medical specialist might be promising ways to increase the relevancy and use of online comparative health care information. Future research should focus on how different groups of people use comparative health care information for different health care choices in real life.

(J Med Internet Res 2016;18(11):e297) doi:10.2196/jmir.4436

KEYWORDS

patients; decision making; choice behavior; qualitative research; quality of health care; hospitals

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Introduction

The Internet is increasingly being used to provide patients with information about the quality of care of different health care providers [1]. The main philosophy behind this quality information—also known as comparative health care information—is that it enables patients to make well-informed health care choices. In health care systems where patients have the right to choose their own providers, quality information can support patients in selecting the best providers and patients can thereby stimulate health care quality improvement [2]. In addition, the information in itself is also thought to empower patients in becoming autonomous health care consumers [3].

Although comparative health care information is widely available internationally [4-7], and patients have been shown to be interested in this information [6], its effect on patients' decision making is still limited [6-10]. A systematic review by Faber and colleagues [6] showed that quality information influenced patients' health care provider choice in less than 5% of cases. Reasons why patients have been reluctant to embrace comparative health care information include unawareness of the availability of information, problems with timely access of the information, difficulty in understanding the complex information, and perceiving it as irrelevant [6,9]. Involving patients in developing comparative health care information is important in order to meet patients' information needs. A body of research has focused on patients' preferences for the content of quality information [11-16]. These studies revealed, for example, that patients value information on both technical and interpersonal quality [15], and that the importance attached to choice aspects differs between patients [14].

However, how information is presented can be as influential as what information is presented when making health care choices [17]. Hibbard and Peters [18(p414)] stated that "the challenge is not merely to communicate accurate information, but to understand how to present and target that information so that it is actually used in decision making." In their conceptual model, they described 3 process goals to enhance the use of comparative health care information: lowering the cognitive effort needed to process the information, making clear what a choice means for people in real life, and making information more salient by highlighting its meaning.

These 3 goals can be accomplished through several presentation strategies, of which we will address a few [18]. The cognitive effort can by reduced by providing a limited amount of information [17] and by using data displays that are easy to evaluate [18]. It has been shown that humans can process and use only a limited amount of information—approximately 4 to 6 aspects—when making choices [11,18,19]. Using displays that transform the information into an evaluative good/bad scale might help people in processing and understanding the information, such as ordering health care providers by performance from best to worse. However, patients' preferences concerning the number of, and order in which, health care providers have to be displayed on websites remain unclear.

Tailoring comparative health care information might contribute to all 3 goals [18]. Kreuter and Skinner [20(p1)] defined tailoring as "any combination of information or change strategies intended to reach one specific person, based on characteristics that are unique to that person, related to the outcome of interest" (p 1). Literature supports the effectiveness of tailored health information or interventions, for example, in the context of tailored communication for cancer patients or tailored interventions to promote health behavior [21-24]. For comparative health care information, tailoring could imply that patients are shown quality information about health care delivered to patients with comparable demographic characteristics. For example, only information that is about patients of comparable age or same ethnicity could be shown. Although the merits of tailoring information might be evident in some specific health care contexts, it is unclear how patients value tailored comparative health care information.

Our study aimed to explore patients' information presentation preferences as well as their values regarding tailored comparative health care information. Information about choosing a hospital for an elective surgery (ie, a total hip surgery) was used in this study as a case example. In the case of an elective surgery, people often have sufficient time to search for information and are able to make well-informed choices. The following research questions were addressed:

1. What are patients' preferences concerning the presentation of comparative health care information. More specifically, what are their preferences for the number of, and the order in which, health care providers are presented on websites showing comparative health care information?

2. What are patients' values regarding tailoring, such as presenting patient reviews of patient subgroups with comparable demographic characteristics (age, gender, or ethnicity)?

Methods

Design

This study was part of a larger research project in which we collaborated with the Dutch Federation of Patients and Patient Organizations (Nederlandse Patiënten en Consumenten Federatie; NPCF) in optimizing their website Consumentendezorg.nl. More specifically, the project focused on comparative health care information on total hip, knee, or cataract surgery. To answer the research questions, we performed focus groups with patients who underwent hip, knee, or cataract surgery and with members of an access panel of Netherlands Institute for Health Services Research (Nederlands instituut voor onderzoek van de gezondheidszorg; NIVEL). The focus groups took place in March 2010 at NIVEL. Each session lasted approximately 2 hours, was facilitated by the same team of investigators (EB moderator; NZ secretary), and followed a structured interview protocol. Participants received a €15 gift voucher and a summary of the main findings.

Recruitment of Participants

Participants were recruited in 2 ways. First, as part of the larger research project, we posted calls on websites of patient organizations for orthopedic patients and patients with eye disorders, on websites of Dutch associations for senior citizens, and on the website of the NPCF. Respondents to a questionnaire

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that was part of the research larger project could also enroll themselves in this study by reporting their interest at the end of the questionnaire [13]. Via this route, 56 patients were included.

We anticipated that 56 potential participants would not be enough to reach saturation; therefore, we also invited 139 members of the NIVEL "Insurants Panel" by mail. The Insurants Panel is an access panel installed and managed by NIVEL and consists of a cohort of insurants from one of the biggest Dutch health insurers. The aim of the panel is to gather information on patients' experiences with, and expectations of, health care in general and their health insurer in particular. Members were recruited for the panel through an announcement in the magazine of the health insurer and by calling them and asking them to join the panel. Compliance with privacy regulations was approved by the Dutch Data Protection Authority (nr. 1309664). For this study, we selected 139 members who were 40 years or older and who had a travel time of less than 45 minutes to the interview location. We used this age criterion because this group would most likely have experience with choosing a hospital. Also, the case example of choosing a hospital for total hip surgery is less relevant for younger people.

Participation in the focus groups took place on a voluntary basis and informed consent of the participants was obtained. Ethical approval of the study was not required because research using interviews that are not taxing or hazardous for participants (ie, the once-only answering of questions that do not constitute a serious encroachment on the participant) is not subject to the Dutch Medical Research Involving Human Subjects Act (Wet medisch-wetenschappelijk onderzoek met mensen).

Interview Guide

The focus group discussion was divided into 2 rounds addressing the different research questions (see Textbox 1). The first part of the interview focused on participants' preferences for information presentation, whereas the second part focused on participants' values regarding presenting comparative health care information about patients with comparable demographic characteristics (ie, tailoring). The website of the NPCF was used as an illustration during the second part of the meeting. The example provided comparative health care information for total hip and knee surgery. The information consisted of orthopedic patients' experiences with the conduct of medical specialists (ie, orthopedists), conduct of the nurses, and information on medicines. Distance to the hospital, the number of hip replacements per year, and the number of knee replacements per year were also displayed. We showed 2 Web pages: one displaying comparative health care information (in columns) for all hospitals within 50 km distance (in rows), and one displaying comparative health care information (in rows) for 3 hospitals (in columns).

Textbox 1. Interview protocol for focus groups.

General Introduction

- Introduction of 2 researchers (moderator and secretary); background information about study; announcements

Part 1

Introduction Part 1

- Introducing oneself and previous experiences with choosing a hospital: "What is your experience with choosing a hospital?"
- Introducing test case (choosing a hospital for a total hip replacement surgery)
- "Imagine that you have to select a hospital for hip replacement surgery. Would you use a website, such as consumentendezorg.nl, that provides comparative information?"
- "Suppose you are using this website. Would you prefer to compare different hospitals and make a choice or would you prefer to see quality information about only one hospital?"
- "How many hospitals would you prefer to see quality information about?"
- "Would you like to see hospitals ranked in alphabetical order, on distance, from good to bad, or ranked according to another criterion?"

Part 2 (the website consumentendezorg.nl of the NPCF was used as an illustration)

Introduction Part 2

- "Suppose that, when you are choosing a hospital for a hip replacement surgery, you can fill in your age on the website. For example, 65 years or older. By doing this, you receive an overview of quality information of hospitals, based on reviews of patients of the same age. What is your opinion about this kind of information?"
- "Suppose that you can fill in information about your gender. By doing this, you receive quality information of hospitals based on reviews of people with the same gender. What is your opinion about this kind of information?"
- "Are there other subgroups of which you would like to see quality information of hospitals?" (When ethnicity, educational level and health status were not mentioned: "What do you think, for example, of quality information of hospitals based on reviews of people with a comparable (high or low) level of education, with the same ethnical background, or with a comparable (low or high) health status?")

Conclusion

- After seeing more information about the website consumentendezorg.nl, would you make use of this website?
- Summary of the group discussion

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Analysis

Sessions were audiotaped and notes were taken with the participants' consent. All audiotaped sessions were transcribed verbatim. The constant comparative method, one of the core analysis techniques in the grounded theory approach [25], was used to analyze the data. First, the transcripts of the focus groups were read and open-coded by 2 researchers independently (NZ and EB). The coded transcripts were compared and a code tree was created. Next, all focus groups were coded using this code tree by the same researchers. The codes were compared; where differences in themes occurred, consensus was reached through discussion with a third researcher (MH).

Results

Participants

A total of 38 people participated in 4 focus groups (see Table 1). Participants in focus groups 1 and 2 were patients that underwent or had to undergo total hip, total knee, or cataract surgery. Participants of focus groups 3 and 4 were members of the NIVEL Insurants Panel. In the fourth focus group, no new information was gathered (ie, data saturation was reached).

Table 1. Characteristics of participants.

Characteristic	Group 1 (n=7)	Group 2 (n=11)	Group 3 (n=9)	Group 4 (n=11)	Total (N=38)
Gender, n (%)					
Men	3 (43)	5 (46)	6 (67)	7 (64)	21 (55)
Women	4 (57)	6 (56)	3 (33)	4 (36)	17 (45)
Age (years), mean (SD)	64.0 (7.3)	66.1 (10.9)	70.1 (6.7)	64.5 (12.4)	66.2 (9.9)
General health status, n (%)					
Excellent	0 (0)	1 (9)	0 (0)	1 (9)	2 (5)
Very good	1 (14)	2 (18)	2 (22)	1 (9)	6 (16)
Good	5 (71)	5 (46)	6 (67)	8 (73)	24 (63)
Fair	1 (14)	3 (27)	1 (11)	1 (9)	6 (16)
Poor	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Education,[a] n (%)					
Low	0 (0)	0 (0)	0 (0)	1 (9)	1 (3)
Average	3 (43)	4 (36)	3 (33)	3 (27)	13 (34)
High	4 (57)	7 (64)	6 (67)	7 (64)	24 (63)
Use of Internet, n (%)					
No use of Internet	1 (14)	0 (0)	0 (0)	1 (9)	2 (5)
Monthly	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Weekly	0 (0)	2 (18)	1 (11)	0 (0)	3 (8)
Daily	6 (86)	9 (82)	8 (89)	10 (91)	33 (87)

[a] Low: primary school, lower level of secondary school; average: lower vocational training, intermediate vocational training or higher level of secondary school; high: higher vocational training or university.

The mean age of the 21 men and 17 women was 66.2 (SD 9.9) years, ranging from 46 to 95 years. The majority of the participants (63%, 24/38) graduated from higher vocational training or had an academic degree, which is not representative of the general population. The cohort was also fairly healthy; only 16% (6/38) perceived their general health status to be fair. Most participants used the Internet on a daily basis (87%, 33/38). Only 2 participants had never used the Internet. Of the participants in groups 1 and 2, 10 underwent total hip surgery, 7 had total knee surgery, and 4 had cataract surgery. Two participants were on a waiting list to undergo one of these surgeries. Of the members of the Insurants Panel, 12 participants underwent an elective surgery at least once in their life, of which 1 participant underwent total knee surgery and 1 had cataract surgery. Six participants had experience with choosing a hospital for consulting a medical specialist or outpatient treatments. Only 1 participant had no experience with choosing a hospital.

Themes

The following main themes emerged from the analysis: (1) number of health care providers to be presented, (2) order in which health care providers are presented, (3) relevancy of tailoring patient reviews, and (4) concerns about tailoring. Although we presented the choice of a hospital for hip surgery as a case example, the discussion revolved around choosing a hospital in general. Therefore, we present the results for all participants together without distinguishing between participants based on the type of surgery they had or the method of recruitment.

