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Viewpoint

The Person-Based Approach to Intervention Development: Application to Digital Health-Related Behavior Change Interventions

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Abstract

This paper describes an approach that we have evolved for developing successful digital interventions to help people manage their health or illness. We refer to this as the "person-based" approach to highlight the focus on understanding and accommodating the perspectives of the people who will use the intervention. While all intervention designers seek to elicit and incorporate the views of target users in a variety of ways, the person-based approach offers a distinctive and systematic means of addressing the user experience of intended behavior change techniques in particular and can enhance the use of theory-based and evidence-based approaches to intervention development. There are two key elements to the person-based approach. The first is a developmental process involving qualitative research with a wide range of people from the target user populations, carried out at every stage of intervention development, from planning to feasibility testing and implementation. This process goes beyond assessing acceptability, usability, and satisfaction, allowing the intervention designers to build a deep understanding of the psychosocial context of users and their views of the behavioral elements of the intervention. Insights from this process can be used to anticipate and interpret intervention usage and outcomes, and most importantly to modify the intervention to make it more persuasive, feasible, and relevant to users. The second element of the person-based approach is to identify "guiding principles" that can inspire and inform the intervention development by highlighting the distinctive ways that the intervention will address key context-specific behavioral issues. This paper describes how to implement the person-based approach, illustrating the process with examples of the insights gained from our experience of carrying out over a thousand interviews with users, while developing public health and illness management interventions that have proven effective in trials involving tens of thousands of users.

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KEYWORDS

person-based approach; Internet; qualitative research; evaluation studies; feasibility studies; health promotion; patient education; professional education; behavior change.

Introduction

Overview

This tutorial paper is intended as an introduction to the person-based approach to intervention development. The first section explains how the person-based approach can contribute to effective intervention development and considers how it relates to other approaches. The second section describes how the person-based approach can be implemented throughout intervention development, illustrating its use with examples from our own development of successful interventions. Finally,

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we present a set of person-based intervention features that are likely to improve acceptability and engagement in most digital interventions.

Aims and Background of the Person-Based Approach

The fundamental aim of the person-based approach is to ground the development of behavior change interventions in a profound understanding of the perspective and psychosocial context of the people who will use them, gained through iterative in-depth qualitative research. There is widespread consensus in the eHealth research community that eliciting and addressing the needs and perspective of the intended intervention user is a vital part of good intervention development [1-3] to ensure (at a minimum) that interventions are usable and engaging. This is a critical issue for eHealth if it is to fulfil its potential and overcome the problems of low uptake and adherence [4]. It is difficult even for expert intervention developers to fully anticipate the priorities and needs of users [5], and so intervention developers already routinely elicit the views of target users in a variety of ways [6,7], but there is surprisingly little debate and detailed guidance concerning how best to do this [8]. The person-based approach provides a process that enables developers to gain vital insights into how different people experience and implement interventions, and a framework to help developers identify the key characteristics that will make an intervention more meaningful, attractive, and useful to those who engage with it.

The person-based approach was developed by our research team through practical experience of creating and evaluating numerous successful health-related interventions, including public health interventions (eg, to manage weight and stress, promote physical activity and hand hygiene) and illness management interventions (to help users cope with dizziness, back pain, fatigue, respiratory conditions, hypertension, diabetes, cancer, stroke, and many more health problems). Hence, the person-based approach is based on over a thousand in-depth interviews to understand users' needs and elicit reactions to our interventions [9-16]. Trials of these interventions in tens of thousands of users have demonstrated that what we have learned has proved effective in practice [17-22]. We therefore feel that it is timely to communicate what we have learned to date and explain the methods we have found useful to understand and respond to the perspectives of people who use our interventions. There are many good routes to developing effective interventions and we do not claim that our approach is the only one, but we believe that new intervention developers will find this guide a useful starting point. Given the limited discussion to date of how the user perspective should be incorporated into intervention development, this paper may also stimulate productive debate among more experienced intervention developers regarding the relative advantages and limitations of alternative ways of incorporating the user perspective.

The person-based approach is not intended to replace but to complement and enrich the well-known "theory-based" and "evidence-based" approaches to incorporating behavioral science into intervention development [23,24]. Theory-based approaches have provided valuable frameworks and models for anticipating and describing the likely influences on behavior [25-27], which can then be mapped onto appropriate behavior change techniques [28]. However, a complementary approach is needed to understand the most effective way of *applying* these models and techniques in the specific context of each intervention and the individuals who will use it. The person-based approach yields vital insights into how different people in different situations perceive and execute the behavioral elements of the intervention, why some elements may be particularly necessary or salient to them—or alternatively may be aversive or problematic—and thus how the intervention can be made more attractive, persuasive, and feasible to implement.

Wider Context of the Person-Based Approach

We refer to this approach as the "person-based" approach to highlight the focus on understanding and accommodating the perspectives of the people who will use the intervention, which we consider essential to maximizing the acceptability and effectiveness of interventions. We use the term "person" rather than "user" or "human" to distinguish our approach from related but somewhat different approaches (see next section for discussion). The generic term "person-centered" was chosen rather than "patient-centered" since the relevant people often include health professionals or healthy members of the community. The term "person-centered" has traditionally been used principally in the context of the person-centered approach to psychological therapy first advocated by Carl Rogers [29]. Although our approach to person-based intervention development was not derived from Rogerian person-centered therapy, it shares the Rogerian emphasis on respect for the autonomy and empathic understanding of the person the intervention is designed for. The term person-centered also has a history in the ethics of respect for personal autonomy in health care [30], which again is consistent with our approach.

The person-based approach to intervention development is not intended to be relevant only to digital interventions, and we have successfully used it to develop offline interventions [31]. However, we consider it particularly relevant to developing digital interventions because people typically use these independently, and so they must be designed with an understanding of how people do this. In addition, the emphasis on autonomy in the person-based approach is consistent with the widely held belief that the Internet can and should be a medium for empowering users [32,33].

The person-based approach has similarities to the use of qualitative methods to elicit user views in "usability testing" [34]. Usability testing is employed in the development of a product (often as a part of user-centered design) to ensure that the product is easy to use and fit for purpose. Usability testing can involve various kinds of qualitative data collection (eg, focus groups, observation, expert panels, interviews, and think aloud studies) at various stages of intervention development (eg, needs and context assessment, building and validating the intervention, real-world use of the intervention) [7]. However, usability testing evolved in the disciplines of human-computer interaction and system design and consequently focuses principally on the technological format of the intervention and the extent that users find it easy and attractive to use and effective for the tasks they need to perform. There are also points

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of convergence between the person-based approach and the evaluation of dimensions of the user perspective such as acceptability, engagement, trust, and satisfaction [35-37]. But whereas ensuring usability, acceptability, and satisfaction are necessary and important objectives, the goals of the person-based approach are more wide-ranging—to ensure that interventions are also motivating, enjoyable, informative, convincing, and most importantly that they change behavior and/or enhance well-being.

Although the person-based approach is not restricted to the development of digital interventions, it is highly compatible with the more in-depth approaches that have evolved within the disciplines of information systems and human computer interaction, such as human-centered and user-centered design [6,38,39]. These approaches seek to understand the user's knowledge, skills, behavior, motivations, cultural background, and organizational context, and they involve users iteratively throughout development [3,6,40]. However, the person-based approach is rooted within the discipline of health psychology and is intended for application to developing health-related behavior change interventions that may or may not include a digital product. Consequently, the person-based approach focuses primarily on the behavior change techniques the intervention is intended to deliver, and their implementation by the people using the intervention, including when they are not online. For example, when eliciting user views we specifically direct our participants to give their reactions not to the webpages or screens but to the intervention content, for example, the arguments made and activities suggested and the barriers they have encountered trying to follow the intervention advice (see next section for more discussion of these methods). Because of this difference in focus, the person-based approach could be usefully incorporated within a multidisciplinary holistic human-centered design framework [3], providing a systematic process for contributing an in-depth health psychology perspective that can be used to help implement the participatory and persuasive design aspects of the framework (see Table 1).

Table 1. An overview of how the person-based approach can be incorporated at each stage of the development of digital health-related behavior change interventions.

Intervention stage[a]	Target output of the person-based approach	Specific person-based approaches undertaken	Activities that may be undertaken as part of wider intervention development context
Planning (months 0-6)	Identification of key behavioral issues, needs, and challenges the intervention must address	Synthesize previous qualitative studies of user experiences of similar interventions	Consultation with experts, members of user groups, other stakeholders (eg, purchasers of health care services)
		Carry out primary qualitative research using open-ended questions to elicit user views of the planned behavior changes (including relevant previous experience, barriers and facilitators)	Examination of relevant theory and evidence from previous trials (complex intervention development)
			Observation of real-life context of intended health care product (user-centered design)
Design (months 3-9)	Creation of guiding principles to help developers summarize and easily refer to features of the intervention identified as central to achieving the intervention objectives	Create guiding principles, comprising: key intervention design objectives (addressing key behavioral issues, needs, challenges identified in Step 1), and key (distinctive) features of the intervention needed to achieve objectives (drawing on intervention planning in Step 1)	Theoretical modeling (complex intervention development) eg, creation of logic model describing hypothesized mechanisms of action of intervention, and/or intervention mapping of behavioral determinants and behavior change techniques
			Creation of personas, scenarios, use cases (user-centered design)
Development and evaluation of acceptability and feasibility (months 6-18)	All intervention components evaluated in detail and optimized from user perspective	Elicit, observe and analyze user reactions to every intervention element (eg, using think-aloud techniques), iteratively modifying intervention to optimize from user perspective	Development of detailed procedures for intervention plus information/advice, manuals, scripts, training, etc, for patients and/or health professionals
		Carry out detailed longitudinal mixed methods case studies to evaluate and optimize independent usage of intervention	Mixed methods evaluation of acceptability, feasibility (complex intervention development)
			Creation and usability testing of prototype product (user-centered design)
Implementation and trialing (starting from months 12-18)	Intervention evaluated in real-life context(s), modified to improve implementation in future contexts	Use mixed methods process analyses to identify further modifications to improve acceptability, feasibility, and effectiveness of intervention for future implementation, or for use in different contexts	Effectiveness and cost-effectiveness evaluated using experimental methods (eg, randomized controlled trials), audits, etc
			Mixed methods process analyses of implementation (reach, fidelity, context effects, etc), mediators, and moderators of intervention effectiveness

[a]Timelines given for each stage are indicative only.

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Overview of the Person-Based Approach to Intervention Development

The first section of this paper describes the process of implementing the person-based approach, explaining how in-depth qualitative research can be used to inform initial intervention planning, to elicit views of intervention elements and materials throughout the intervention development, and to understand usage and outcomes during intervention implementation. We illustrate the process and the insights it can generate using brief examples from the wealth of experience we have accumulated during the development, evaluation, and successful implementation of a range of very different interventions. We also describe how to encapsulate the most important insights from the process in "guiding principles", which provide a means of specifying and communicating the key objectives and distinctive features of interventions. The second part of the paper then outlines and discusses a set of common guiding principles that have emerged as useful across most of our interventions. This paper can provide only an introduction to the approach; our team will be publishing a series of supplementary papers shortly providing further detail and illustration of how it can be implemented.

The Process of Incorporating a Person-Based Approach Into Intervention Development

Core Elements of the Person-Based Approach

The person-based approach is incorporated into intervention development first through in-depth qualitative research with users and then through the development of "guiding principles" that state the key intervention design objectives and describe the key features of the intervention required to achieve each objective. These processes are discussed in detail below and examples from our own intervention development are presented to provide illustration. An overview of the person-based approach is shown in Table 1, which illustrates how the person-based approach can be integrated within the wider context of the activities undertaken during intervention development.

Qualitative research is central to the person-based approach at all stages of intervention development and evaluation, including planning and design, early development, acceptability and feasibility testing, and evaluation in clinical trials and real-life settings. In many cases, the research and development will not move through these stages in a linear fashion but will instead go through development-evaluation-development cycles in order to make improvements to the intervention based on data gained during evaluation phases [23]. The following two sections explain in more detail how qualitative research can be used to inform intervention development in each phase.

Using Qualitative Research to Inform Intervention Planning

At the planning stage, we regard drawing on theory, evidence, and the perspective of the people who will use the intervention as equally important and complementary. Theory and previous quantitative research can provide insight into the intervention components that have potential to be effective or cost effective but often do not offer clear guidance about which are most important or how best to implement them in a particular context. After completing a rigorous process of intervention mapping or causal modeling, using evidence from existing quantitative primary research, systematic reviews, and meta-analyses, intervention designers are often faced by a bewildering range of behavior change techniques that could be used, with no clear evidence on which to base selection of particular combinations. Qualitative research or expert and user consultation is often deployed to attempt to resolve this problem, but this element of theory-based intervention development is often somewhat ad hoc, piecemeal, and not well articulated. The person-based approach provides an explicit and rigorous process for exploring and analyzing the attitudes, understanding, needs, and situation of the people who will be using the intervention in order to select those intervention components that seem the most acceptable, feasible, and salient to them—and crucially to avoid the inclusion of those that are disliked or seen as impractical or intrusive (Textbox 1; [41]). Exploratory qualitative research at this stage can also suggest the need for intervention components or characteristics that have not been considered or previously used in this context (and hence may not yet be evidence-based).

Textbox 1. An illustration of qualitative research identifying potential intervention features which are unacceptable to users.

At the planning stage of developing a behavior-change app, we carried out focus groups with smartphone users (N=19) to explore the kinds of app features that were viewed as acceptable or unacceptable [41]. One app feature that computer scientists and behavior change experts have been excited about is context sensing, which enables mobile phones to sense where a person is (eg, near a fast food restaurant) and their likely emotional state, in order to send intelligent notifications to support behavior change at key points (such as if a person becomes stressed). However, we found that participants were skeptical about these intelligent notifications, as they believed that the sensing might be inaccurate. They also felt that even when accurate, context sensing might have a negative effect on behavior change, for instance by pointing out that someone was close to a fast food outlet that they had not previously noticed. Based on this lack of trust, we decided not to use context sensing to detect potential behavior change moments, but instead to use it to try to identify times that users would find it convenient and appropriate to receive notifications.

It may be possible to draw on existing qualitative research to understand the perspective of people who will use the intervention; if sufficient relevant research is completed, it may even be possible to carry out a qualitative synthesis of relevant user views. For example, when developing the POWeR weight management intervention, we carried out a synthesis of qualitative research on experiences of weight management interventions [42]. This suggested that providing regular face-to-face support for weight management might be problematic in the longer term, as it might promote dependency on this support to maintain weight loss. We concluded that brief nurse support for our intervention might be preferable to regular nurse support, and in our feasibility study of implementing

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POWeR [18] in a primary care setting, long-term outcomes did indeed prove better for those with only brief nurse support.

Often there is little or no high-quality qualitative research that is directly relevant to the specific intervention context (eg, a patient with a particular health condition and a particular intervention approach for that health condition). If there is a lack of qualitative research to provide guidance, then it is useful to carry out your own, in order to fully understand users' perspectives before designing an intervention (see Textbox 2; [43-45]). It is beyond the scope of this paper to give detailed guidance on how to carry out the very wide range of qualitative methods that can be used, but the examples given provide references to practical illustrations.

Textbox 2. Qualitative research conducted to inform intervention planning.

When planning an online intervention to promote prudent antibiotic prescribing across Europe, it was unclear which intervention strategies might be most acceptable to general practitioners (GPs). No existing research had explored GPs' attitudes to the variety of different intervention strategies that aimed to promote more prudent prescribing of antibiotics, and it was unknown whether GPs' attitudes might vary across Europe countries. We conducted 52 interviews with GPs from several European countries, exploring perceptions and experiences of strategies aimed to reduce unnecessary antibiotic prescribing [43]. GPs valued interventions that allowed discussion of prescribing practices between colleagues and the use of diagnostic tests to ensure appropriate prescribing. GPs' views were highly consistent across countries, suggesting that a single intervention could be suitable across European countries without requiring significant tailoring for each country. An online intervention was therefore created that supported the use of diagnostic tests and an in-house seminar to facilitate discussions of prescribing between colleagues. This intervention proved very acceptable [44] and successful [45] across six European countries.

Target users may vary in their requirements of an intervention or in their beliefs about their health condition. Views may vary depending on a range of characteristics, such as gender, cultural background, health literacy, or previous experiences. It is therefore vital for intervention developers to consider who they need to talk to, so that they can purposively sample [46] a diverse range of users who vary in characteristics that are considered important. This helps ensure that the researcher has insight into all relevant perspectives, enabling the intervention to be tailored to the different types of people who might use it.

When carrying out interviews to explore user views, it is valuable to use very open-ended questions that allow the respondents flexibility to interpret and answer the question in their own way, for example, asking "How do/did you feel about making this behavior change?". Using very open questions enables the researcher to capture novel responses that might not have been predicted from theory, or by the intervention developer [47]. Focus groups are also well suited to this kind of exploratory qualitative research since group discussion about a topic can lead in unexpected directions and give lay people confidence to express views that contradict the assumptions of the researcher. Fewer open-ended questions (eg, addressing specific dilemmas relating to intervention design, or mapping onto pre-existing theoretical categories) can be used at a later stage of the interview or focus group to check respondent views of aspects of the intervention that the developer is particularly interested in, or that respondents may not have considered spontaneously. However, there is a risk that using questions that ask specifically about particular topics may lead participants to express views of dimensions of the intervention that do not matter greatly to them, making it harder for the intervention developer to distinguish what is really important to prospective users. See Textbox 3 [48-50].

Textbox 3. An illustration of qualitative research to inform intervention planning.

In the early stages of planning an exercise intervention to reduce the risk of falling in older people, we carried out focus groups and interviews. The interview questions (which were based on the Theory of Planned Behavior) asked specifically about the perceived advantages and disadvantages of carrying out fall prevention exercises and how easy or difficult this would be to do. This study generated an extensive list of potentially relevant barriers and facilitators to uptake and adherence [48]. The focus groups asked more open questions about people's experiences and views of falls prevention. It was this study that most clearly revealed the crucial barrier—that almost all older people saw falling as meaning that they were becoming frail and dependent, and therefore they completely rejected the idea that they were at risk of falling or had any need of a falls prevention intervention [49]. This insight allowed us to identify the core characteristic of an acceptable intervention as being a positive approach to improving balance in order to maintain fitness and independence, rather than preventing falling [50].

Creating Guiding Principles to Guide Intervention Design

During the intervention planning phase, it is useful to produce guiding principles that can be consulted throughout the planning and development phases to ensure that a coherent focus underpins the intervention. The guiding principles consist of two elements: (1) intervention design objectives, and (2) key features of the intervention that can achieve these aims. The intervention design objectives articulate the intention to address the key context-specific behavioral needs, issues, or challenges that have been identified during the planning stage. By also then summarizing the key features of the intervention that will achieve these objectives, the guiding principles succinctly capture the characteristics of the intervention that should optimize its acceptability, feasibility, and therefore effectiveness.

The guiding principles are not intended to be exhaustive and do not replace the more extensive documentation of how the elements of the theoretical model underpinning the intervention map onto the behavior change techniques used. Instead, they are intended to complement this detailed planning by helping developers to summarize and easily recall and refer to features of the intervention that intervention planning has identified as central to achieving the intervention objectives. Hence, intervention planning provides a complete and generalizable map of all the generic behavior change elements in an intervention, whereas the guiding principles highlight the distinctive and particular qualities of the intervention—how it

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seeks to solve the challenges that the intervention addresses in ways that differ from previous interventions.

To provide the context for the guiding principles, it is useful to first clearly state the intervention objectives, in terms of behavior change and outcomes. It is also useful to briefly describe the key characteristics of the target users of the intervention, in terms of their psychosocial characteristics and the behavioral context in which they will be using the intervention (eg, motivation to change their behavior or potential barriers to using certain intervention components). This process can be considered analogous to systems design approaches that create "personas" and "scenarios" [51] but places more emphasis on the psychological aspects of the user and their context. Textbox 4 and Table 2 outline the process of creating guiding principles.

Textbox 4. Illustration of the process of creating guiding principles.

Context of intervention:

1. State objectives of the intervention, in terms of behavior and outcomes

For example: To support users of exercise referral schemes to increase their physical activity levels (minutes per week) for at least 12 months.

2. Briefly describe relevant aspects of users and their context

For example: People with long-term health conditions referred to an exercise referral scheme, which will provide human support for increasing physical activity. May have limited education and familiarity with computers, low baseline levels of activity, limited confidence, skills, and motivation to undertake activity.

3. Identify key behavioral issues, needs, or challenges the intervention must address.

For example: Currently low long-term adherence to activity in people referred to schemes. Qualitative research links this to barriers to undertaking facility-based education (cost, travel, time, dislike of social environment in facilities).

Create guiding principles (see Table 2):

describe key intervention design objectives

describe key features of the intervention needed to achieve objective

Table 2. Creating guiding principles.

Intervention design objectives	Key features
To help people to maintain their activity independently	Digital intervention to build autonomous motivation, self-regulation skills (eg, graded goal setting and self-monitoring) and confidence to become their own physical activity coach.
To help people maintain exercise in the long term	Focus on creating sustainable lifestyle physical activity habits rather than relying on supervised facility-based activities.
To reassure people with long-term health conditions that exercise is safe for them	Encouragement and reassurance for undertaking physical activity with long-term conditions provided in terms of condition-specific advice on consequences of activity, modeling examples of others with similar health conditions, links to local in-person support (including exercise referral scheme).