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Number of Health Care Providers

Most participants preferred a website with an overview of information about different health care providers, rather than information about one specific hospital only. Concerning the number of providers to be presented, different preferences emerged. Some wanted to compare approximately 5 providers, sometimes supplemented with a more specialized provider. Most of these participants wanted to select these providers based on the distance from their home to the hospital. On the other side, one participant preferred to compare all possible providers including providers from abroad. Others preferred to decide for themselves how many providers are shown:

> *So I think about five or six. That I think will be sufficient. At a certain point it will become a little too much.* [female, group 2]
>
> *This website is limited to hospitals in the Netherlands. There are also <hospitals> in Germany, especially in a number of cities. A link to their websites would be useful if they exist.* [male, group 1]
>
> *Let me choose a number of hospitals, from a very long list, which I want to include in my comparison.* [male, group 2]

The complexity of the disease/surgery, the clarity of the overview, and the results of the search could influence the preferred number of providers to be presented:

> *If I would need a less standard surgery, I would search harder than when I have the feeling: a hip is a pretty routine surgery.* [female, group 2]
>
> *I would compare five hospitals and if the results offer little choice, expand it to 10 or more.* [male, group 3]

Order of Health Care Providers

As for the order of health care providers, participants also varied in their preferences. Some liked to see providers ordered from short to long distance, a few preferred to see providers ordered from good to bad on a specific quality criterion, whereas others wanted to decide themselves how providers were ordered:

> *I would prefer distance.* [female, group 3]
>
> *Hospitals ordered from 10 to 0...so from good to bad.* [male, group 4]
>
> *I think there should be a choice in order, you must be able to decide if you prefer an alphabetical order, or geographical, or ordered on quality of this or that.* [male, group 4]

Relevancy of Tailoring Information

We asked participants what they thought about only presenting patient reviews that were given by patients of comparable age, gender, or ethnicity. Three different opinions were identified. The majority did not prefer subgroup-specific presentation of patient reviews for any of these characteristics:

> *Why would the opinion of a seventy-year-old patient be more important to me compared to an opinion of a 40-year-old? There are so many essential factors.* [male, group 1]
>
> *Do I find it important that a 60-year-old patient with a Turkish background is satisfied about their hip replacement or a 50-year-old Dutchman, I don't think it matters.* [male, group 1]

Some welcomed subgroup-specific information in all cases and a minority would prefer subgroup-specific information only in the case of a significant effect:

> *The chance of complications increases when you are older; more chance of infections and this [older] patient will probably give a review on how the hospital dealt with this.* [male, group 2]
>
> *If there is a significant effect, it could be interesting to show it. But if research revealed that there is no significant effect, there is no need to present it.* [female, group 2]

Other participants were interested in information differentiation if differences were related to physical differences or the reason for the surgery:

> *[Regarding differentiation on gender] If it is anatomically a different kind of hip, but I think it is the same.* [female, group 1]
>
> *I would be more interested in whether someone had a hip replacement after a trauma or whether surgery was performed because of a degenerative process.* [female, group 2]

Concerns of Tailoring

Several participants were concerned about the representativeness of information when only subgroup-specific information would be provided. These concerns were mainly related to the smaller sample sizes that result from tailoring, and a few participants felt that the results could be biased:

> *The numbers will decrease. If you split this information, what is then the value?* [male, group 1]
>
> *I don't see the relevance of age. You only get a more limited answer.* [male, group 3]

For some participants, it would be too complicated to present subgroup-specific information on websites:

> *For goodness' sake, keep the website as simple as possible.* [male, group 3]

Level of Information

It is important to note that the need to compare medical specialists instead of hospitals was a recurring topic discussed in all 4 groups. Most participants wanted to choose a particular specialist instead of a hospital:

> *The problem with this information is that there's a lot of information on results of hospitals and specialties overall, but there's no information about specialist A or specialist B.* [male group 1]

The specialist did not form the basis for all participants, however, as one participant made clear:

> *No, it's not about the specialist. It's about the hospital. There you will find a certain specialism. It depends on your abilities, the distance, your physical*

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condition, the type of disease you have. So of course you will look at hospitals. [male, group 4]

Discussion

Principal Results

Our qualitative study focused on patients' information presentation preferences and values regarding tailored comparative health care information. Comparative health care information about total hip surgery in hospitals was used as a case example. Participants' preferences differed concerning how many and in which order health care providers should be presented on a website. Most participants had no interest in tailored information based on age, gender, or ethnicity. The need for more information about the medical specialist when choosing a hospital was stressed by several participants.

Comparison With Prior Work

Previous studies have shown that the order of information presentation can greatly influence the attention people pay to particular parts of that information [26]. As for the effect of ordering health care providers in comparative health care information, research of Damman and colleagues [27] showed that ordering providers alphabetically resulted in more effective use of the information (eg, respondents chose the top-performing provider more often) than ordering on performance. However, other studies showed positive effects of ordering providers on performance [28,29]. These differences might reflect, as we found, that people differ in their preferences concerning the order in which health care providers should be presented on websites.

Although tailoring might enhance the relevance of online comparative health care information, our findings showed that the majority of participants had no interest in tailored information. That is, they did not value reviews of patients of the same age, gender, or ethnicity. These results are not in line with our expectations. Earlier studies about health care choices showed that patients, in general, prefer information about people comparable to themselves in terms of age, socioeconomic status, or geographic area [11]. For now, we can only speculate about these contradictory findings. Perhaps patients do not see the added value of tailored comparative health care information because the disadvantages (eg, more complicated information and less patient reviews available) outweigh the advantages (eg, more personally relevant information). Some participants were interested in information provided by patients with comparable preconditions before surgery. Maybe they felt that disease characteristics are more related to the reported quality indicators than demographics. As tailoring entails presenting information according to characteristics that are related to the outcome of interest [20], it should be determined in future research whether tailoring comparative health care information based on disease characteristics (eg, health status before surgery) is perceived as more relevant.

One comment persistently made by several participants was that they wanted information about the medical specialist rather than the hospital. The importance of the medical specialist in health care decision making [13,30] and the need for information about specialists' interpersonal and communication skills and expertise [14] is also revealed in other research. The availability of online doctor-rating websites is growing and these websites have gained popularity among patients internationally [31-34]. Although "doctor bashing" is a concern regarding these websites, most studies show that these websites provide favorable ratings of doctors [31,32] and evidence exists that these ratings correlate with survey measures of patient experiences [35,36]. Other drawbacks of these rating websites are that reviews of doctors are often based on only a few reviews [37], and privacy issues of individual doctors are at stake. Drawbacks of public disclosure of success rates of medical specialists also exist, for example, motivating surgeons to avoid high-risk patients and unjustly damaging specialist's reputations. Future research should examine the effects of presenting comparative health care information for individual health care providers instead of hospitals on the use of the information by patients. Also, the entitlement of patients to access this relevant information should be carefully balanced against potential side effects.

This study focused on choosing a hospital in the case of an elective surgery that was not life threatening. It could be that preferences for information presentation are different when people have to choose a health care provider in a more acute and/or life-threatening situation. In acute situations, people have fewer or no opportunities to find and process comparative health care information. This stresses the importance of making information as easy to understand as possible. It has also been shown that people have different information needs depending on the disease or condition [13,38]. Whether preferences for how information should be presented also differ among diseases is yet unknown.

Implications for Website Designers

Our results have implications for website designers. First, we recommend involving the intended users in the development of comparative health care information. Second, it is important to limit the amount of information that is presented. Finally, participants expressed different information presentation preferences, information needs, and values regarding tailored comparative health care information. This emphasizes the need for flexible, user-friendly websites, or "information on demand." A review by Vaiana and McGlynn [39] also mentioned that websites need to be responsive to different users and that the "one-size-fits-all" approach needs to be challenged. By providing information on demand, patients themselves can have an active role in the health care information that is supplied [39]. Patients can select, for example, how many health care providers are shown, how providers are ordered, or which quality aspects are shown. Seeing tailoring in a broader perspective rather than in the classical definition in which information is tailored to someone's unique characteristics, providing information on demand, or tailoring information presentation might help to meet patients' information needs and increase the relevancy of online comparative health care information.

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Limitations

The strength of our study lies in the high number of participants in our qualitative research and the richness of opinions expressed by these participants. We used the interactional nature of focus groups to unravel participants' opinions [40]. A limitation of our study is that participants were not representative of the general population. Participants were highly educated, which might be reflected in the expressed concerns about representativeness of data and the preference for tailored information only in the case of significant differences between subgroups. These 2 constructs (ie, representativeness and significant differences) might not come so easily to mind of people with a low education. Although we did not ask for their ethnic background, most participants appeared to be of Dutch origin. We do not know whether the preferences of ethnic minorities are different, especially when it comes to tailoring information based on ethnicity. Second, we only analyzed participants' perceptions about online comparative health care information. It is well known that a person's perception may not align with his/her actual behavior in practice. Although almost all participants had experience with choosing a hospital, most participants were not facing an actual hospital choice for hip surgery at the time of the focus groups. They either already had undergone this surgery or had no experience with hip problems. From the decision-making literature, it is known that people often have difficulties anticipating their preferences should their needs change [41]. The theory of constructed preference posits that preferences are often constructed in the process of deciding [42]. Third, preferences of people appear to be sensitive to the way a choice is described or what information is provided [18]. This means that the content and presentation format of the NPCF website might have influenced the thoughts and ideas of participants in some way. These limitations have to be taken into account when interpreting our results. It also stresses the need for research that investigates in real life how people use comparative health care information in health care choices.

Conclusions

The preferences for how comparative health care information should be presented differ between people. This is true for how many and in which order health care providers should be presented and whether the information should be tailored based on demographic characteristics. This reflects the challenges designers of online comparative health care information are facing. Providing possibilities for information on demand and showing information about the medical specialist might be promising ways to increase the relevancy of online comparative health care information for patients. It is also important to examine in real life how different groups of people use comparative health care information in different health care choices.

Acknowledgments

We thank all participants for sharing their experiences and thoughts with us. The Netherlands Organisation for Health Research and Development (ZonMw) funded this study.

Conflicts of Interest

None declared.

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Abbreviations

NIVEL: Nederlands instituut voor onderzoek van de gezondheidszorg [Netherlands Institute for Health Services Research]
NPCF: Nederlandse Patiënten en Consumenten Federatie [Federation of Patients and Patient Organizations]

Edited by G Eysenbach; submitted 17.03.15; peer-reviewed by A Moser, M Emmert, U Sander; comments to author 15.08.15; accepted 15.10.16; published 28.11.16.

Please cite as:
Zwijnenberg NC, Hendriks M, Bloemendal E, Damman OC, de Jong JD, Delnoij DMJ, Rademakers JJD
Patients' Need for Tailored Comparative Health Care Information: A Qualitative Study on Choosing a Hospital
J Med Internet Res 2016;18(11):e297
URL: http://www.jmir.org/2016/11/e297/
doi:10.2196/jmir.4436
PMID:27895006

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Original Paper

How Professionals Share an E-Care Plan for the Elderly in Primary Care: Evaluating the Use of an E-Communication Tool by Different Combinations of Professionals

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Abstract

Background: Home-dwelling elderly patients with multimorbidity are at risk of fragmentation of care because of the many different professionals involved and a potentially unclear level of communication. Multidisciplinary communication seems to occur incidentally. Mutual feedback is needed for a professional team to provide consistent care and adequate support to the patient system. eHealth technology can improve outcomes.

Objective: The aim of this study was to evaluate the use of a tool, Congredi, for electronic communication by professionals for the care of home-dwelling elderly patients.

Methods: The research group was recruited through general practices and home care organizations. Congredi, a tool designed for multidisciplinary communication, was made available for professionals in primary care. It consists of a care plan and a communication channel (secure emailing). Professionals opened Congredi records for elderly patients who had 2 or more professionals involved. The records were the unit of analysis. Data were gathered from the Congredi system over a period of 42 weeks.

Results: An inclusion rate of 21.4% (203/950) was achieved; nearly half of the participants were nurses. During the study, professionals were active in 448 patient records; female professionals were prevalent. In the patient records, 3 types of actions (care activities, emailing, and process activities) were registered. Most activities occurred in the multidisciplinary records (mean 12.2), which had twice the number of activities of monodisciplinary records (6.35), and solo records had a mean of 3.43 activities. Most activities were care activities (mean 9.14), emailing had a mean of 0.89 activities, and process activities had a mean of 0.29.