The first stage of creating the guiding principles themselves is to formulate the intervention design objectives, which serve to focus the developers' attention on the need to address these issues. For example, qualitative development work for our PRIMIT hand hygiene intervention [13] revealed that most people felt that they already washed their hands often enough; a primary aim of the intervention was therefore to convince people that washing their hands more often was necessary and beneficial [13]. Second, for each intervention design objective we identify some key features of the intervention needed to achieve the aim (Textbox 5; [11]). The intervention planning process may suggest appropriate behavior change techniques or other intervention elements. Note that the focus and content of the principles can vary greatly since the relevance of different aspects of the intervention content and delivery depend on the intervention context and the behavioral issues identified. For example, the key features might include a characteristic relevant to the technology used (such as providing only very brief intervention modules if mobile phones will be used for delivery), or perhaps the implementation setting (eg, embedding the intervention within primary care).

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Textbox 5. An illustration of creating guiding principles.

Our online weight management intervention (POWeR) was created for obese adults, to be implemented in primary care. A key objective of POWeR was for it to produce sustainable weight loss, which could be maintained in the long term.

Qualitative research conducted at the planning stage was extremely useful in helping us to understand our users' needs [11]. Our inductive interviews (N=25) highlighted that overweight adults:

- had experienced multiple previous failed attempts at dieting
- attributed previous unsuccessful weight loss attempts to feelings of deprivation and regimes that disrupted their lifestyle, were effortful and unsustainable (like calorie counting)

We therefore decided on two main intervention design objectives:

- to persuade users that the POWeR approach to weight management will be effective
- to promote long-term adherence and maintenance of weight loss

The key intervention features chosen to achieve our aims are shown below.

Key features to persuade users that the POWeR approach to weight management will be effective:

- a distinctively different approach containing new, surprising, and interesting content, eg, "POWeR tools" (self-regulation techniques)
- explicitly evidence-based, presenting scientific rationale for recommendations and proof of their effectiveness
- trusted and credible sources; developed by named team of medical and behavior change experts, non-commercial, linked to their own primary care team

Key features to promote long-term adherence and maintenance of weight loss:

- emphasis on building autonomous motivation, non-prescriptive approach (eg, no forbidden foods, choice of eating plans and goals)
- focus on creating lifestyle-compatible long-term habits (less reliance on conscious self-regulation through calorie counting, diary keeping)
- self-efficacy and positive affect promoted by encouraging and rewarding achievable goals, modeling overcoming barriers using engaging stories

Using Qualitative Research During Intervention Development, Evaluation, and Implementation

Once an intervention has been fully planned and a prototype version created, further qualitative research is essential to gain insight into whether the intervention is acceptable, interesting, persuasive, easy to use, and feasible for people to adhere to. Think-aloud interviews are particularly useful as they ask people to give their immediate reactions to every element of the intervention and allow the researcher to also observe how it is used [52]. As user feedback is gained, changes can be made to the intervention and then further interviews can be conducted to check whether the changes made are suitable. The development phase is therefore best viewed as an iterative cycle moving between user feedback and changes to the intervention.

It is important to note that this process is different from co-design with members of the target population. Sometimes developers seek the opinions of users concerning what elements and characteristics they believe the intervention should include. A potential problem with this approach is that it encourages users to try to anticipate the needs of others, which they are unlikely to do well, rather than simply reporting their own experiences and views, which they do very well. We find that users are naturally expert at telling us what they like or dislike about our intervention, but most users are understandably less able to generate effective behavior change techniques or good design solutions.

It can sometimes be difficult to decide when to implement a change based on user feedback and when not to. If feedback indicates that a feature is potentially off-putting, then it seems prudent to make improvements to the feature. Equally, if feedback reveals participant beliefs that are inconsistent with intervention content, then it makes sense to address these beliefs in the intervention. The guiding principles can be consulted to ensure that any changes implemented are consistent with these principles (Textbox 6; [11]). There are sometimes instances where practical constraints limit the ability for user feedback to be implemented. For instance, in the development phase of a decision-making tool for antibiotic prescribing, a few GPs wanted information specific to their GP practice to be incorporated into the tool, but that level of tailoring for individual practices was not feasible, so this change was not implemented [53].

Textbox 6. An illustration of making intervention modifications based on guiding principles.

In the development phase of POWeR (our online weight loss intervention), some participants were concerned at the absence of calorie counting in the intervention, as they were used to this approach in previous diets they had tried (and failed to maintain) [11]. However, calorie counting was not consistent with our core objective of promoting long-term maintenance of weight loss by creating healthy habits, rather than using onerous and intrusive self-regulation techniques. Consequently, we chose instead to explain at greater length the rationale for POWeR's use of alternatives to calorie counting (eg, making simple changes to eating habits and using weekly weighing to monitor the success of these). We also included calorie counting as an aid that could be used briefly to "diagnose" where it might be possible and beneficial to change eating habits.

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After a prototype intervention has been refined with feedback from think-aloud interview data, it is useful to ask people to try out using the intervention on their own and then afterwards interview them about their experiences. This provides insight into how people perceive and use an intervention when alone, which might be different from when a researcher is present [54]. This evaluation stage also allows participants to try out behavioral changes and provide feedback about how well the intervention supported the changes they tried. It is helpful for participants to keep a diary of aspects of the intervention that they found helpful or unhelpful, easy or hard to use, and elements they particularly liked or disliked. This can then be drawn on during retrospective interviews to aid participants in discussing aspects that were pertinent to them.

Further intervention modifications may be suggested by the findings of feasibility studies, full scale trials, or when implementing interventions "in the wild". Including qualitative studies can be extremely valuable in trial and implementation settings, where they are now recommended as part of the wider mixed methods evaluation of implementation [55]. In the implementation context, qualitative research can provide detailed information about how participants experience the intervention and allow exploration of factors or processes that might be involved in adherence to or outcomes from the intervention, enabling researchers to further optimize the intervention (Textbox 7; [56]).

Textbox 7. An illustration of the use of a qualitative study in a feasibility trial.

We designed an online intervention (SPaCE) to support parents and caregivers of young children with mild to moderate eczema. Qualitative interviews carried out in the context of our feasibility trial of SPaCE revealed that the majority of participants who received health care practitioner support in addition to the website did not find it more helpful than the website alone [56]. As the health care practitioner support was not highly valued and as trial findings showed it did not lead to better outcomes, support was therefore removed from SPaCE for the main trial.

Practical Considerations

One potential problem that researchers face when carrying out changes to their interventions in the development phase or following evaluation phases is the potential for changes to be costly. This sometimes means that development time can become neglected or squeezed in order to save money. This is particularly the case if computer programming or web design input must be purchased, which is often expensive, meaning that multiple iterations of changes to a digital intervention can become too costly for a researcher's budget. One solution is to create prototype versions of pages on paper (sometimes referred to by website developers as wireframes), with each page representing a screen to be shown in the intervention (eg, [53]). Some teams develop close collaborations with programmers and flexible in-house software, which makes iterative modifications of interventions less costly and time-consuming [57]. Our solution is to use LifeGuide, an open-source software platform developed by the University of Southampton that allows researchers to change intervention design and content during the development phase [58]. These changes can be made quickly and easily by the behavioral researcher, who does not need previous programming experience. However, we recognize that due to constraints on resources, it is not always feasible to implement the person-based approach fully or at every stage of intervention planning, development, and evaluation.

Common Person-Based Guiding Principles

In the previous section we outlined the process of using in-depth qualitative research throughout all stages of intervention development and evaluation. We also outlined how qualitative research during the early stages of intervention planning (coupled with insights from existing theory and evidence) can be used to inform guiding principles that identify the key design objectives and key features of the planned intervention. Through our experience of intervention development, we have accumulated a set of person-based intervention features that appear to improve acceptability and engagement in most digital interventions. The following sections describe these objectives and features, which are summarized as common guiding principles in Table 3. These common guiding principles do not provide an exhaustive or prescriptive list of the desirable qualities of an intervention but illustrate common insights that arose from the person-based development process.

Typically, users of digital interventions must feel motivated and confident to use the intervention on their own, and so we have found self-determination theory [59,60] particularly relevant to understanding how users respond to our interventions. The intervention features included within our common guiding principles have therefore been organized under three design objectives relevant to the constructs of self-determination theory. Self-determination theory predicts that intrinsic motivation to engage with health behavior change will be enhanced by supporting users' need for autonomy (ie, feeling self-directed), increasing users' sense of competence (control and confidence), and enhancing users' perceived relatedness or support from the intervention. These three objectives are closely linked and interdependent and are therefore addressed by many of the key features outlined below.

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Table 3. Guiding principles common to many interventions.

Intervention design objective	Key intervention features
To promote user autonomy	Offering users choice where possible (eg, of goals, tools, timing, method of implementation)
To promote user competence	Providing clear structure and (optional) guidance, examples, stories modeling successfully overcoming barriers, graded goal-setting, minimizing conscious effort and lifestyle disruption where possible
To promote a positive emotional experience and sense of relatedness	Using positive (autonomy-supportive) language throughout, giving rationale for advice, acknowledging and addressing concerns
	Ensuring all communications provide something interesting, enjoyable, relevant, and helpful for the user
	Reciprocating intervention usage by providing immediately rewarding feedback
	Following best practice to maximize accessibility, usability, and trust

Promoting Autonomy

In all of our interventions, we seek to enhance intrinsic motivation (for both intervention usage and engaging with health behavior change) by support users' need for autonomy. We consider supporting users' autonomy to be vital for all our interventions because it can encourage users to internalize the advice and behavioral strategies we provide, enabling them to follow and implement these over the longer term and empowering them to become their own health coach [11,61]. Paradoxically, this could result in lower usage of the intervention itself as users become less reliant on an extrinsic guide for their behavioral choices. Promoting autonomy can be challenging, since the very purpose of an intervention and the behavior change techniques it provides are to offer extrinsic support and guidance. We therefore support autonomy by offering users a choice in how they engage with the intervention and implement the advice provided, including the goals they set, strategies they use, and aspects of the timing, order, and delivery of intervention content [62]. For example, we have found that users are more likely to engage with particular elements of the intervention, such as electronic prompts or notifications, if they have opted to receive them and retain control over when and how frequently they are received [15]. This approach means that although we do use computer-tailoring to ensure that users are not given advice they will definitely see as inappropriate or irrelevant, where possible we allow what has been termed "self-tailoring" [63], that is, user selection of relevant topics, information, or strategies.