Conclusions: An e-communication tool (Congredi) was usable for improving multidisciplinary communication among professionals. It even seemed to yield results for 40% of the professionals who used the e-care plan on their own. The content of the tool provided an active communication practice, with significant increases observed in the actions that must be shared for the effective coordination of care.

(J Med Internet Res 2016;18(11):e304) doi:10.2196/jmir.6332

KEYWORDS

eHealth; primary care; elderly; email; nurses; general practitioners; medical informatics; Internet

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Introduction

Worldwide the population of people older than 60 years will grow from 12% to 22% between 2015 and 2050 [1]. People over the whole world are living longer and live in their own homes as long as possible [1]. Many of the elderly will, at some point in time, need multidisciplinary professional care as a result of function loss and decreased self-care capabilities because of multimorbidity and problems in the physical, psychological, and social domains [2]. This group is at risk for the timely signaling of health risks, for aligning treatments, and for coordinating their care [2-4]. In the Netherlands in 2007, approximately 500,000 home-dwelling older persons with increased risk were identified; this is approximately a quarter of the population aged 65+ years [3]. This number is expected to increase to 1 million in 2030 in the Netherlands [5]. Among the older persons, 80% have been in recent contact with their general practitioner and half receive professional care [5]. A Dutch study shows that approximately 300,000 older persons are admitted to hospitals every year, often with nonexistent or poor multidisciplinary handover information [6]. A substantial part (20%-32%) of these hospital admissions seem to be avoidable by improving the continuity and organization of care [7]. However, because of the multidisciplinary character of care for this patient group, the care tends to be fragmented, and professionals seem to be unaware of each other's involvement [3,8,9].

The quality of primary care could improve if it were less fragmented [10]. Wagner's chronic care model (CCM) forms a theoretical base for multidisciplinary collaboration. It focuses on a well-informed, active patient system collaborating with a prepared, proactive, and professional team to align treatment in multidisciplinary practices [2,11]. Gee et al [12] found that with the recent advancements in technology, adding eHealth options can strengthen the CCM. They developed an eHealth Enhanced Chronic Care Model (eCCM) and added a complete feedback loop between the patient system and professional team (Figure 1) [12,13]. This complete feedback loop encompasses productive interactions between the patient system and professionals about the data and information on which they can reflect from the perspectives of knowledge and wisdom by using eHealth technologies. Collaboration between the patient system and the professional team is the basis of the model, for which effective collaboration among the professionals is a precondition. Continuity and alignment of care are improved by effective communication among professionals [14,15].

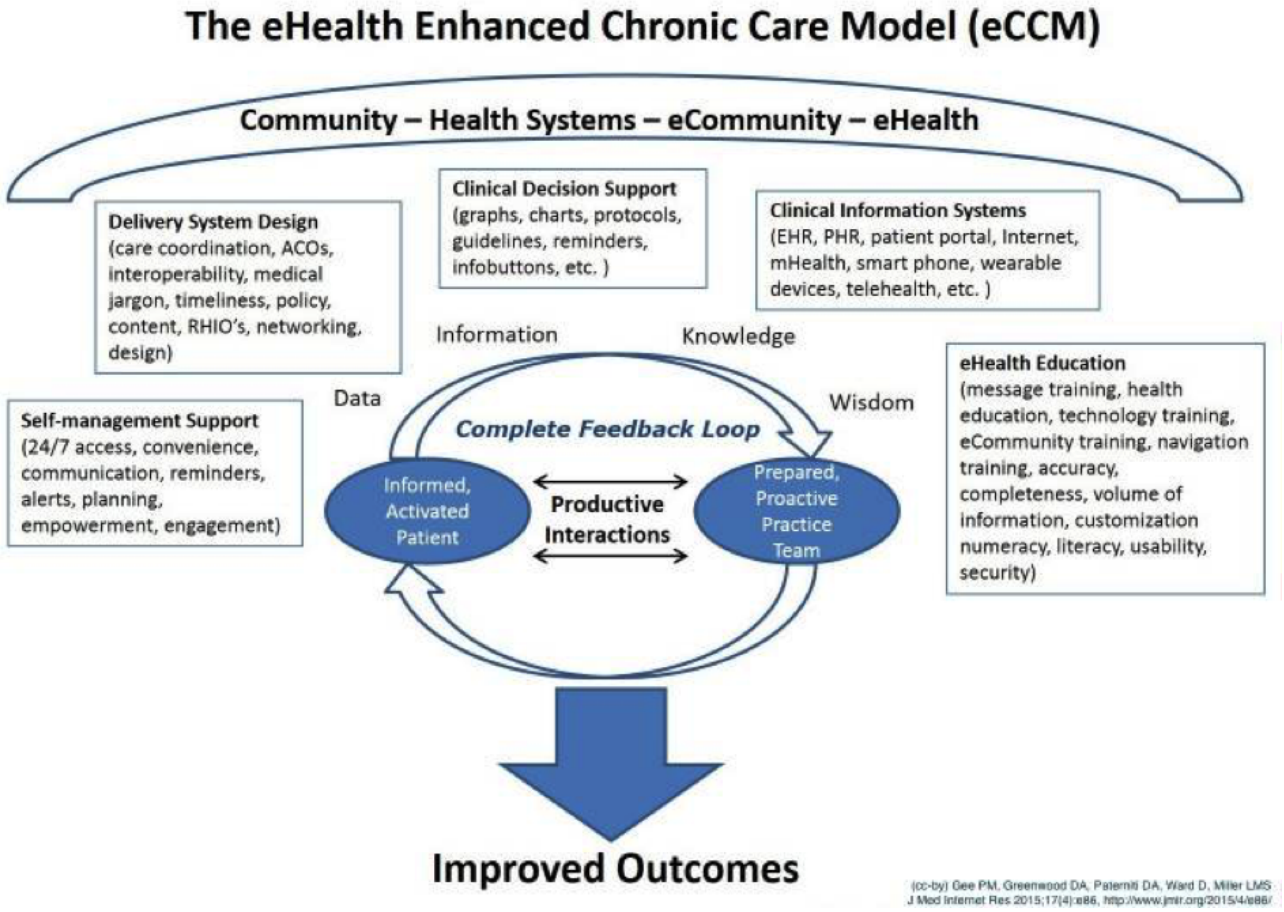
Multidisciplinary collaboration in primary care is aimed at monitoring health risks and developing care plans; it is, however, unclear how such collaboration takes place [2]. The general practitioner or district nurse indicates the increasing needs of the elderly and makes an individual care plan. Usually, there are casual contacts among the involved professionals, and the contact frequency varies per case [15]. Some quantification was found in a report from 2010, which showed that for patients with diabetes and chronic obstructive pulmonary disease, multidisciplinary consultation occurs approximately once a month [10]. Communication among professionals is hampered by busy agendas, and if such contacts do take place, they are often incidental, with information being exchanged orally and not shared with others involved.

To improve the coordination of care for elderly and chronically ill patients, eHealth tools show potential, such as the sharing of care plans and online health communities [12,16-18]. Health care providers in The Hague realized this and started experimenting with a communication tool developed by a general practitioner, Congredi (Convenient Fastguide BV) in 2012 [19]. They surmised that the coordination of care would benefit if multidisciplinary communication increased. In 2013, a feasibility study of Congredi was performed on a sample in 2 neighborhoods. This showed that Congredi lived up to the original functional specifications and that professionals were motivated to continue exploring the use of Congredi. Also, a larger number of professionals than expected took part because of active early adopters who inspired their colleagues (41 instead of the expected 15). They were motivated to continue in cocreation as they had important requirements to be included in the new version of the tool and the supplier was perceived as cooperative [20]. An important requirement for these professionals was a link to their own administration system; adjustments in this area were made in the next release of Congredi, which was used for this study. The question was then raised whether an electronic communication tool for professionals could improve multidisciplinary communication and whether this would affect the integration of care. A precondition is that such a tool is actually used by professionals.

The aim of this study was to evaluate the use of a tool for electronic communication and coordination (Congredi) by professionals in the care of home-dwelling elderly patients.

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Figure 1. The eHealth Enhanced Chronic Care Model. ACO: accountable care organizations; RHIO: regional health information organization; EHR: electronic health record; PHR: electronic patient health record or patient portal.



Methods

Design

In this descriptive study, data were gathered from the Congredi system over a period of 10 months (42 weeks) and analyzed.

The following research questions were addressed:

1. How many and which professionals are linked to Congredi records?

2. How many and which actions are performed by the professionals in Congredi records?

3. Is there a relationship between the combination of professionals in the care plan and performed actions?

Intervention

Congredi is a communication tool that was designed for multidisciplinary communication among professionals in primary care [19]. It is an easily accessible Web-based application and is compatible with existing health information technology but can also function as a stand-alone solution. It can be used on mobile phones, tablets, and computers. Congredi consists of a care plan that is usable at any moment in time. Within the care plan tasks can be delegated and feedback is received immediately. In addition, there is a communication channel (secure emailing) so the professionals can communicate asynchronously and at their own convenience.

To start Congredi, a professional opens a record for a patient and starts making a care plan, which is based on the patient-centered SFMPC (social, functional, mental, physical, and communication) domain model [8]. The professionals involved with this patient can be invited to link and can thus view the record, including the shared care plan. The activities that the professionals perform within the patient records are grouped into 3 categories. First, there are care activities, which consist of the following: (1) assessment of the current problems, structured by applying colors to current problems and automatically organizing according to SFMPC domain (Figure 2); (2) care actions, actions needed to address the problems of the patient (Figure 3); (3) observations of the care process and evaluation; and (4) care action adaption is performed after evaluating the care actions. Second, there is communication by secure emailing for sending and receiving emails to colleagues within Congredi (Figure 4). The content of the emails is only visible to those directly involved. Third, some process activities are also registered, namely, (1) becoming a coordinator, as it is possible to change the person who coordinates the record; a general practitioner occasionally starts the record and later "hands over" to the nurse; and (2) inviting involved professionals to link, which can occur at different moments in time during the care process. Congredi operates alongside the monodisciplinary electronic health records of the diverse professionals; it makes patient-related communication about current multidisciplinary problems possible.

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Because of multidisciplinary communication, all professionals can update the care plan as the care develops. Thus, professionals are informed about the actions of their colleagues. One professional coordinates the record and is responsible for linking other professionals.

Figure 2. Congredi problem inventory: problems listed in text and in the social, functional, mental, physical, and communication (SFMPC) domains.

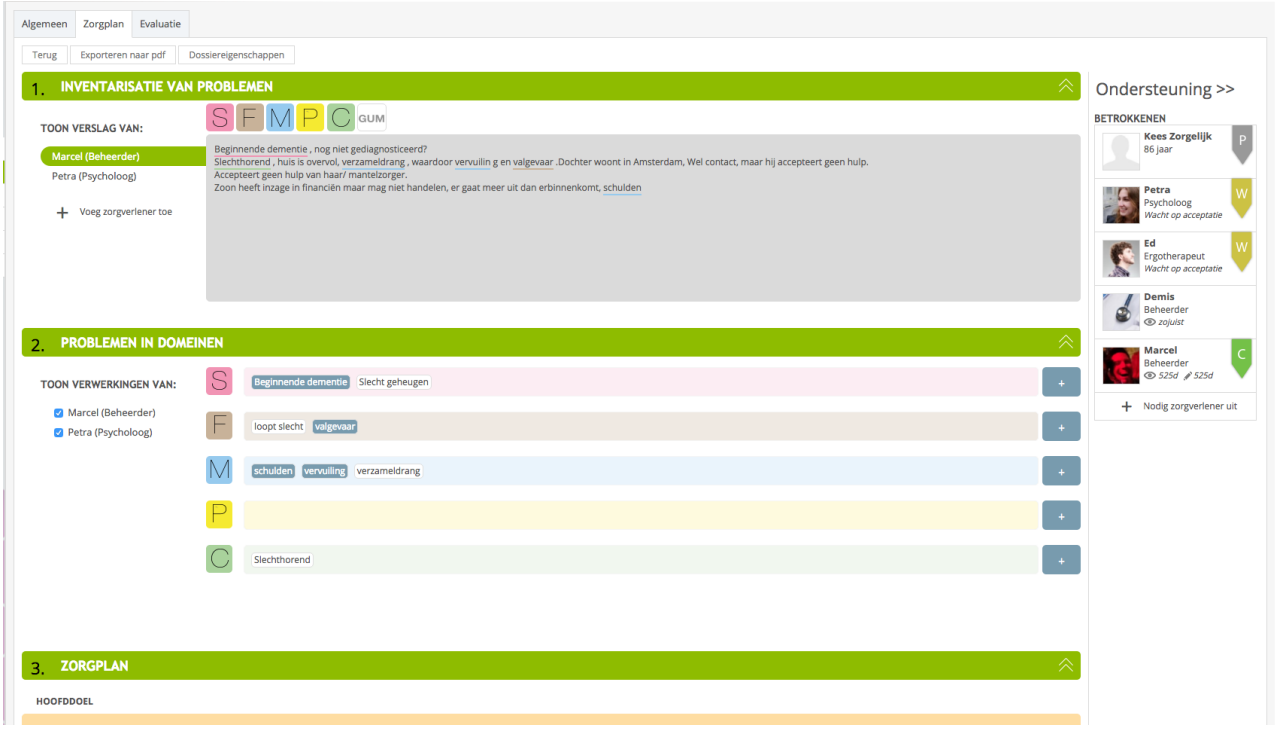
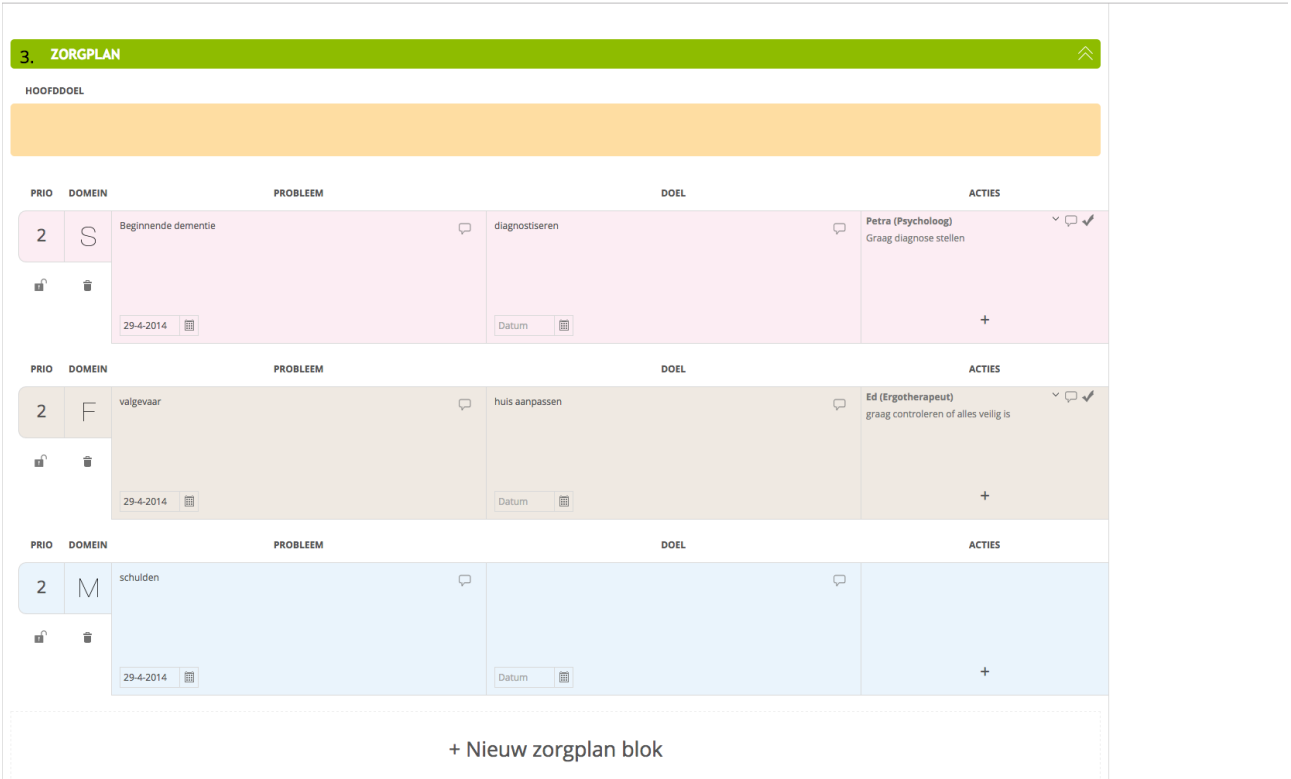
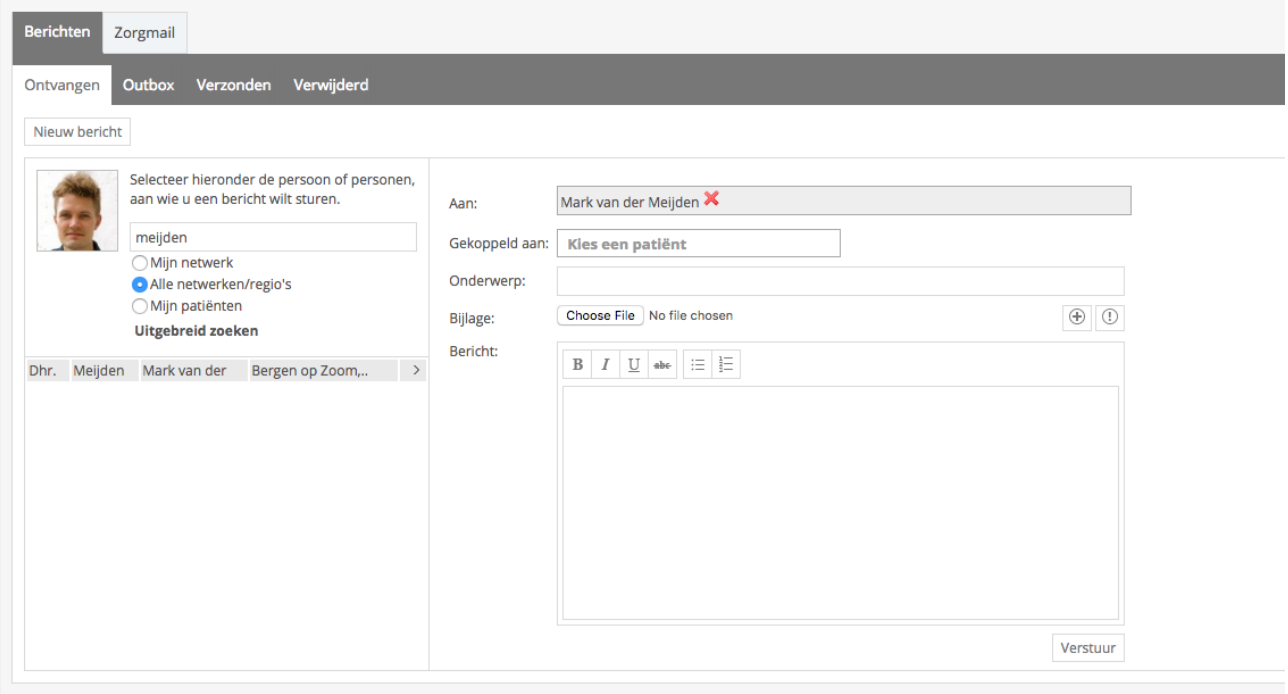


Figure 3. Congredi care plan: problems, aims and actions shown in social, functional, mental, physical, and communication (SFMPC) action blocks.



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Figure 4. Congredi email module: secure email for professionals about their patients.



Research Group and Recruitment Procedure

The intervention Congredi was introduced to facilitate multidisciplinary communication about mutual patients at any time and place that was convenient to each professional. For this study, all general practitioners (n=300) and home care organizations with district nurses (n=650 nurses) in The Hague region were approached to participate; digital media were used, and the directors of home care organizations were approached personally. Professionals entered the study by applying for access to Congredi via their managers; they were then able to log-in to Congredi and received a standard half-day training.

They were then able to open a Congredi record for each patient in their care. The criteria for the patients were that they were home-dwelling elderly patients with 2 or more professional health caregivers. Patients had to give permission to open a Congredi record and share their care plan with other professionals.

Various types of professionals could participate in Congredi. In this study, we distinguished 3 groups of professionals: nurses (N), general practitioners (G), and other professionals (O). Others could be physiotherapists, psychiatrists, geriatricians, social workers, and elderly consultants.

Variables and Measures

Data were retrieved from the Congredi system at the end of the observation period, after 10 months (42 weeks), to answer the following research questions:

1. How many and which professionals are linked to patient records?

2. How many and which actions are performed in care plans?

3. Which relationship exists between combinations of professionals and performed actions in patient records?

The following variables were measured: (1) characteristics of health care professional using Congredi, that is, demographic data (age, sex), discipline (general practitioner, nurse, other professional), and whether coordinator of patient record (yes or no); (2) characteristics of patients in Congredi, that is, demographic data (age, sex); (3) multidisciplinary combinations of health professionals in Congredi, namely, coordination of patient record, combinations of health care professionals linked in a patient record, and number of health care professionals linked to each patient record; and (4) activities performed by health care professionals in Congredi, that is, frequency of activities (care, email, and process activities) and period in which activities took place per record (number of weeks).

Statistical Analysis

The results were analyzed using IBM SPSS 20 (IBM Corporation). The unit of analysis is the Congredi record of a patient (patient record). The demographic statistics of the population are described in frequencies and percentages. Analyses of variance, including Bonferroni post hoc tests, were performed to examine mean differences between subgroups.

Results

Characteristics of Professionals and Patients

Of the 300 general practitioners and 650 nurses who were approached to participate, 21.4% (203/950) actually took part. Among the professionals, 75.9% (154/203) were female. The age group between 30-50 years was 49.3% (74/203).

Nearly half of the participating professionals were nurses (47.3%, 96/203); these included different types of nurses active in primary care, such as district nurses, case managers for dementia, and nurse specialists. General practitioners (19.2%, 39/203) and other professionals (33.5%, 68/203), including

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elderly consultants, physiotherapists, gerontologists, and social workers, were also active in Congredi.

In total, professionals opened 532 patient records. Each patient record had a coordinator; the coordinator was a nurse in 80% (423/532) of the patient records, a general practitioner in 16% (75/532), and other professionals in 4% (33/532).

In 84 records, no further action was taken. In the remaining 448 patient records, actions were taken. Within these records, more than half of the patients were female (63%, 282/448). The largest age group was 80-90 years (45.1%, 202/448), and 13.9% (62/448) of the patients were older than 90 years.

The number of weeks the professionals were active in Congredi varied: 37.9% (77/203) were active between 1 and 26 weeks and the rest were active between 27 and 42 weeks. A total of 32.5% (66/203) stopped within a week.

Combinations of Professionals and Level of Action in Patient Records

Several combinations of professionals (Table 1) were found to be active in patient records. “Active” was defined as taking 1 or more actions within a patient record. On the basis of the participation of professionals, 3 types of patient records could be distinguished. The first type is referred to as “solo” in which 1 professional was linked; 41.1% (184/448) of the records were solo records. The second type of patient record was “mono” in which at least 2 professionals of the same discipline were linked; 14% (63/448) were monodisciplinary records. The third type was named “multi” with professionals from different disciplines; 44.9% (201/448) were multidisciplinary records.

In the multidisciplinary records, a nurse’s participation was the most, that is, in 96.5% (194/201) of the records. This was followed by participation of general practitioners (81.6%, 164/201) and other professionals (36%, 73/201). Both the solo and monodisciplinary records consisted primarily of nurses (80.9%, 149/184 and 88.9%, 56/63, respectively). In the multidisciplinary records, the most frequent combination of professionals was general practitioner-nurse (GN 63.7%, 128/201), followed by the combination nurse-other professional (NO 18.4%, 37/201) and the combination general practitioner-nurse-other professional (GNO 14.4%, 29/201).

Activities Undertaken by Multidisciplinary Combinations in Patient Records

In the Congredi records, 3 types of professional actions (care activities, emailing, and process activities) were registered. Most activities occurred in the multidisciplinary patient records, with a mean number of 12.2 activities per record (Table 1). When professionals worked in monodisciplinary patient records, the mean number of activities was 6.35, and in solo patient records the mean number was 3.43.

Table 2 presents the relation between the activities performed in patient records (care, email, and process activities) and the multidisciplinary combinations of professionals who performed them. Multidisciplinarity was related to the level of activity.