There can be a tension between supporting users' autonomy, while still providing clear guidance on how users can best change their behavior. Qualitative research in the intervention development phase is vital for helping us to establish what users are comfortable doing on their own and when clear directives or examples to follow are needed and appreciated. For example, our qualitative piloting of the POWeR weight management intervention showed us that users struggled to select their own appropriate healthy eating goals when asked to fill in blank response boxes. Users were much more successful at setting appropriate healthy eating goals when they were first invited to select a couple of specific, relevant, and achievable goals from a drop-down list of examples before creating one goal of their own choice [11]. Our experience fits with other studies showing that offering too much choice can be overwhelming [64] and that offering complete navigational control can result in lower intervention usage than "tunneling" core intervention content to ensure that users access essential intervention ingredients in a coherent manner (eg, working through motivational, goal-setting, and

implementation planning elements of the intervention in a logical order) [65].

Promoting Competence

Competence can be promoted by encouraging users to identify changes to their behavior that minimally disrupt their lifestyle and that can more easily evolve into healthy habits that do not rely on continued effortful self-regulation. We also try to ensure as far as possible that physical access to the intervention content fits with users' daily routines and, where appropriate, typical usage of digital devices. For example, we now design our interventions so that the content can be delivered in smaller bite-sized chunks at convenient moments in order to fit with increasing use of portable devices (eg, smartphones, tablets) as compared to more traditional computer-based "sessions" that require users to allocate a longer block of time.

We also address competence within our interventions by incorporating well-established theory-based behavior change techniques [66], such as graded goal setting (encouraging people to make small achievable behavior change steps to increase their confidence through experiences of success), social modeling of overcoming obstacles, using stories or testimonials from other users (which also increases relatedness), implementation planning [67], and providing tailored feedback based on self-reported progress towards goals (congratulating success in goal achievement and providing remedial advice if goals have not been achieved).

Promoting a Positive Experience and Relatedness

The way that behavior change techniques are communicated to people undertaking behavior change interventions is crucial to engagement and adherence, influencing how receptive they are to the advice provided. We understand that the behavior change process can be onerous and challenging and that adherence to interventions is often a low priority for users. We therefore place particular emphasis on attempting to provide users with an enjoyable, positive, and interesting experience of the intervention that can motivate intentions to engage with it

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[68,69]. Described below are a number of strategies that can be used to foster a positive intervention experience.

First, we always introduce our intervention content and behavior change techniques using a positive autonomy-supportive (ie, non-directive) tone that invites rather than instructs or directs users to try a particular tool or technique. Imperatives and words such as "should", "must", or even "we/experts recommend" are avoided wherever possible as they imply extrinsic rather than intrinsic motivation. Instead, we provide an explanation of the scientific rationale or supportive evidence and then invite users to decide for themselves whether following the suggestion will be beneficial, which promotes trust in the advice and is less likely to provoke resistance (Textbox 8; [56]).

Textbox 8. Creating a positive intervention experience by using an autonomy-supportive tone.

In our SPaCE intervention to help parents manage their children's eczema [56], behavioral suggestions and advice were introduced using phrases like "some people find it helpful to…" or "you *can* try…" that encouraged users to try out the different suggestions for themselves to see what worked best for them. Parents using SPaCE were also invited to take a 2-week challenge to increase their use of emollient moisturizers; to motivate them to do so we provided anecdotes from other people's experiences of how they got the most out of using emollients for managing their child's eczema and how they benefited from the 2-week challenge (eg, "I started using an emollient chart when my daughter got a bit older, and it was great for getting her involved in looking after her skin").

Relatedly, we ensure that feedback uses non-judgmental language at all times, which can also enhance perceptions of relatedness by showing users that they are respected. For example, knowledge quizzes are a core element of "Healthy Living with Diabetes", an intervention developed for people with lower levels of health literacy to encourage physical activity in people with diabetes (ISRCTN43587048). Feedback on incorrect answers is phrased as "surprise" rather than "wrong" and also reassures users that giving an incorrect answer is alright and perhaps even expected (eg, "it is not surprising that you think that controlling your sugar levels is the most important thing to do in diabetes—in the past, this is what doctors thought too"). Similarly, users of the POWeR weight management intervention who do not make progress toward their goals are first congratulated for persevering or reassured that slow progress is normal before remedial advice is offered (eg, "don't worry, many people have weeks like this" or "don't be too hard on yourself! It is important to give yourself credit after you have had a slip, rather than telling yourself off, especially if you have managed to stop at the slip").

Acknowledging and addressing users' concerns about using an intervention or implementing its advice can also help to earn users' trust by showing them that they are understood and listened to. The inductive qualitative research we conduct during the intervention planning and development phases can help to identify the specific concerns, barriers, and misconceptions that users may have about the intervention itself or the behavior change process. The intervention can then be modified so that these concerns are acknowledged and addressed before seeking to change users' knowledge, attitudes, or behaviors (Textbox 9; [13]).

Textbox 9. Enhancing relatedness by acknowledging and addressing beliefs and concerns.

Qualitative piloting of the PRIMIT intervention to promote hand hygiene [13] revealed that users were concerned that frequent hand-washing might be obsessive and could lead to dry skin. Many people also believed that respiratory viruses were transmitted entirely by air and not by hand-to-mouth contact. To address concerns about hand-washing, we provided advice on how to use moisturizers to prevent dry skin and modeled frequent hand-washing as considerate and prudent rather than obsessive behavior. We also included at an early stage of the intervention compelling evidence that hand-washing could reduce flu transmission. An FAQ section was added collating answers to other common problems and concerns revealed by our qualitative piloting.

A second key feature of our interventions is to ensure that all communications provide something useful and relevant for the user. In focus groups we ran with young adults to explore their experiences and views of health apps, we discovered that users can be extremely annoyed by email prompts or push notifications and may actually feel harassed by them [15]. We therefore try to ensure that prompts and notifications create a positive experience by incorporating new, additional intervention content that offers something useful or interesting to the individual users at the time it is received [70]. For example, notifications triggered by a smartphone-based intervention for stress management ("Healthy Mind") (ISRCTN67177737) give users new, interesting facts about a tool in the app before inviting them to actually use it (eg, "did you know that thinking positively can protect your body against stress? That's because positive emotions lower your heart rate and blood pressure after something stressful happens").

Similarly, we try to provide our users with some immediately useful and rewarding communication (eg, tailored feedback) in return for any time spent completing intervention activities (eg, self-reflection, self-monitoring, answering knowledge quizzes). Think-aloud studies conducted alongside the development of an intervention to support the self-management of minor stomach and bowel complaints ("Gut Instincts") showed us that users preferred intervention usage to be a reciprocal interaction [71]. Users' interest in reflecting on or answering questions about their symptoms, thoughts, or behaviors was maintained only if this was immediately reciprocated by appropriate personalized feedback. Our experiences are consistent with findings from reviews showing that self-monitoring tools are most effective when they also provide feedback on users' performance or progress [72,73].

Finally, we follow existing best practice for maximizing the accessibility, usability, and credibility of the intervention for a wide range of people, including those with lower levels of literacy [74] or cognitive impairments [75] (eg, using short sentences, list and audio-visual formats, tailoring where appropriate). We follow existing guidance on usability and

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interface design to ensure that users can navigate and process our interventions as quickly and painlessly as possible (eg, large font size/buttons, minimal scrolling/clicking, consistent page layouts, clear signposts, etc [76,77]). We recognize that users can become overwhelmed or bored if presented with too much information to read, process, and implement in one go. To minimize this, we present only the information that is essential for the user to read at a specific point in time with any additional non-essential information provided as an optional click-through [9].

There is already a wealth of literature and published guidelines that suggest further strategies for enhancing trust in and credibility of interventions [78-82]. These include providing options to receive personally relevant or tailored information; a professional and consistent visual appearance; error free and up-to-date content; usable interface; provision of supporting evidence for the information provided; details and credentials of the team responsible for developing the intervention; providing reassurances about what data are collected from users, how that data will be used in the delivery of the intervention, and how that data will be securely stored; and opportunities to contact and provide feedback to the intervention team (either via the intervention or in a follow-up interview).

Conclusions

The purpose of the person-based approach is to ground intervention design in a rigorous, in-depth understanding of the psychosocial context of the people who will use the intervention, derived from iterative in-depth qualitative research. This approach can be used in the development of any intervention involving self-management but has particular relevance to optimizing autonomous engagement with digital interventions. In this context, the person-based approach could readily be integrated with and contribute to user-centered design by highlighting the psychosocial issues relevant to the behavioral change process, in addition to the (equally important) issues relating to usability and engagement with technology that are traditionally the principal focus of user-centered design.

The person-based approach can also usefully complement theory-based and evidence-based intervention development; indeed, it seems self-evident that intervention design can benefit greatly from being not only theory-based and evidence-based but also person-based. Theory-based and evidence-based approaches to intervention development provide a comprehensive and generalizable analysis of all the potentially relevant theoretical constructs and behavior change techniques, and evidence for which have proven effective in other contexts. However, the person-based approach is crucial for identifying which intervention design features are likely to be most important in the context of a particular population and intervention and provides sensitive guidance on how to implement them in a way that will be acceptable and persuasive to users.

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Conflicts of Interest

None declared.

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Original Paper

Mobile-Web App to Self-Manage Low Back Pain: Randomized Controlled Trial

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Abstract

Background: Nonspecific low back pain (NLBP) is the diagnosis for individuals with back pain that has no underlying medical cause (eg, tumor, infection, fracture, herniated disc, spinal stenosis). The American College of Physicians (ACP) and American Pain Society (APS) recommend multidisciplinary treatments for NLBP that lasts more than 4 weeks. This approach, however, is impractical for many physicians to implement, and relatively few providers offer NLBP treatment that meets the joint ACP-APS guidelines.

Objective: This study evaluated the efficacy of a mobile-Web intervention called "FitBack" to help users implement self-tailored strategies to manage and prevent NLBP occurrences.

Methods: A total of 597 adults were recruited, screened, consented, and assessed online at baseline, at 2 months (T2), and at 4 months (T3). After baseline assessments, participants were randomized into three groups: FitBack intervention, alternative care group that received 8 emails urging participants to link to six Internet resources for NLBP, and control group. The FitBack group also received weekly email reminder prompts for 8 weeks plus emails to do assessments. The control group was only contacted to do assessments.

Results: Users of the FitBack program showed greater improvement compared to the control group in every comparison of the critical physical, behavioral, and worksite outcome measures at 4-month follow-up. In addition, users of the FitBack program performed better than the alternative care group on current back pain, behavioral, and worksite outcomes at 4-month follow-up. For example, subjects in the control group were 1.7 times more likely to report current back pain than subjects in the FitBack group; subjects in the alternative care group were 1.6 times more likely to report current back pain at 4-month follow-up. Further, the users of the FitBack program showed greater improvement compared to both the control and alternative care groups at 4-month follow-up on patient activation, constructs of the Theory of Planned Behavior, and attitudes toward pain.