Problem assessment, which takes place at the beginning of a care process, was found in 84.1% (169/201) of the patient records; in most cases it was performed once (53%, 107/201), with a mean number of 1.26. Care actions, which are planned on the basis of problem assessment, were registered in 72.6% (146/201) of the patient records; in nearly 50% (95/201), care actions occurred more than once (mean 1.72). Observations, which occur between evaluative notes during the care process, were registered in 97% (195/201) of the patient records, mostly in records in which nurses were active (mean 4.09). Care action adaption, which takes place in relation to the goal of the care process, was found in 70% (141/201) of the patient records (mean 2.07). Emailing was used in 31.4% (63/201) of the patient records (mean 0.89). Handing over coordination to a colleague was registered in 28.4% (57/201) of the patient records. Inviting involved colleagues to link occurred a mean 1.88 times, ranging from 1 to 8.

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Table 1. Combinations of health care professionals collaborating in patient records (N=448).

Category	Combination[a]	Combination, n (%)	Actions, mean	Actions, SD	Actions, minimum	Actions, maximum
Solo	Total	184 (41.1)	3.43	2.30	1	13
	G	23 (12.5)	1.91	1.20	1	7
	N	149 (80.9)	3.68	2.39	1	13
	O	12 (6.5)	2.40	1.14	1	5
Monodisciplinary	Total	63 (14.0)	6.35	3.78	1	22
	G	5 (7.9)	2.40	1.14	1	4
	N	56 (88.9)	6.64	3.79	2	22
	O	2 (3.2)	8.00	1.41	7	9
Multidisciplinary	Total	201 (44.9)	12.20	11.25	2	95
	GNO	29 (14.4)	21.21	14.07	7	54
	GN	128 (63.7)	9.66	7.38	2	45
	NO	37 (18.4)	15.03	15.89	4	95
	GO	7 (3.5)	7.77	2.99	3	11
Combination including	Total	201				
	G	164 (81.6)				
	N	194 (96.5)				
	O	73 (36.3)				

[a]G: general practitioner; N: nurse; O: others.

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Table 2. Activities in multidisciplinary patient records by different combinations of professionals.

Activities	Frequency or mean	Total (N=201), n (%)	GNO[a] 29 (14.4), n (%)	GN[b] 128 (63.7), n (%)	GO[c] 7 (3.5), n (%)	NO[d] 37 (18.4), n (%)	*P* value
Care activities							
Total care activities	Mean	9.14	15.79 (GN, GO)[e]	6.87 (GNO, NO)	4.86 (GNO)	12.62 (GN)	<.001
Problem assessment	Mean	1.26	1.90 (GN, GO)	1.06 (GNO, NO)	0.71 (GNO)	1.54 (GN)	<.001
	0	32 (15.9)	1 (3.4)	27 (21.1)	2 (28.6)	2 (5.4)	
	1	107 (53.2)	13 (44.8)	69 (53.9)	5 (71.4)	20 (54.1)	
	2 and 3	59 (29.4)	12 (41.4)	32 (25.0)	0 (0.0)	15 (40.5)	
	>4	3 (1.5)	3 (10.3)	0 (0.0)	0 (0.0)	0 (0.0)	
Care action	Mean	1.72	3.59 (GN, GO, NO)	1.31(GNO)	1.14 (GNO)	1.78 (GNO)	<.001
	0	55 (27.4)	1 (3.4)	45 (35.2)	2 (28.6)	7 (18.9)	
	1	51 (25.4)	4 (13.8)	34 (26.6)	2 (28.6)	11 (29.7)	
	2 and 3	70 (34.8)	12 (41.4)	39 (30.5)	3 (42.9)	16 (43.2)	
	>4	25 (12.4)	12 (41.4)	10 (7.8)	0 (0.0)	3 (8.1)	
Observations	Mean	4.09	7.24 (GN, GO)	3.21 (GNO, NO)	2.00 (GNO)	5.08 (GN)	.006
	0	6 (3.0)	0 (0.0)	5 (3.9)	1 (14.3)	0 (0.0)	
	1-3	124 (61.7)	11 (37.9)	92 (71.9)	6 (85.7)	15 (40.5)	
	4-6	35 (17.4)	6 (20.7)	18 (14.1)	0 (0.0)	11 (29.7)	
	>6	36 (17.9)	12 (41.4)	13 (10.2)	0 (0.0)	11 (29.7)	
Care action adaption	Mean	2.07	3.07	1.28	1.00	4.22	.07
	0	60 (29.9)	3 (10.3)	47 (36.7)	3 (42.9)	7 (18.9)	
	1	49 (24.4)	5 (17.2)	35 (27.3)	1 (14.3)	8 (21.6)	
	2 and 3	69 (34.3)	11 (37.9)	38 (29.7)	3 (42.9)	17 (45.9)	
	>4	23 (11.4)	10 (34.5)	8 (6.3)	0 (0.0)	5 (13.5)	
Emailing							
Emails sent	Mean	0.89	1.83	0.70	0.43	0.89	.13
	0	138 (68.7)	16 (55.2)	94 (73.4)	5 (71.4)	23 (62.2)	
	1	33 (16.4)	4 (13.8)	22 (17.2)	1 (14.3)	6 (16.2)	
	2 and 3	18 (9.0)	4 (13.8)	8 (6.3)	1 (14.3)	5 (13.5)	
	>4	12 (6.0)	5 (17.2)	4 (3.1)	0 (0.0)	3 (8.1)	
Process activities							
Becoming coordinator	Mean	0.29	0.31	0.32	0.14	0.19	.39
	0	144 (71.6)	21 (72.4)	87 (68.0)	6 (85.7)	30 (81.1)	
	1	56 (27.9)	7 (24.1)	41 (32.0)	1 (14.3)	7 (18.9)	
	2 and 3	1 (0.5)	1 (3.4)	0 (0.0)	0 (0.0)	0 (0.0)	
Invite involved professionals to link	Mean	1.88	3.28 (GN, GO, NO)	1.77 (GNO)	1.00 (GNO)	1.32 (GNO)	<.001
	0	15 (7.5)	0 (0.0)	9 (7.0)	1 (14.3)	5 (13.5)	
	1	74 (36.8)	5 (17.2)	43 (33.6)	5 (71.4)	21 (56.8)	
	2 and 3	95 (47.3)	13 (44.8)	71 (55.5)	1 (14.3)	10 (27.0)	
	>4	17 (8.5)	11 (37.9)	5 (3.9)	0 (0.0)	1 (2.7)	

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[a]GNO: general practitioner, nurse, and other professional.

[b]GN: general practitioner and nurse.

[c]GO: general practitioner and other professional.

[d]NO: nurse and other professional.

[e]The codes in parentheses (eg, GN, GO) indicate the groups with a significant mean score.

Discussion

Principal Findings

In this study, the use of a tool for electronic communication and coordination (Congredi) by professionals in the care of home-dwelling elderly patients was evaluated. The evaluation underscores the usability of Congredi for professionals in primary care because a large group of professionals (n=203) were active in 532 patient records. Three research questions were examined.

To answer the first question, "How many and which professionals are linked to Congredi records?" a total of 203 professionals were identified, at an inclusion rate of 21.4% (203/950). Nurses represented the largest discipline at approximately half of the sample, besides general practitioners, and various other disciplines.

The second question was "How many and which actions are performed in Congredi records?" To answer this question, the patient records were divided into 3 categories. Patient records in which professionals worked on their own were defined as solo records (184/448, 41.1%). When several colleagues of the same discipline were linked, this was considered a monodisciplinary record (63/448, 14.0%). The largest group involved colleagues from different disciplines; these were defined as multidisciplinary records (201/448, 44.9%). The highest level of activity was found in the multidisciplinary records (mean 12.2), but even in the solo records there was activity at a mean level of 3.43. The majority of the activities were care activities (mean 9.14; email had a mean of 0.89 and process activities 0.29). In care activities, the action that was performed most frequently was observations (mean 4.09), and other care activities (problem assessment, care action, and care action adaption) were found to be at a mean level of approximately 2. Emailing took place at a mean level of 0.89. Within the category of process activities, "inviting involved colleagues to link," which is a new action in the care process when using e-communication, took place at a mean level of 1.88. The action that was taken the least was "handing over coordination" (mean 0.29).

In answer to the third question, activity was found to increase with multidisciplinarity within the patient record. Most activities occurred in the multidisciplinary patient records, with a mean number of 12.2 activities per record (Table 1). When professionals worked in monodisciplinary records, the mean number was 6.35, and in solo records it was 3.43.

The conclusion is that Congredi is well used; there is significantly more activity when more disciplines are present in a record, and this is a prerequisite for effective care [21]. The results of this study therefore underscore the feasibility of Congredi to facilitate multidisciplinary communication concerning the care of home-dwelling elderly patients. Congredi might also be feasible in handover situations because different professionals can look at the same record and note their observations and activities. Therefore, every professional is informed of the latest situation. The findings of other studies show that handover situations are a great risk for this population [3,22]. The results of our study show that this risk can be alleviated with a digital communication system, including a patient record. More research is needed to verify whether the quality of care does, in fact, increase.

Observations Concerning Implementation

Further diffusion of this innovation is promising. A participation rate of 21.4% was achieved, which is quite successful for an innovative intervention. An explanation might be found in Rogers' theory on diffusion of innovation. He found that in the first phase of diffusion the adoption rate is generally approximately 16%, with innovators and early adopters using it [23]. It is posited that the point at which innovations tend to diffuse in society to the level where they can sustain themselves is when the early and late majorities become active after the innovators and early adopters (16%) [23].

In nearly half of the patient records, multidisciplinary communication about care problems actually took place. This is a high rate. Part of the higher adoption rate in this study could be explained by the regional approach with which the context was managed. It could also be explained by the stepwise implementation based on feedback by the users (choice of communication tool, feasibility study, decision to evaluate the innovation) and support at an administrative level.

When implementing an e-communication tool in primary care, it is interesting to examine not only whether the professionals use the tool but also whether it has potential to support them in their professional work methods. In this study, we found that the care plan was used as it was intended; problems were assessed, actions were defined, observations were noted, and actions were adapted (Plan-Do-Check-Act cycle). Problems were listed in 85% (169/201) of the patients' records. In most cases, the number of problems during the study period did not increase (in more than half of the cases, only one problem was registered); in a third, there was more than one problem, which could be a signal for higher complexity (Table 2). Care actions were defined in approximately three-fourths of the records; in half of the records more than one action was taken. Observations were found in nearly all the records; sharing them with colleagues is a form of integrating care because professionals can act on the observations of colleagues. Care actions were adapted in over two thirds of the records; in half this took place more than once. This could indicate instability. In conclusion, a relatively active multidisciplinary practice was shown in relation to the duration of the study (10 months).

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New Functionalities in Care Process

Congredi also offers new functionalities for professionals compared with usual care. Understanding how professionals use these functionalities is important for the further implementation of this program.

First, it is now possible for coordinating professionals to actively invite their colleague to link to a mutual patient record. This can be viewed as strengthening the network around the elderly; in this way, the relevant professionals have a direct overview of the situation and can thus take relevant action. This was done by the professionals in more than 90% of the patient records. In combinations with nurses and general practitioners (GN), 2 or more other professionals were invited during the 10 months. Because the relevant colleagues actively shared a care plan, it could be supposed that they perceive this functionality as supportive to their work process.

Second, sharing observations about patients took place on a large scale. Making observations was not new, but the transparency of sharing observations that could influence actions of other professionals was new. The exchange of such relevant information could result in a better-informed professional team, as indicated in the eCCM [12]. Further research could be done to determine whether this has an effect on decreasing the fragmentation of care.

Third, emailing within the patient record was a new function of the e-communication tool, which made it possible to view the care plan and the email communication together. This was expected to be experienced by the professionals as an improvement. Emailing took place in 31.4% of the patient records at a mean level of 0.89. This level was lower than expected, which might be explained by the fact that there are other email channels that are already in use.

All of the functionalities gained by using an e-communication tool are important prerequisites for effective communication among professionals about a patient care plan. This study shows that linking colleagues and sharing observations, which could result in stronger networks and integrated care, appealed to the users the most.