Conclusions: This research demonstrated that a theoretically based stand-alone mobile-Web intervention that tailors content to users' preferences and interests can be an effective tool in self-management of low back pain. When viewed from the RE-AIM perspective (ie, reach, efficacy/effectiveness, adoption, implementation fidelity, and maintenance), this study supports the notion that there is considerable value in this type of intervention as a potentially cost-effective tool that can reach large numbers of people. The results are promising considering that the FitBack intervention was neither supported by professional caregivers nor integrated within a health promotion campaign, which might have provided additional support for participants. Still, more research

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is needed on how self-guided mobile-Web interventions will be used over time and to understand factors associated with continuing user engagement.

Trial Registration: Clinicaltrials.gov NCT01950091; http://clinicaltrials.gov/ct2/show/NCT01950091 (Archived by WebCite at http://www.webcitation.org/6TwZucX77).

(J Med Internet Res 2015;17(1):e1) doi:10.2196/jmir.3130

KEYWORDS

low back pain; Internet; mobile; app; computers; prevention; self-treatment

Introduction

Nonspecific low back pain (NLBP), defined here as temporary back pain with no medical signs of a serious underlying condition (eg, cancer, infection, fracture, spinal stenosis) [1], is a pervasive and expensive public health problem in the United States [2-4], experienced by four out of five adults at some point in their lives [5,6]. Back pain is the leading cause of work-related disability and one of the most frequent reasons patients visit a doctor [7,8]. Costs incurred by US back pain sufferers are staggering, estimated at US $90.7 billion [9] and growing [2,10]. People with back pain spend 60% more on health care than those without back pain [10,11]. Most people with low back pain do not visit a physician [12,13] because episodes of NLBP resolve spontaneously [14], but of those who do see a doctor, 30% experience pain and disability a year later [15] and few return to normal activities [14].

Businesses lose 100 million work days per year [11], with back pain accounting for 5.5% of *all* productivity loss in the United States—about US $2,200 per employee per year [16,17]. Even employees with minor back pain lose 4.6 hours of productivity a week due to decreased performance on the job [18,19]. Beyond its economic toll, NLBP causes significant physical and psychological suffering [20,21].

Although no consensus has been reached about the best treatment for NLBP, multidisciplinary approaches reduce employee sick leave [22-24] and are cost-effective [25,26], and early NLBP management is the best approach to preventing chronic back pain [14]. Individuals who experience an episode of acute NLBP can become caught in a cycle of chronic pain and disability if they avoid appropriate activity in fear of exacerbating their pain [27,28]. Recommended NLBP treatments often involve specialized clinics, which are costly and not widely available [6,26,29,30], and insurance companies often don't cover multidisciplinary treatments [15,31]. The Joint Clinical Practice Guidelines from the American College of Physicians and American Pain Society [1,32] recommend inclusion of psychosocial assessments and multidisciplinary treatments that last more than 4 weeks for back pain, but such care plans are not normally conducted [30] because most physicians lack sufficient time and training to implement recommended procedures [6,26].

An alternative approach is to develop an NLBP intervention that could be widely available online without requiring medical supervision. Although many websites offer education or treatment, none offer self-management interventions for NLBP that have been empirically tested for efficacy. We developed "FitBack", an online program with responsive design architecture (accessible to computers and mobile devices) [33] that provides a self-management intervention that promotes use and self-monitoring of cognitive and behavioral strategies to improve self-care and back pain prevention behaviors with tailored information and support using gain-framed messaging [34,35].

In the research reported here, we tested FitBack in a randomized design (Clinicaltrials.gov NCT01950091) with a population of adults at increased risk for chronic back pain due to a recent episode of NLBP. We hypothesized that the intervention would improve self-reported outcomes of pain, functionality/quality of life/well-being, engagement in behaviors to help or prevent back pain, work productivity, and that it would be correlated with theoretically relevant psychosocial mediators of behavior change (patient activation, knowledge, attitudes, self-efficacy, behavioral intentions), and that user acceptance would be positive.

Methods

Intervention Program

FitBack is a multiple-visit online program that provides adults with NLBP education and behavioral strategies to manage current pain and prevent future pain episodes. The app's responsive design approach [33] allows users to access the program from multiple devices and screen sizes (mobile phone, tablet, computer). The interactive framework was developed in consultation with a panel of pain professionals with expertise in orthopedic surgery, physical therapy, and pain psychology. These experts also helped develop content, approved scripts, and participated in app reviews during the development of FitBack. Care was taken to recommend only activities that the participants could do safely with minimal equipment while unsupervised.

The intervention uses a self-tailored cognitive-behavioral approach, based on (1) expert panel and American Pain Society (APS) recommendations [1], (2) formative research in this and previous online physical activity studies with sedentary individuals (NCT01579240) [36,37], (3) the theoretical benefits of behavioral control espoused in social cognitive theory (SCT) [38,39], and (4) the Theory of Planned Behavior (TPB) [40,41]. The FitBack user experience is designed to allow users control over the cognitive and behavioral strategies they use to impact their NLBP and to develop and support users' self-efficacy related to pain management and prevention. Interventions based on TPB have recently been shown to produce large effects on behavior in online interventions [42].

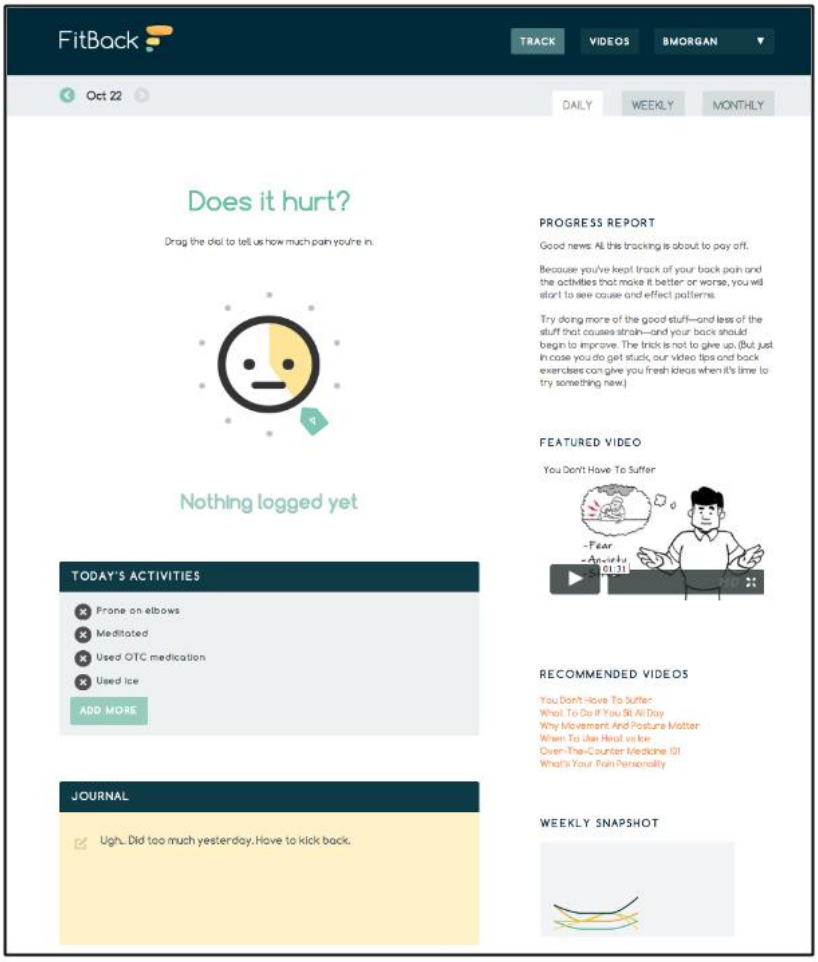
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Using a pain and activity self-monitoring tool and gain-framed text and video messages, FitBack helps users develop a self-tailored approach to manage any current NLBP and activate behaviors for prevention of future NLBP. Text articles and videos are segmented to address issues and self-care activities specific to job type: people who sit most of the day (sitters), stand most of the day (standers), drive most of the day (drivers), and do a substantial amount of lifting each day (lifters).

The FitBack intervention is designed to encourage users to adopt appropriate pain prevention behaviors, tracking them against self-reported pain level during brief repeat interactions. Users receive weekly emails with gain-framed pain self-care messages and prompts to return to the FitBack program to track pain and self-care activities. At each return visit, users are encouraged to report their current level of back pain using a 10-point "pain dial" (Figure 1) adapted from the Wong Baker pain scale [43]. Users also track their daily pain management activities using an "activity picker" populated with pain self-care activities in four categories (rest and relief, mindfulness, general fitness, and back pain-specific stretching and strength exercises) developed with the panel of pain experts and physicians. The activity picker also allows users to add their own custom activities. A journaling feature prompts users to record notes and experiences related to their pain management efforts. FitBack provides users with simple 7-day and 30-day graphs to identify trends in pain level as associated with each category of self-management activity.

Users have unlimited access to 30 brief (1-4 minute) videos on general aspects of pain and pain management, cognitive and behavioral strategies to manage and prevent pain (eg, controlling fear of pain, mindfulness and relaxation, use of heat and ice, over-the-counter medications, benefits of staying active), and instructional videos on specific strength and stretching exercises tailored by job type (sitter, stander, driver, lifter). Videos used gain-framed messaging delivered by an animated whiteboard-style coach (Figure 1) and behaviorally focused live-action instructional videos on ergonomics and exercises. Messages in the weekly emails, links within the activity picker, and recommendations within the FitBack program repeatedly link users to the video content.

Figure 1. FitBack daily tracking page. Users indicate intensity of current pain (top left), can add current pain prevention activities (middle left), and use the journal tool (bottom left). Users can access featured and recommended videos (right) and charts of activities and pain (snapshot and link bottom right).