Another finding of this study was that approximately 40% of the professionals, the solo records, did not use Congredi as a multidisciplinary communication tool; they opened patient records but did not invite colleagues to link. Half of this group did, however, perform actions within the patient records. Through some personal communications, an explanation was given that Congredi helped them structure their own work more than the tools they had at their disposal. Because electronic administration tools in home care organizations in the Netherlands are primarily directed at cost administration in contrast to supporting nurses in their nursing work and because by far the largest discipline that worked solo in the care plan was the group of nurses (80%), this might be a motive. Most general practitioners already have an effective electronic administration tool. This could explain why a relatively small group worked alone and why the general practitioners in solo records were less active than the nurses and other professionals. Professionals continually strive for easy access between tools such as Congredi and their own professional administration systems; the feasibility study showed that not having a direct link influenced their motivation to participate actively in multidisciplinary communication. Facilitating work processes logistically should be a focus in further implementation.

Clarification Needed

During the study, the focus was on whether the professionals would use the tool and were able to use it. This goal was successfully achieved as professionals entered the study and patient records were opened. During the analysis, another question surfaced: Which frequency of actions in an electronic communication tool makes it successful? In other words, what level of activity in the patient records means that the tool is successful within the work process? In this study, the results show quite a variance in the number of actions in multidisciplinary patient records. In some patient records, there was little action, and in others there was much more. It is possible that professionals are just not using the tool. Another reason could be that factors related to the patient's situation influence the number of communications. Two studies about interprofessional communication in primary care give some indication. An observational study in primary practice stresses the fact that frequent communication through different communication channels is effective [24]. Peeters et al [25] found that there tends to be no interdisciplinary communication if nothing is wrong. The insight that depending on the situation patients rely more or less on the support of professionals could help with implementation. Therefore, if there is little communication in a stable situation, professionals do not need to be disappointed, and when there is deterioration in the patient's situation, more contact is expected. The findings in the literature also show that patients seem to appreciate the possibility of e-communication with their professional [26].

Strengths and Limitations

A methodological strength of the study was the large number and diversity of participating professionals and patient records. In addition to a relatively high participation rate, active communication was found among the professionals. As discussed previously, this was mainly due to the management of the context within which the innovation took place.

A limitation was that little comparison with "usual multidisciplinary communication" was found in the literature. It would be interesting to determine how the degree of peer communication within Congredi relates to multidisciplinary communication without Congredi. One study showed some quantification of structural communication on a yearly basis as perceived by the professionals, but because it was not specified per patient, a comparison with this study cannot be made [10].

In this exploratory study of multidisciplinary communication using electronic tools, quantitative data were used; this is an important first step to gain insight into the use of e-communication by professionals. Studying registered data has a limitation. For more insights into barriers and facilitators, qualitative data might be useful.

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Conclusions

In conclusion, Congredi has the potential to improve multidisciplinary communication for home-dwelling elderly patients with 2 or more professional health caregivers. In this study, it was used by a large group of professionals for their patients. Congredi seems to support professional work processes, and it offers new functions that have the potential to improve quality of care. Further research is needed to understand its implementation for different groups of patients.

Acknowledgments

This project was financially supported by CZ Health Insurance Company. CZ had no role in the study.

Conflicts of Interest

MvL is a member of the Supervisory Board of Convenient. Convenient is the parent company to which Fast Guide, the developer of Congredi, belongs.

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Abbreviations

CCM: chronic care model
eCCM: eHealth Enhanced Chronic Care Model
SFMPC: social, functional, mental, physical, and communication

Edited by G Eysenbach; submitted 08.07.16; peer-reviewed by P Gee, P Seth; comments to author 25.08.16; revised version received 13.10.16; accepted 18.10.16; published 24.11.16.

Please cite as:
de Jong CC, Ros WJG, van Leeuwen M, Schrijvers G
How Professionals Share an E-Care Plan for the Elderly in Primary Care: Evaluating the Use of an E-Communication Tool by Different Combinations of Professionals
J Med Internet Res 2016;18(11):e304
URL: http://www.jmir.org/2016/11/e304/
doi:10.2196/jmir.6332
PMID:27884811

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Original Paper

A Web-Based Patient Portal for Mental Health Care: Benefits Evaluation

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Abstract

Background: Treatment for mental illness has shifted from focusing purely on treatment of symptoms to focusing on personal recovery. Patient activation is an important component of the recovery journey. Patient portals have shown promise to increase activation in primary and acute care settings, but the benefits to tertiary level mental health care remain unknown.

Objective: To conduct a benefits evaluation of a Web-based portal for patients undergoing treatment for serious or persistent mental illness in order to examine the effects on (1) patient activation, (2) recovery, (3) productivity, and (4) administrative efficiencies.

Methods: All registered inpatients and outpatients at a tertiary level mental health care facility were offered the opportunity to enroll and utilize the patient portal. Those who chose to use the portal and those who did not were designated as “users” and “nonusers,” respectively. All patients received usual treatment. Users had Web-based access to view parts of their electronic medical record, view upcoming appointments, and communicate with their health care provider. Users could attend portal training or support sessions led by either the engagement coordinator or peer support specialists. A subset of patients who created and utilized their portal account completed 2 Web-based surveys at baseline (just after enrollment; n=91) and at follow-up (6 and 10 months; n=65). The total score of the Mental Health Recovery Measure (MHRM) was a proxy for patient activation and the individual domains measured recovery. The System and Use Survey Tool (SUS) examined the use of functions and general feedback about the portal. Organizational efficiencies were evaluated by examining the odds of portal users and nonusers missing appointments (productivity) or requesting information from health information management (administrative efficiencies) in the year before (2014) and the year after (2015) portal implementation.

Results: A total of 461 patients (44.0% male, n=203) registered for the portal, which was used 4761 times over the 1-year follow-up period. The majority of uses (95.34%, 4539/4761) were for e-views. The overall MHRM score increased from 70.4 (SD 23.6) at baseline to 81.7 (SD 25.1) at combined follow-up (P=.01). Of the 8 recovery domains, 7 were increased at follow-up (all P<.05). The odds of a portal user attending an appointment were 67% (CI 56%-79%) greater than that of nonusers over the follow-up period. Compared with 2014, over 2015 there was an 86% and 57% decrease in requests for information in users and nonusers, respectively. The SUS revealed that users felt an increased sense of autonomy and found the portal to be user-friendly, helpful, and efficient but felt that more information should be accessible.

Conclusions: The benefits evaluation suggested that access to personal health records via patient portals may improve patient activation, recovery scores, and organizational efficiencies in a tertiary level mental health care facility.

(J Med Internet Res 2016;18(11):e294) doi:10.2196/jmir.6483

KEYWORDS

efficiency, organizational; electronic health records; mental health; mental disorders; patient activation

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Introduction

Mental illnesses are one of the highest contributors to the global disease burden, accounting for the greatest proportion of years lived with disability [1]. Over the past few decades, mental health treatments have shifted from being purely symptom focused to adopt a recovery philosophy—that is, supporting patients in their personal journey of self-discovery and regaining control of their path to wellness [2]. In order for patients to set and achieve their personal wellness goals, they must be activated in their care. In people with schizophrenia, patient activation is correlated with recovery attitudes [3]. Patients and carers with increased activation in their care develop the knowledge, skills, and confidence [4] to manage their illness effectively, which may lead to the engagement in self-management behaviors [5]. There are many challenges to activating patients, and strategies for facilitating activation, recovery, overall well-being, and self-management are needed.

Enhancing access to health care information for patients and their carers promotes active partnership between patients and health care providers. Patient portals linked to a hospital's electronic medical record (EMR) data repository allow patients and/or designated carers to access their personal health information [6], which may facilitate patient activation. Many positive patient outcomes have been reported following implementation of patient portals, including improved adherence to treatment, reduced medical errors and adverse drug reactions, better communication between the patient and provider, perceived improvement in care quality, increased patient engagement, and an increased sense of autonomy [7-9], although these findings are not consistent across studies [8,10]. To date, studies have been conducted in acute or long-term care settings for people with physical illness, and the effects of implementation of patient portals have not been examined in mental health care. Considering that many of the documented improvements align well with recovery philosophy (ie, increased sense of autonomy, patient engagement, and patient-provider communication), implementation of a patient portal in a mental health care facility would have the potential to positively impact both clinical outcomes and recovery.

Implementation of a patient portal in a health care facility must provide benefit not only to the patients but also to the organization. Patient portals have been proven to have some positive impact on organizational efficiencies. One review reported that portal users had a quicker decline in the rate of office visits and a slower increase in the number of telephone contacts compared with the control group [7], while another reported provider time savings from in-person clinic appointment avoidance owing to portal communication [8]. On the other hand, a realist review showed that there was no decrease in health resource utilization [8]. In 5 of the 8 studies included in the review, health resource utilization increased [11], which could be expected with increased access and use of the system. Thus, it remains unclear whether these effects are positive or negative overall. Furthermore, these reports do not pertain to mental health, which has a different care structure, and portal use may have a different organizational impact on a facility serving this population.

The purpose of this study was to conduct a benefits evaluation of a patient portal for patients undergoing treatment for serious or persistent mental illness. The objectives were to examine the effects on (1) patient activation in care, (2) recovery, (3) productivity, and (4) administrative efficiencies.

Methods

Study Design and Setting

This observational cohort study—reported according to STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines [12] and the CONSORT-EHEALTH (Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth) extension [13]—was carried out at a tertiary level mental health care facility (Ontario Shores Centre for Mental Health Sciences, Whitby, Canada), which offers inpatient (16 units, 326 beds) and outpatient services (>60,000 visits per year in 26 clinics) to those with serious and persistent mental illnesses (see Multimedia Appendix 1) [13]. This study was approved by the Research Ethics Board of Ontario Shores Centre for Mental Health Sciences.

Recruitment

All inpatients and outpatients (or their carers) receiving care from December 2014 to December 2015 were eligible to register for a portal account and were invited to participate. Patients were approached by the engagement coordinator (clinical educator) and provided with information about the portal. Portal users were defined as those who chose to register in the portal between December 2014 and November 2015. Users were also recruited through the health information management department when patients made contact for their health information, although most were enrolled through the engagement coordinator. The design of the recruitment strategy likely resulted in an overrepresentation of participants with higher technological literacy and/or motivation to participate in their own care and less severe illness. Likewise, those with lower computer literacy or motivation to be involved in their care or more severe illness were likely underrepresented. This bias should be recognized as an important limitation to the study. The first steps of implementation, however, were to assess the functionality and the benefits of using the portal; we therefore decided to first implement with the intent of recruiting early adopters. Work is underway to identify and address barriers to portal use in patients who are more resistant to use. Informed consent was waived by the research ethics board for analysis of deidentified data pulled from the organization's EMR data repository. In a subset of participants completing Web-based surveys, consent to participate was implied by completing the surveys after being invited by detailed email communication from the study coordinator.

Portal Design

The patient portal (Ontario Shores HealthCheck Patient Portal; Figure 1) is a vendor application (Medical Information Technology, Inc (Meditech), Westwood, MA, USA) that accesses personal health information documented in the EMR. It was designed to meet the following objectives: (1) to allow

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patients access to view their information from the EMR; (2) to give patients another method by which to request medication renewals; (3) to provide patients with the ability to view their outpatient appointments generated through Meditech's "Community Wide Scheduling" module; (4) to allow patients to conveniently update their demographic or contact information; (5) to provide patients with access to educational materials, such as discharge instructions; (6) to provide a medium for communication between patients and physicians and/or interprofessional outpatient clinician team members; and (7) to maintain flexibility to allow for future development and iterations to meet evolving needs of patients and clinicians. The hospital's privacy officer (Leader, Privacy and Access) was a member of the project implementation team, and the Information and Privacy Commissioner of Ontario's Privacy by Design model [14] was operationalized to ensure security.

Users accessed the portal through any Web browser on a computer or electronic device with Internet connectivity. Users were able to show, print, and share their record with health care providers at other facilities in support of maintaining continuity of care. The portal functions included were predetermined by those available from the vendor. For the purpose of this evaluation, 3 functional components were defined: (1) e-views, (2) e-visits, and (3) e-requests for prescription renewal.

E-views refers to the function allowing users to view parts of their electronic health record, including reports, discharge summaries, allergies, demographics, and their ambulatory medication list. They could also view upcoming appointments and a list of people to whom the users had given consent to access their chart, and they could view and send requests to update their demographic information.

E-visits refers to the function enabling secure messaging with their primary clinician or most responsible physician.

E-requests for prescription renewal refers to the function enabling electronic prescription renewal.