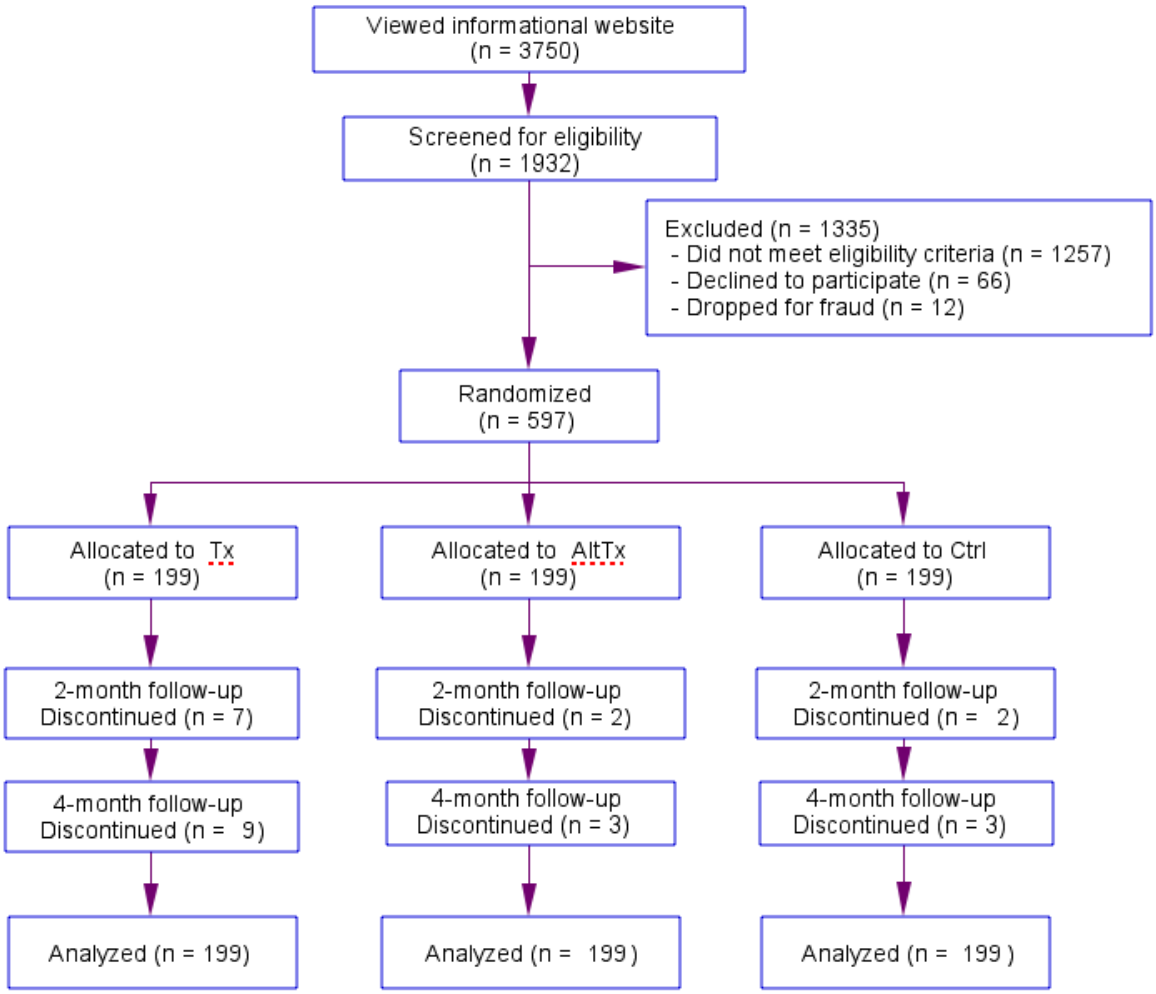
Research Design

The study was a 3-arm randomized controlled trial on the Internet with three assessments: pre-test (T1), post-intervention at 8 weeks after pre-test (T2), and post-intervention at 16 weeks after pre-test (T3; see Figure 2). After screening into the study, agreeing to the online informed consent, and submitting the T1 assessment, the total sample of 597 participants was randomized

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into (1) treatment group (n=199), which used the FitBack intervention, (2) alternative care group (n=199), which received 8 emails with links to 6 websites with information about low back pain, or (3) usual care control group (n=199), which only received emails as requests to complete the assessments.

Figure 2. Research design flowchart for FitBack program evaluation.



Recruitment

Overview

After approval by an Institutional Review Board (IRB) for protection of human subjects, the study was conducted entirely on the Internet, with recruitment and assessments hosted by Survey Console, a provider of online survey tools. The study was conducted in partnership with a large health insurer who promoted the project to client companies.

Four companies (trucking, manufacturing, technology, and a corporate headquarters) with a total of approximately 12,000 employees agreed to promote the research project via their preferred in-house communication channels. Some companies relied on flyers and hard copy media, whereas others used the company website, electronic media, and email.

Recruitment efforts were launched simultaneously in all four companies, but after 30 days, fewer than half the desired number of participants had signed up, and visits by potential participants to the informational website (see below) had declined dramatically. Consequently, while recruitment by the four companies continued, we initiated supplemental online recruitment of participants not affiliated with the four companies via online resources (eg, trucker websites, craigslist and other online classified ads, Facebook). We also sent emails to 1200 participants from previous unrelated research projects who had indicated an interest in possible involvement in future projects.

Eligibility

Participants recruited through collaborating companies were required to (1) be 18 to 65 years of age living in the United States (because it was a National Institutes of Health Small Business Innovation Research grant), (2) be employed at least half time (which is typical for employees to receive health benefits), retired, or a family member of an employee at one of the four collaborating companies; one participant per family, (3) have experienced low back pain within the past 3 months, (4) not be experiencing back pain so intense it interfered with

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everyday life, (5) have no history of medical care for back pain or prescription medications for back pain, (6) not be participating in a monitored exercise program for back pain, (7) have a working email address, (8) respond to an online video demonstrating that they had access a computer that could play video on the Internet, and (9) be cleared of medical risks by an online screening survey (see below). When recruitment was expanded to open Internet enrollment, a new parallel online screening process was developed with the same requirements, except that all potential participants were required to report that they were employed at least half time with any employer.

Participant Screening

Interested individuals linked to an information website that described the research project and eligibility requirements. If still interested, they linked from there to a 5-15 minute online screening questionnaire to determine eligibility. The online screening questionnaire collected information on demographics, employment status, workplace, and possible medical risk factors.

The screening survey included 40 required questions about back pain history, including current and recent pain (ie, current back pain intensity of 6 or higher; no back pain in past 6 months; continuous back pain for more than 3 months; taking medication for back pain; on a monitored exercise plan for back pain) and health conditions that might contribute to back pain (ie, cancer, infection, fracture risk, cauda equina syndrome, rheumatoid arthritis, numbness in arms or legs, major muscle weakness). These questions were adapted from an instrument developed by the APS [1,32] in consultation with the panel of pain experts and physicians to identify potential study participants whose medical condition might be compromised by participating in the research. Individuals who did not meet the back pain history (n=468), medical (n=706), or other eligibility (n=83) criteria were not accepted to participate (Figure 2).

Procedures

Overview

After submitting the screening survey, eligible individuals were emailed a link to an informed consent. Participants read and agreed to the consent, after which they provided contact information, including email, mailing address, and telephone number. After their data were checked for fraud (see below), participants were emailed a link to the T1 assessment. Personal privacy was protected with a unique user ID and password for each participant.

After submitting the T1 assessment, each participant was emailed his or her experimental group assignment (treatment, alternative care, or control group). Intervention and alternative care group members subsequently received 8 weekly reminder emails to either log on to FitBack (treatment) or access the 6 website links included in the email (alternative care). The automated emails were delivered via Mail Chimp, an online email campaign service provider.

The protocol for prompting intervention participants who failed to submit assessments within 4 days of the first email included up to 4 email reminders at 3-day intervals, followed by a telephone call about 10 days after the fourth email reminder. The call attempted to verify that technical difficulties were not responsible for the lack of participant communication. This protocol was developed based on our experiences in other online studies and was approved by our IRB. We believe that it allowed for conscientious follow-up of participants without undue harassment.

Group Assignment

Intervention group members received log-in information and a link to the FitBack intervention website, and were enrolled to receive the 8 program emails with content and prompts related to NLBP self-management (described above). Participants who did not make an initial visit to FitBack within 2 weeks (17/199, 8.5%) of the assignment email were telephoned once by the research staff. The call was framed as a check-in to verify the participants were receiving the emails, and the caller encouraged the recipient (during a telephone interaction or via voicemail) to visit the program. Participants were not contacted further by the research staff, and we did not attempt to determine who clicked to open their reminder messages.

The alternative care group received an initial email and 8 reminder emails, each of which included links to 6 websites about NLBP [44-48]. The websites provided a choice of popular, educational, and medically oriented online resources. We did not attempt to follow up with participants who did not open their emails.

After the initial group-assignment email, control group members were contacted by email only with links to the T2 and T3 assessments.

Assessments

Two months after submitting their T1 assessment, participants were emailed a link to the T2 survey. After T2, use of FitBack by treatment group participants and the list of websites for the alternative care group remained available, but reminder emails were discontinued. Two months after T2 (4 months after T1), participants were emailed a link to the T3 assessment. The protocol to encourage submission of T2 and T3 assessments was similar to that used for T1 assessments. All participants were mailed a check after submitting each assessment: US $40 for T1, US $50 for T2, and US $60 for T3. Participants in the treatment and alternative care groups received no financial incentives to use the websites made available to them.

Fraudulent Activity

A problem with Internet studies is that researchers are rarely in direct contact with participants. Our previous online studies have found some applicants each time who attempt to screen-in to a study by providing false information (eg, same name or IP address shows inconsistent age, gender, ethnicity, or country) [36,37,49-51]. Consequently, in this study, participant demographic data was checked for fraudulent information against our database of about 20,000 records of previous Internet study applicants, and 12 individuals were dropped (Figure 2). To prevent fraudulent attempts to qualify by subsequently re-taking the screening survey and changing responses, disqualified applicants were not informed about exactly why they had not qualified.

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Measures

Physical Outcomes

Back Pain

An individual's back pain is an indicator of physical quality of life [52]. Participants' current back pain was assessed with a Yes/No item: "Do you have low back pain now?" In addition, a set of back pain measures asked about level of back pain, frequency of back pain, intensity of back pain, and duration of back pain.

Functionality, Quality of Life, and Well-Being

Functionality and Quality of Life

A 10-item scale, adapted from the Multidimensional Pain Inventory Interference Scale (MPI) [53] and the Interference Scale of the Brief Pain Inventory [54], assessed functionality and quality of life during the past 2 months. Participants were asked how back pain interfered in different areas of their lives (day-to-day activities, mood, and productivity at work). Response options were on a 10-point scale (1=does not interfere, 10=completely interferes). The scale showed good reliability (alpha=.94).

Dartmouth CO-OP (Function, Well-Being, and Quality of Life)

The 9-item Dartmouth CO-OP (Dartmouth Primary Care Cooperative Information Project) scale [55] measures different aspects of patient health status, including function (physical endurance, emotional health, role function, and social function), well-being (overall health, change in health, level of pain), and quality of life (overall quality of life and social resources/support). Response options were on a 5-point scale with a higher score indicative of poorer health status for each scale. A total sum score was computed, and the scale showed adequate reliability (alpha=.78).

Behavioral Outcome

Prevention-Helping Behaviors

Four items were designed for the study to assess how often in the past 2 months participants engaged in behaviors intended to help or prevent back pain (eg, In the last 2 months, how often did you do exercises specifically to prevent recurrence of your back pain?). Response options were on a 5-point scale and a mean score computed with a higher score indicative of more engagement in helping behaviors. The measure showed acceptable reliability (alpha=.76).

Worksite Outcomes

Worker Productivity

The 4-item Work Limitations Questionnaire (WLQ) [56] was used to assess the degree to which a participant's back pain interfered with work (eg, In the past 2 weeks, how much of the time did your physical health or emotional problems make it difficult for you to get going easily at the beginning of the workday?). Response options were on a 5-point scale and a mean score computed with a higher score indicative of greater productivity. The scale showed adequate reliability (alpha=.76).

Presenteeism

The 6-item Stanford Presenteeism scale [57] was adapted to assess the extent to which workers' back pain inhibited them from doing their jobs (eg, Despite having my back pain, I was able to finish hard tasks in my work.). Response options were on a 5-point scale and mean score computed with a higher score indicative of more effective work practices. The scale showed adequate reliability (alpha=.77).

Other Constructs

Patient Activation Measure

The Patient Activation Measure (PAM) is a reliable probabilistic scale that assesses activation of patients to take responsibility for their own health [58,59]. A 10-item scale was adapted from the PAM short form to reflect care for low back pain. Participants were asked about their perceptions of taking responsibility for care for their low back pain. Response options were on a 4-point scale and a mean score computed with a higher score indicative of better functioning. The scale showed good reliability (alpha=.79).

Theory of Planned Behavior Constructs

Knowledge

A total of 14 items based on teaching points in the program assessed improvement in knowledge about back pain (eg, Fear and worry do not influence the intensity of low back pain. When your back hurts, doing simple back exercises many times a day is the best remedy). Item response options were "true" and "false". The number of correct items was summed and divided by total number of items to reflect the proportion of items answered correctly.

Behavioral Intentions

The TPB suggests that behavioral intentions can predict adoption of new behaviors [40,41]. To assess participant intentions to perform the activities recommended in the program, a 14-item scale was created (eg, The next time you experience back pain, how likely is it that you will take action to use the right amount of activity to help you get better faster?). Response options were on a 7-point scale and a mean score computed with a higher score indicative of more intention to perform the activities. The scale showed good reliability (alpha=.90).

Self-Efficacy

The importance of behavioral self-efficacy to engage in recommended behaviors is supported by both social cognitive theory [38,39] and the TPB [40,41]. To assess this construct, a 13-item scale was developed. Participants were asked how confident they were in their ability to use the behaviors recommended in FitBack (eg, How confident are you in your ability to use back exercises to reduce your low back pain?). Response options were on a 7-point scale (1=not at all confident, 7=extremely confident) and a mean score computed with a higher score indicative of greater levels of self-efficacy to use the practices taught in the program. The scale showed good reliability (alpha=.93).

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Attitudes Toward Pain

Attitudes toward pain complicate perceptions of pain and quality of life [52,60] and are linked by the TPB to self-efficacy and intentions to attempt behavioral remedies [40,41]. A 10-item adaptation of the short version of the Survey of Pain Attitudes (SOPA) [61,62] focused on two of the seven pain domains of the SOPA. The items formed two subscales: a 6-item control scale to assess the extent to which a person believes he or she can control pain, and a 4-item emotion scale to assess the extent to which a person believes his or her emotions affect the experience of pain. Response options were on a 5-point scale and a mean score computed for each scale with a higher score indicative of more positive attitudes. Both the control and emotion scales showed good reliability (alphas=.81 and .95, respectively).

Catastrophizing of Pain

Fear of pain might indicate vulnerability or a tendency to catastrophize about a painful problem. A 4-item scale that explains 54% of the variance of the Tampa Scale for Kinesiophobia [63] was adapted to assess the degree to which a participant catastrophizes pain with a focus on back pain (eg, My back pain puts my body at risk for the rest of my life). Items were assessed on a 4-point scale and a mean score computed with a higher score indicative of greater levels of catastrophizing. The scale showed adequate reliability (alpha=.77).

Process Outcomes

User Satisfaction

Four items were administered at T2 and T3 to both treatment and alternative care group participants for comparison purposes. They included satisfaction with information on back health provided, likelihood of recommending the resources to a friend, value for self-treatment of low back pain, and value for preventing back pain occurrence. Response options were on a 7-point scale with a higher score indicative of greater satisfaction with the program.

Website Usability

The System Usability Scale (SUS) is a 10-item survey [64] for assessing the usability of a product, including websites, cell phones, interactive voice response systems, and TV applications [65]. We used it to ascertain participants' attitudes toward the functionality of the FitBack program. It consists of five positively worded items (eg, I think that I would like to use FitBack frequently) and five negatively worded items (eg, I found FitBack unnecessarily complex) on a 5-point agree-disagree rating scale. When scoring the SUS, the items are rescaled so that when they are summed they range from 0 to 100. An overall sum score was computed with a higher score indicative of more positive attitudes toward the program. The SUS can be scored as a percentile rank and compared with 500 other studies in a process comparable to grading on a curve, with a score of 68 considered average [64,65].

Perceptions of Employers

Five items were used to assess how employees would view an employer who made the FitBack program available. The stem was "If my employer made FitBack available to all company employees", and responses included, "I would feel like my company cares about me"; "I would feel a greater commitment to my company". Response options were on a 6-point scale with a higher score indicative of a more favorable impression of the employer.

Understanding and Implementation Survey

A 7-item survey was designed to ascertain to what degree the participant understood and implemented the teaching points of the FitBack program (eg, Did you understand program recommendations about using heat or ice to help deal with back pain when it occurs?). Categorical response options were "yes", "yes, somewhat", "no", "not much", and "not at all".

Statistical Methods

Preliminary Analysis

Chi-square tests and one-way analysis of variance models were used to compare the three groups to determine whether the groups differed at baseline on the demographic characteristics, the outcome measures, and the mediating measures. None of these analyses was found to be statistically significant at $P<.05$, suggesting randomization produced initially equivalent groups.

All 597 participants completed the T1 assessment, 586 (2% attrition across all participants; n=11; 7 treatment, 2 alternative care, 2 control) completed T2, and 582 (3% attrition across all participants; n=15; 9 treatment, 3 alternative care, 3 control) completed T3 (Figure 2). Participants who completed all three assessments (580/597, 97.1%) were compared to those who did not (17/597, 2.8%) on study condition, demographic characteristics, baseline outcomes, and baseline back pain measures. No statistically significant differences were found with the exception of the baseline intention score. Participants who did not complete all three assessments had significantly ($t_{594}=2.22$, $P=.049$) lower intention scores than those who did complete all assessments (3.45 vs 4.07, respectively). However, mean differences were associated with a small effect size (Cohen's $d=.27$) [66].

Missing Data

Rates of missing data ranged from 0-5% at T1, 2-5% at T2, and 3-8% at T3. Despite the low rates of missing data, one fully imputed data set was generated for this intent-to-treat analysis as it produces less bias then other missing data techniques, such as list-wise deletion and last observation carried forward [67]. Missing data were imputed using IVEWare [68], which uses all available data to impute missing data via a sequential regression approach. The observed and imputed data were compared to ensure they showed similar distributions [69].

Analytic Models

The critical analysis focused on the physical outcome measure of current pain, which ascertained whether or not a study participant was currently experiencing back pain ("yes" or "no" response option). Logistic regression models were used to determine whether study condition predicted current back pain status at T2 and T3, separately, with the T1 response as a covariate.

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All other analyses of outcome measures and mediating constructs utilized multivariate analysis of covariance (MANCOVA) models to test for group differences on study outcomes at T2 and T3, separately, with the T1 score as a covariate and study condition as a three-level predictor (1=treatment, 2=alternative care, 3=control). If the overall test was significant, then follow-up planned contrasts (treatment vs alternative care and treatment vs control) were examined. Eta-square is provided as a measure of effect size with the convention .01 small, .06 moderate, and .14 large [66]. Finally, independent *t* tests were used to compare the FitBack participants and alternative care participants on four program satisfaction items administered as part of the T2 and T3 surveys.

Results

Participants

Participants were 597 workers recruited from our worksite partner (n=244) and the general work population (n=353). Worker job types and other demographic information are shown in Table 1. About half of the participants (302/597, 50.6%) indicated they currently had low back pain. Chi-square statistics and associated *P* values show that experimental groups did not differ on demographic characteristics. All analyses reported in the analysis section below were also completed with worker recruitment type (ie, worksite partner vs general work population) as a factor in each analysis. These analyses found no significant effect for the interaction of worker recruitment type and condition. That is, there were no differential condition effects across worker recruitment type. Thus, this factor and interaction were dropped from all the analysis models.

Participant-reported pain characteristics for each of the three study conditions are described in Table 2. Chi-square tests were computed to compare groups on all items; only one item (duration of pain) was significantly different (*P*=.04) with the control group and treatment group reporting somewhat higher percentages in two different response categories.

Analyses

Physical Outcomes

Current Back Pain

Rates of current back pain were 48%, 54%, and 50% for the treatment, alternative care, and control participants, respectively, at T1 (χ^2_{597}=1.78, *P*=.41); 42%, 46%, and 49% at T2 (χ^2_{597}=2.00, *P*=.37); and 29%, 41%, and 41% at T3 (χ^2_{597}=7.61, *P*=.02). Two contrasts were created: treatment (=0) vs control (=1) and treatment (=0) vs alternative care (=1). Logistic regression models were run with the contrasts as the outcomes, with T2 and T3 current back pain scores as predictors, while controlling for T1 current back pain score. Current adjusted back pain status at T2 was not a statistically significant predictor of either contrast. At T3, however, current adjusted back pain status was a significant predictor for both the treatment vs control (OR 1.72, 95% CI 1.11-2.68, *P*=.02) and treatment vs alternative care (OR 1.60, 95% CI 1.03-2.50, *P*=.035) contrasts. Subjects in the alternative care group were 1.6 times more likely to report current back pain than subjects in the FitBack treatment group and subjects in the control group were 1.7 times more likely to report current back pain than subjects in the FitBack treatment group.

Back Pain Measures

Table 3 provides means and standard deviations for all other outcome measures and the other constructs at each time point across all three study conditions, and Table 4 provides the results of the MANCOVA models testing for group differences at the T2 and T3 assessments, including effect size measurements. The overall *F* for the back pain measures was significant at T3, but not at T2. The treatment vs control follow-up comparison was statistically significant at T3, but not at T2.

Functionality, Quality of Life, and Well-Being

For this physical outcome measure, the overall tests were significant at both T2 and T3. In addition, the treatment vs control follow-up comparison was statistically significant at both T2 and T3.

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Table 1. Study demographic characteristics.