Recommended frequency of use was not specified to users; rather, it was recommended to utilize educational resources, pamphlets, website, and other materials to support them with navigation within the system, as needed. Users received email notifications when new information was available in the portal.

Figure 1. Home page of the patient portal.



Portal Implementation and Enrollment

The portal implementation project was sponsored by Canada Health Infoway (CHI) and developed by Meditech to leverage the EMR's data. Version 1 of the portal was released to the organization in December 2014. A total of 9 users pilot-tested the portal in December 2014 and provided feedback before it was rolled out to the entire organization later that month. Increased functionality and updates will be available with the next scheduled upgrade on November 1, 2016. There were no changes to the portal over the course of the data collection period (Meditech 6.07, Portal 1.0).

Enrollment was limited to inpatients or outpatients registered at Ontario Shores and their proxy users. Access and services were provided at no cost to the patient, and users continued to have access to their records following discharge.

At this stage the level of human involvement was high. At an organizational level, care providers, health care professionals, information technology, clinical informatics, health information management, and professional practice were involved in the planning and implementation of the portal. CHI provided additional support as project sponsors. They provided a detailed project structure and benefits evaluation delivery model [15] and were available as a resource and guide throughout the course of the project. Clinicians received training through a video and access to a demonstration account to experience portal use and a learning management system module. Clinicians received further training through the medical advisory council, nursing council, other professional councils, and on-unit services. Training was included in clinical orientation for new hires. A process to support clinicians with enrolling users was built into the EMR. Formal training was not provided to users, but support sessions were facilitated by peer support specialists and the engagement coordinator and available for users to attend on an ongoing basis.

Benefits Evaluation

A standard benefits evaluation model and framework was used to evaluate this initiative [15]. CHI designed a model for completing benefits evaluations for information systems that is based on the DeLone and McLean Information Systems Success

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model and takes 6 interdependent variables into account: system quality, information quality, system use, user satisfaction, individual impact, and organizational impact [16]. This benefits evaluation framework focuses on the relationship between the implementation of an effective solution, the adoption of the solution, and the resulting effects. Applying this evaluation method and framework is effective in understanding progress made toward objectives, identifying barriers, and communicating successes [15]. This evaluation further utilized Infoway's System and Use Survey Tool (SUS) from the system, information, service, use, and satisfaction indicators of the benefits evaluation framework to evaluate the implementation of this patient portal.

Outcomes Measures

Table 1 presents the study timeline.

Table 1. Study timeline.

Period	Dates	Activity
Preimplementation (2014)	January 2014 to December 2014	Used to compare administrative efficiencies and productivity (retrospective analysis based on those who enrolled after going live).
Go live	December 2014	Implementation date.
Recruitment	December 2014 to December 2015	Ongoing recruitment. Completion of preportal surveys.
MHRM[a] (>6 months) follow-up	May 2015 to December 2015	Completion of postportal survey (MHRM).
SUS[b] (>3 months) follow-up	March 2015 to December 2015	Completion of SUS.
Postimplementation (2015)	January 2015 to December 2015	Post–portal implementation efficiencies and productivity.

[a]MHRM: Mental Health Recovery Measure.

[b]SUS: System and Use Survey Tool.

Demographics

Demographics (age and sex) for the overall populations were extracted from the EMR data repository via structured query language (SQL) report. Factors related to diagnosis, such as symptoms and severity, may affect portal use; however, because a number of patients had multiple diagnoses or misdiagnoses that were changed over the course of their admission, a clear description of participants' diagnoses was not possible. Demographics for the subset of individuals completing the Web-based surveys were self-reported.

Portal Usage

The number of patients who registered for the portal and number of times each function was used was pulled from the data repository via SQL reports.

Productivity

Appointments missed by users and nonusers were pulled from EMR reporting data for the year before (2014) and the year of (2015) portal implementation.

Administration Efficiencies

The number of requests for information for users and nonusers was pulled from the EMR reporting data for the year before (2014) and the year of (2015) portal implementation.

Surveys

Mental Health Recovery Measure

Portal users were prompted to complete the Mental Health Recovery Measure (MHRM) at registration and 6 and 10 months following portal registration. The MHRM includes 8 recovery domains, which were examined to determine changes in recovery across the study period. Activation is seen as central to self-management, which literature indicates is linked to improving patient involvement in and having a more patient-centered organization of health care delivery [17]. Because these concepts align with the MHRM, it was chosen as a proxy measure for activation since fiscal constraints prevented the use of more traditional measures of activation. A link to the Web-based survey was available on the portal. The survey did not link to the user's account and therefore results were anonymous. An email reminder was sent at 6 and 10 months to prompt completion of the follow-up survey.

System and Use Survey Tool

A link to the SUS was available on the portal 6 and 10 months after portal registration to examine users' experiences with e-visits, e-views, and e-requests for prescription refill. A small subset of users pilot-tested the surveys at 3-month follow-up. Because no changes were made, these results were included in the analysis. Free-text answers to the SUS (administered as described above) provided qualitative feedback regarding experiences with portal use.

Bias

The design of this study may introduce bias when comparing portal users with nonusers for organizational measures as the users were interested in and motivated to use the portal, which may translate into increased interest and motivation to participate in treatment.

Sample Size

The entire organizational patient population was used for observation. The target sample size for survey completion was 60, based on the CHI (study sponsor) statement of work.

Statistical Methods

Data for analyses were extracted through reporting software interfacing with the organization's data repository and exported

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into Microsoft Excel 2010 for data analyses. Descriptive analyses were completed by calculating the number and percentage of service users who registered on the portal and the average of the number of log-ins per user from December 2014 to December 2015 (ie, data usage).

Missed appointment (ie, appointment kept vs appointment missed) and requests for information (ie, health information requests made vs health information not requested) data for users and nonusers were inputted to OpenEpi (version 3) [18] to calculate the odds ratio (OR) for the 2014 and 2015 data.

Changes in the overall MHRM and each of the recovery domains were examined using *t* tests [19]. Basic coding was completed for the free-text sections of the SUS. As participation in the 10 months or more follow-up surveys was low, responses to 6 and 10 months or more follow-up surveys were combined for MHRM and SUS analyses to meet CHI requirements.

Results

Demographics

Age and sex data were available for 3158 patients who were admitted between December 2014 and November 2015 and for 432 of the participants who registered for portal access in the same time frame. A similar proportion of patients (1756/3158, 55.6%) and portal users (266/432, 61.6%) were female. Age distribution was relatively similar, although older adults (aged ≥65 years) may have been slightly underrepresented in the subset of portal users (Table 2).

Table 2. Age distribution in the whole organization and in portal users.

Age range	Organization N (%)	Portal users N (%)
Total	3158 (100)	432 (100)
Under 20	577 (18.27)	60 (13.9)
20-34	887 (28.09)	169 (39.1)
35-49	632 (20.01)	123 (28.5)
50-64	561 (17.76)	71 (16.4)
65-74	197 (6.24)	6 (1.4)
75-84	176 (5.57)	2 (0.4)
Over 84	128 (4.05)	1 (0.2)

Portal Usage

Over the year-long follow-up period, 461 service users (44% male, n=203) registered for the portal and were designated as users. The majority of users were between the ages of 25 and 34 years. The portal was used 4761 times with the majority of log-ins for e-views (n=4539, 95.3%), followed by e-visits (n=210, 4.4%) and e-renewal of prescriptions (n=12, 0.3%).

Productivity

In 2014 (the year before the portal launch), the odds of a user attending a scheduled appointment were 17% greater than that of nonusers (OR 1.17, 95% CI 1.08-1.26). In 2015 (the year of the follow-up period), the odds of a user attending a scheduled appointment were 67% greater than that of nonusers (OR 1.67, 95% CI 1.56-1.79).

Administrative Efficiencies

In the entire population, there was a 61% decrease in the number of requests for information from 206 in 2014 to 80 in 2015. In users, there was an 86% decrease in the number of requests for information from 23 in 2014 to 3 in 2015. In nonusers, there was a 57% decrease in the number of requests for information from 183 in 2014 to 77 in 2015.

Surveys

In total, 91 users completed the SUS immediately following registration, and 65 users completed the SUS at combined follow-up. The median and mode response period was the 6-month follow-up.

Mental Health Recovery Measure

Self-reported demographics (Table 3) were similar between those completing the MHRM at registration (44% males with a median age category of 20-34 years) and follow-up (41% males with a median age category of 20-34 years). Table 4 shows the change in MHRM scores. The total MHRM score increased from 70.4 (SD 23.6; n=79) to 81.7 (SD 25.1; n=54) at follow-up (P=.01). Of the 8 domains, 7 increased from baseline to follow-up (Overcoming Stuckness, Self-Empowerment, Basic Functioning, Overall Well-Being, New Potentials, Spirituality, Advocacy/Enrichment; all P<.05).

System and Use Survey Tool

Of those who completed the SUS at follow-up (n=65), 48% (n=31), 22% (n=14), and 34% (n=22) reported that they utilized the e-views, e-renewal of prescriptions, and e-visits, respectively. Few users completed free-text questions of the SUS at follow-up (n=16); 3 themes each were identified for e-views and e-requests for prescription refill, and 2 themes were identified for e-visits (Table 5).

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Table 3. Self-reported demographics of users completing the Mental Health Recovery Measure survey at portal registration and follow-up.

Demographic information	Registration (N=91) n (%)	Follow-up (N=65) n (%)
Sex	n=86	n=51
Male	38 (44)	21 (41)
Female	48 (56)	30 (59)
Age category, years	n=87	n=50
Under 20	18 (21)	6 (12)
20-34	26 (30)	18 (36)
35-49	26 (30)	15 (30)
50-64	15 (17)	9 (18)
65-74	1 (1)	1 (2)
75-84	1 (1)	1 (2)

Table 4. Differences between baseline and follow-up in the 8 domains of the Mental Health Recovery Measure.

MHRM[a] domain	Baseline		≥6-Month follow-up		Pre-post differences[b]			
	n	Mean (SD)	n	Mean (SD)	Mean difference	Degrees of Freedom (df)	*t* test	*P* value[c]
Overcoming Stuckness	91	10.8 (3.0)	55	11.9 (2.6)	−1.0	143	−2.121	.04
Self-Empowerment	90	10.1 (3.8)	55	11.5 (4.0)	−1.3	110	−2.019	.04
Learning and Self-Redefinition	91	10.6 (3.6)	56	11.3 (3.3)	−0.6	144	−1.104	.27
Basic Functioning	90	9.2 (3.4)	55	10.8 (3.8)	−1.6	142	−2.674	.01
Overall Well-Being	92	7.9 (4.2)	56	9.9 (4.2)	−2.1	111	−2.856	.005
New Potentials	88	9.1 (4.0)	56	10.5 (3.7)	−1.3	141	−2.052	.04
Spirituality	92	3.9 (2.5)	56	4.9 (2.5)	−1.0	145	−2.426	.02
Advocacy/Enrichment	92	9.1 (3.0)	54	10.9 (3.6)	−1.9	143	−3.404	.001
Total	79	70.5 (23.6)	54	81.7 (25.1)	−11.3	130	−2.636	.01

[a]MHRM: Mental Health Recovery Measure.

[b]Pre refers to baseline and post refers to ≥6-month follow-up.

[c]Statistical significance was defined as $P<.05$.

Table 5. Thematic analysis of free-text questions of the System and Use Survey.

Function	Benefits	Improvement
E-views	Autonomy: "It is an excellent tool to cultivate autonomy." "Just having my own access has given me freedom as a patient."	PHI[a] not up-to-date: "The only report that was uploaded was from a psychologist that I saw a few months ago. No other reports in the past 6 months have been uploaded to the patient portal." More information: "My file doesn't show history of visits, but just appointment dates."
E-requests for prescription refill	User-friendly: "Easy to use." Helpful: "This system is very helpful for appointment reminders." Satisfaction: "I am happy to see it works."	
E-visits	Efficiencies: "The system saves a lot of time and money." Satisfaction: "I'm happy with the system."	

[a]PHI: personal health information.

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Discussion

Principal Findings

This study is the first to report the outcomes of the implementation of an EMR-linked portal for inpatients and outpatients receiving services at a tertiary facility specializing in severe and persistent mental illness. The novel findings of this study are that implementation of the portal for inpatients and outpatients resulted in activation of service users and/or carers and in improved recovery scores according to the MHRM domains. At the organizational level, productivity was increased with fewer missed appointments and administrative efficiencies were realized with a reduced number of requests for information in the year following compared with the year before portal implementation.

Strengths and Limitations

The main strength of this study is that data to examine organizational productivity and administrative efficiencies were available through EMR reporting software for the whole organizational population. Users self-selected registration and enrollment; therefore, the results of this study reflect actual use as we may expect this sample to be reflective of the population who would choose to use the portal in reality. Additionally, research personnel had minimal effect on the implementation of the portal. Because the entire patient population of the hospital and its associated clinics was followed up for the duration of this study, it has high internal validity. Results may be generalizable to other tertiary care mental health hospitals and outpatient clinics with similar organizational context; however, because the results are specific to this organization, generalizability to other contexts may be limited. This study is limited in that there is no control group for the MHRM. Changes in recovery over time may be a result of continuing mental health treatment and may not be associated with activation or portal use. Results may have been stronger if the well-validated Patient Activation Measure (PAM) was used to measure patient activation instead of the MHRM; however, patient activation and recovery are strongly associated [3]. Hence, it was determined that the MHRM would be an acceptable surrogate measure because budgetary constraints prevented use of the PAM. Convenience sampling was used to recruit the subset of users completing the SUS and this subset was not necessarily representative of all the users. Additionally, the administration of the surveys via anonymous Web-based survey software ensured confidentiality but prevented analysis using repeated-measures design. It is unknown how many (if any) of the users completed the survey at both baseline and follow-up or if these samples are different in composition. Demographics suggest compositions were similar.

Comparison With Prior Work

In the literature, the effects of patient portal implementation on organizational productivity and administrative efficiencies are equivocal [7,8,11]. In this study, the odds of portal users attending an appointment were 17% greater than that of nonusers before portal implementation and 67% greater than that of nonusers in the year following portal implementation, showing increased organizational productivity. Administrative efficiencies were also realized with an overall 61% decrease in the number of requests for information with an 86% and 57% decrease in users and nonusers, respectively. Overall, the estimated administrative time efficiencies related to requests for information by users was low (10-40 hours; data not shown) because of the small number of requests made by users in both 2014 and 2015. The results, however, suggest that with increased access to information and/or activation of users, considerable improvements in time efficiencies could be realized.

One of the primary purposes of portal implementation was to activate patients and/or carers to improve outcomes and recovery. A study examining the effects of patient portals on patient activation in acute care settings showed no association between patient activation and use of the patient portal [20]. In our study, patient activation, assessed by the overall MHRM score, increased over the follow-up period suggesting that engagement with the patient portal increased activation. It should be considered, however, that the purpose of recovery-oriented mental health treatment is to help patients reach their personal goals, which requires a certain amount of activation. Patient portals may be beneficial in this clinical population as increased activation through treatment may motivate portal use and portal access may support goal achievement. Future research may be warranted to examine these relationships to enable portal functionalities to optimally support patient recovery.

The overall MHRM score and 6 of the 8 recovery domains were improved over the follow-up period. This study is the first to explore the effects of patient portal implementation on recovery in its users. The change in MHRM over the 6-10 month follow-up period (baseline, 70.7; follow-up, 81.7) was similar to the change in MHRM over a 3-6 month "Wellness Management and Recovery" program delivered to persons with mental illness (baseline, 80.2; follow-up, 88.4) [21]. Because there was no control group, it is uncertain whether improvements in recovery were accelerated by the patient portal or whether they were usual improvements with treatment. The fact, however, that this study elicited similar changes in MHRM as an intensive wellness management and recovery program suggests this is an important topic for future research.

Conclusions

In conclusion, this benefits evaluation provides early evidence to suggest that access to electronic health records through a patient portal may have positive effects on patient activation and recovery in a population with serious and persistent mental illness. With the current functionality, there was a notable improvement in productivity with lower odds of a missed appointment for the users compared with nonusers. Future research is planned to conduct focus groups to more thoroughly examine patient experiences and to examine longitudinal effects of increased portal functionalities on mental health symptoms, recovery, and health care utilization.

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Acknowledgments

This project was sponsored by Canada Health Infoway, who provided financial support and the framework and guidance for the benefits evaluation.

Authors' Contributions

SK, TN, and SR were involved in the conceptualization, design, and implementation of the study. AH was involved in data collection. AH and MS analyzed and interpreted the data. MS drafted the manuscript. All authors critically reviewed and approved the final version of this manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT EHEALTH form V1.6.2 [13].

[PDF File (Adobe PDF File), 994KB - jmir_v18i11e294_app1.pdf]

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Abbreviations

CHI: Canada Health Infoway
CONSORT-EHEALTH: Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth
EMR: electronic medical record
MHRM: Mental Health Recovery Measure
OR: odds ratio
PAM: Patient Activation Measure
SQL: structured query language
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
SUS: System and Use Survey Tool

Edited by CL Parra-Calderón; submitted 11.08.16; peer-reviewed by J Apolinário-Hagen, L Wang, TR Soron; comments to author 05.09.16; revised version received 06.10.16; accepted 22.10.16; published 16.11.16.

Please cite as:
Kipping S, Stuckey MI, Hernandez A, Nguyen T, Riahi S
A Web-Based Patient Portal for Mental Health Care: Benefits Evaluation
J Med Internet Res 2016;18(11):e294
URL: http://www.jmir.org/2016/11/e294/
doi:10.2196/jmir.6483
PMID:27852556

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Letter to the Editor

Response to "Older Cancer Patients' User Experiences With Web-Based Health Information Tools: A Think-Aloud Study"

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(J Med Internet Res 2016;18(11):e273) doi:10.2196/jmir.6613

Letter

We read with great interest the paper by Bolle et al that highlights the important determinants of usability and perceived usefulness of Web-based health information among older adults [1]. This paper is both timely and important. Web-based health information is increasingly being seen as an efficient means of patient education; however, the health information needs of older adults are often neglected [2]. Therefore, understanding how to improve Web-based tools for older adults would be hugely beneficial.

The authors conclude that older cancer patients are able to use cancer information websites and find them useful. However, there are certain clarifications that seem necessary before adopting these findings into common practice.

Firstly, we note that participants were recruited from PanelCom, a service which recruits cancer patients via email and conducts most studies online [3]. Such patients are likely to be more experienced with Web-based technology than the average older adult and hence have a higher threshold for detecting usability issues.

Second, when searching for health information, patients tend to first use generic queries in Web search engines as opposed to directly accessing specific medical websites [4,5]. Therefore, the authors' assessment of the navigational usability of these websites does not accurately reflect the true usage pattern of such websites.

Finally, it is important to bear in mind that Web-based tools must balance the differing needs of distinct patient groups. For example, increasing the size of text also increases the need for scrolling on a page, an issue which 9% of participants objected to. Hence recommendations that enhance the ability to personalize Web-based tools are preferred over generalized recommendations.

Notwithstanding these considerations, it is clear that factors such as the content delivered, readability, and the use of multimedia all influence the likelihood of the use of Web-based information tools by older adults. Other factors that might determine perceived usefulness also include the currency, authorship, and bias contained within health care information, all of which could be potential avenues for future research. Furthermore, although the authors touch upon the importance of interpersonal communication with physicians together with Web-based tools, the true value of integrating the tools within the patient consultation could also be further explored. Health care professionals are well placed to point patients using the Internet in the right direction and help them to identify relevant data amid an "information overload." There is also evidence to

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suggest that the recommendation of Web-based tools by a physician increases perceived usefulness and compliance [6,7].

In light of these findings, there is still a need for good quality Web-based health information that considers the requirements of older adults. This study is valuable to help elucidate the path to developing useful informational tools for such a group of patients. Although some areas of clarification exist, the authors clearly make a unique contribution to a field in which there is a dearth of existing literature. Future designers of Web-based information tools would do well in considering the pertinent factors identified, in addition to others that have not been completely explored in the past.

Conflicts of Interest

None declared.

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Edited by L Fernandez-Luque; submitted 04.09.16; peer-reviewed by M Isomursu; accepted 16.09.16; published 16.11.16.

Please cite as:
Gokani SA, Kerry G, Sharma E, Ash J, Zargaran AK, Rasasingam DS, Mittal A
Response to "Older Cancer Patients' User Experiences With Web-Based Health Information Tools: A Think-Aloud Study"
J Med Internet Res 2016;18(11):e273
URL: http://www.jmir.org/2016/11/e273/
doi:10.2196/jmir.6613
PMID:27852559

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Letter to the Editor

Authors' Reply: Response to "Older Cancer Patients' User Experiences With Web-Based Health Information Tools: A Think-Aloud Study"

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Comment on: http://www.jmir.org/2016/11/e273/

(J Med Internet Res 2016;18(11):e289) doi:10.2196/jmir.6934

We greatly appreciate the thoughtful comments of Gokani and colleagues [1] in response to our article "Older Cancer Patients' User Experiences With Web-Based Health Information Tools: A Think-Aloud Study" [2]. We are happy to elaborate on the points for which they request further clarification.

First, they have concerns about our recruitment strategy of study participants via a patient panel (PanelCom) that would lead to participants being more experienced Internet users as compared to the average older adult. However, it is a misunderstanding that PanelCom is a service which "recruits cancer patients via email." As explained in the paper (under the subheading 'study design, setting, and sample' in the methods section), PanelCom is a panel of cancer patients who previously participated in studies of the Departments of Communication Science and Medical Psychology and consented to be contacted again in future studies. These previous studies were not necessarily online; especially older participants were mostly recruited in hospitals. Nevertheless, (older) patients that have no experience with Web-based technology are not likely to use Web-based health information tools. Hence they were not the target population of this study. However, 61% of our sample does consist of participants that have no to very little experience in using a computer or tablet (ie, 0-2 hours per week; see table 1 in the paper).

The second point of concern that Gokani et al raise is that the usage pattern of the websites we have tested might be different had we also taken search queries in search engines such as Google into account. We agree (under subheading 'cancer information websites' under materials in the methods section, where we mention that people tend to look no further than the first page of the search results), and we took this into account by selecting two websites that were the first results on Google for searches for the Dutch words for "chemotherapy," "cancer," and "hospital." Furthermore, the aim of the current study was to identify usability issues in order to make recommendations for the design of usable Web-based health information tools for older patients as a preparation for the systematic development of a web-based health information tool, the Patient Navigator. The Patient Navigator will be provided by hospitals and healthcare providers. This means that users will directly access

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the website rather than a search engine. The question how older (cancer) patients search for online health information covering the whole navigational usage pattern remains an interesting question for future research. Moreover, we agree that the factors suggested by Gokani et al such as currency, authorship, and bias contained within healthcare might influence perceived usefulness and that these factors should be investigated in future research.

Third, Gokani et al suggest that recommendations are needed that enhance the ability to personalize Web-based tools rather than generalized recommendation. Indeed, the digital nature of Web-based tools allows the tailoring of the design and information to individual needs and preferences of patients, which is why we recommend tailoring on websites for older cancer patients (under the subheading 'comparison with prior work and practical implications' in the discussion section). A simple way of self-tailoring is our recommendation to "avoid large amounts of information on a page. If possible, display options on 1 page, for example, first provide an overview with options, and then (after visitors choose what information they wish to read) the relevant information." Limited information on a webpage would make it possible to provide patients with a large font size to enable them to avoid scrolling. We agree with Gokani et al that more research is needed on other ways of tailoring that could benefit older patients, such as mode tailoring and message frame tailoring, next to content tailoring (see work by our research group [3,4]).

Finally, Gokani et al comment that "the true value of integrating the tools within the patient consultation could also be further explored." We couldn't agree more with this comment. Hence, this is the next step in our research project. We expect that the Patient Navigator will help patients in processing information and in preparing for the consultation with their healthcare provider. At the moment we are collecting the data to evaluate the clinical use of the Patient Navigator.

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Edited by G Eysenbach; submitted 01.11.16; peer-reviewed by S Medlock, P Burns; accepted 01.11.16; published 16.11.16.

Please cite as:
Bolle S, Romijn G, Smets EMA, Loos EF, Kunneman M, van Weert JCM
Authors' Reply: Response to "Older Cancer Patients' User Experiences With Web-Based Health Information Tools: A Think-Aloud Study"
J Med Internet Res 2016;18(11):e289
URL: http://www.jmir.org/2016/11/e289/
doi:10.2196/jmir.6934
PMID:27852557

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