	Treatment n=199		Alternative care n=199		Control n=199		χ^2 (df)	*P*
Characteristic	n	%	n	%	n	%		
Female	116	58.3	117	58.8	125	62.8	1.02 (2,597)	.600
Hispanic/Latino	20	10.1	24	12.1	23	11.6	0.44 (2,597)	.804
Race							10.31 (10,597)	.413
American Indian/Alaskan Native	2	1.0	1	0.5	1	0.5		
Asian	14	7.0	10	5.0	11	5.5		
Black or African American	16	8.0	17	8.5	10	5.0		
White or Caucasian	152	76.4	158	79.4	163	81.9		
Multiracial	12	6.0	6	3.0	5	2.5		
Other/unknown	3	1.5	7	3.5	9	4.5		
Marital status							11.82 (8,597)	.159
Married or living with a partner	126	63.3	139	69.8	144	72.4		
Divorced	20	10.1	15	7.5	23	11.6		
Widowed	1	0.5	2	1.0	0	0.0		
Separated	7	3.5	3	1.5	6	3.0		
Single	45	22.6	40	20.1	26	13.1		
Highest level of education							8.77 (8,597)	.362
Less than high school graduate	2	1.0	0	0.0	2	1.0		
High school graduate/GED	24	12.1	16	8.0	13	6.5		
Some college	57	28.6	64	32.0	75	37.7		
College degree	75	37.7	78	39.2	76	36.7		
Graduate school	41	20.6	41	20.6	36	18.1		
Annual household income (USD)							11.70 (10,597)	.306
Less than $20,000	10	5.0	9	4.5	13	6.5		
$20,000 - $39,999	38	19.1	28	14.1	36	18.1		
$40,000 - $59,999	45	22.6	38	19.1	52	26.1		
$60,000 - $79,999	37	18.6	34	17.1	24	12.1		
$80,000 - $99,999	26	13.1	29	14.6	29	14.6		
More than $100,000	43	21.6	61	30.7	45	22.6		
Employment status							12.75 (12,597)	.388
Full time	144	72.4	143	71.9	143	71.9		
Part time	28	14.1	31	15.6	30	15.1		
Retired	3	1.5	1	0.5	0	0.0		
Volunteer	3	1.5	0	0.0	2	1.0		
Homemaker	15	7.5	17	8.5	17	8.5		
Unemployed	1	0.5	6	3.0	4	2.0		
Non-working student	5	2.5	1	0.5	3	1.5		
Worker classification							1.82 (6,597)	.936
Sitter	124	62.3	124	62.3	124	62.3		

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	Treatment n=199		Alternative care n=199		Control n=199		χ^2 (df)	*P*
Characteristic	n	%	n	%	n	%		
Stander	50	25.1	51	25.6	49	24.6		
Lifter	22	11.1	23	11.6	22	11.1		
Driver	3	1.5	1	0.5	4	2.0		

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Table 2. History of back pain.

	Treatment n=199		Alternative care n=199		Control n=199		χ^2 (df)	*P*
History	n	%	n	%	n	%		
Do you have back pain now?							1.78 (2,597)	.410
Yes	95	47.7	108	54.3	99	49.7		
No	104	52.3	91	45.7	100	50.3		
How bad is your current back pain?							10.05 (10,302)	.435
Mild and comes and goes	45	47.9	43	39.8	40	40.0		
Mild and does not vary much	11	11.7	14	13.0	13	13.0		
Moderate and comes and goes	33	35.1	40	37.0	36	36.0		
Moderate and does not vary much	4	4.3	5	4.6	10	10.0		
Severe and comes and goes	1	1.1	5	4.6	1	1.0		
Severe and does not vary much	0	0.0	1	0.9	0	0.0		
In the last two months have you experienced back pain?							3.57 (8,594)	.964
Rarely	11	5.5	13	6.5	14	7.0		
Once in a while	59	29.6	48	24.1	47	23.6		
Sometimes	73	36.7	76	38.2	80	40.2		
Often	54	27.1	58	29.1	55	27.6		
Always	1	0.5	3	1.5	2	1.0		
No pain, does not apply to me	1	0.5	1	0.5	1	0.5		
When you experienced back pain in the last 2 months, how intense was the pain?							14.78 (12,594)	.253
Mild; it came and went	45	22.7	44	22.2	35	17.7		
Mild and it did not vary much	35	17.7	28	14.1	26	13.1		
Moderate; it came and went	81	40.9	95	48.0	85	42.9		
Moderate and it did not vary much	31	15.7	20	10.1	39	19.7		
Severe; it came and went	4	2.0	8	4.0	10	5.1		
Severe and it did not vary much	1	0.5	2	1.0	3	1.5		
Severe as anything I can imagine	1	0.5	1	0.5	0	0.0		
When you experienced low back pain in the last 2 months, how long did it usually last?							13.01 (6,590)	.043
Up to 30 minutes	36	18.4	26	13.3	23	11.6		
30 minutes to 6 hours	57	29.1	79	40.3	78	39.4		
6 to 24 hours	63	32.1	47	24.0	45	22.7		
Days to weeks at a time	40	20.4	41	20.9	52	26.3		
For a month or more	0	0.0	3	1.5	0	0.0		
When you experienced back pain, what do you think is the primary cause of it?							19.08 (16,597)	.264
Recurrence of a previous pain event	18	9.0	11	5.5	20	10.1		
Overuse	18	9.0	20	10.1	17	8.5		
Lifting or straining	38	19.1	36	18.1	36	18.1		
Twisting	7	3.5	4	2.0	8	4.0		
Abrupt movement	3	1.5	7	3.5	10	5.0		
Sitting or standing for too long	77	38.7	71	35.7	56	28.1		

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		Treatment n=199		Alternative care n=199		Control n=199		χ^2 (df)	*P*
History		n	%	n	%	n	%		
	Unusual physical activity	9	4.0	8	4.0	3	1.5		
	Minor injury or accident	1	0.5	2	1.0	3	1.5		
	Don’t know	29	14.6	40	20.1	46	23.1		

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Table 3. Descriptive statistics for study outcomes by study group.

	T1[a]		T2[b]		T3[c]	
	mean	SD	mean	SD	mean	SD
How bad is your low back pain?						
Treatment	0.96	1.26	0.82	1.22	0.56	1.00
Alternative care	1.22	1.43	1.03	1.43	0.89	1.30
Control	1.09	1.34	1.16	1.47	0.98	1.43
How often have you experienced low back pain?						
Treatment	2.86	0.92	2.64	1.04	2.16	1.12
Alternative care	2.93	0.95	2.63	1.02	2.39	1.05
Control	2.90	0.94	2.76	0.95	2.52	1.06
When you experienced low back pain, on average how intense was the pain?						
Treatment	2.59	1.15	2.23	1.20	2.11	1.46
Alternative care	2.63	1.17	2.26	1.24	2.23	1.30
Control	2.84	1.18	2.52	1.29	2.55	1.41
When you experienced low back pain, on average how long did it usually last?						
Treatment	2.52	1.03	2.28	1.05	2.03	1.01
Alternative care	2.56	1.02	2.25	1.03	2.16	0.97
Control	2.62	1.01	2.36	1.03	2.28	1.04
Functionality and quality of life						
Treatment	3.83	1.90	3.27	1.69	3.03	1.88
Alternative care	3.93	1.97	3.45	1.90	3.31	2.00
Control	4.03	2.00	3.85	2.22	3.74	2.22
Dartmouth CO-OP						
Treatment	20.41	5.02	19.30	5.18	18.84	5.39
Alternative care	20.66	4.74	19.87	5.16	19.42	5.26
Control	21.01	4.96	20.84	5.92	20.65	5.64
Prevention-helping behaviors						
Treatment	2.48	0.84	3.09	0.84	3.18	0.91
Alternative care	2.47	0.81	2.88	0.82	2.97	0.87
Control	2.48	0.79	2.64	0.85	2.74	0.89
Work productivity						
Treatment	4.09	0.74	4.14	0.68	4.26	0.72
Alternative care	4.09	0.65	4.16	0.69	4.23	0.75
Control	4.08	0.72	4.08	0.78	4.14	0.74
Presenteeism						
Treatment	3.88	0.79	4.05	0.79	4.15	0.74
Alternative care	3.10	0.47	4.02	0.77	4.01	0.82
Control	3.75	0.79	3.86	0.81	3.92	0.81
Patient activation						
Treatment	3.14	0.45	3.38	0.50	3.51	0.50
Alternative care	3.10	0.47	3.34	0.51	3.37	0.53
Control	3.09	0.46	3.11	0.53	3.14	0.53

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		T1[a]		T2[b]		T3[c]	
		mean	SD	mean	SD	mean	SD
Knowledge							
	Treatment	0.50	0.16	0.59	0.13	0.61	0.14
	Alternative care	0.47	0.17	0.55	0.16	0.54	0.15
	Control	0.47	0.16	0.50	0.16	0.51	0.16
Behavioral intentions							
	Treatment	4.02	1.08	4.59	1.07	4.90	1.15
	Alternative care	4.07	1.14	4.48	1.16	4.65	1.26
	Control	4.08	1.18	4.03	1.12	4.12	1.20
Self-efficacy							
	Treatment	3.80	1.13	4.54	1.15	4.98	1.23
	Alternative care	3.76	1.19	4.44	1.26	4.67	1.24
	Control	3.75	0.79	3.87	1.26	3.99	1.31
Survey of pain attitudes: control scale							
	Treatment	3.19	0.87	3.69	0.79	3.86	0.79
	Alternative care	3.31	0.89	3.56	0.95	3.70	0.89
	Control	3.23	0.87	3.31	0.95	3.37	0.94
Survey of pain attitudes: emotions scale							
	Treatment	2.96	1.28	3.32	1.28	3.38	1.22
	Alternative care	3.01	1.32	3.30	1.27	3.47	1.29
	Control	2.92	1.30	3.08	1.28	3.28	1.35
Catastrophizing of pain							
	Treatment	2.25	0.58	2.26	0.57	2.25	0.64
	Alternative care	2.23	0.61	2.22	0.62	2.22	0.67
	Control	2.22	0.59	2.30	0.65	2.33	0.71

[a]T1: pre-test

[b]T2: post-intervention at 8 weeks after pre-test

[c]T3: post-intervention at 16 weeks after pre-test

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Table 4. Results of multivariate/univariate analysis of covariance models testing for group differences[a] at T2[b] and T3[c].

	Overall test			Specific group comparisons					
				Treatment vs alternative care			Treatment vs control		
	F	*P*	η^{2d}	*F*	*P*	η^2	*F*	*P*	η^2
Back pain									
T2	1.25	.266	.008	N/A[e]	N/A	N/A	N/A	N/A	N/A
T3	2.54	.010	.017	1.62	.169	.016	4.41	.002	.043
Functionality, quality of life, and well-being									
T2	3.19	.013	.011	0.70	.496	.004	5.88	.003	.029
T3	3.69	.005	.012	0.97	.377	.005	6.76	.001	.033
Prevention-helping behaviors									
T2	23.60	.026	.07	9.32	.017	.02	33.83	.017	.08
T3	17.61	.013	.06	6.88	.025	.02	46.81	.009	.11
Worksite outcomes									
T2	1.14	.338	.004	N/A	N/A	N/A	N/A	N/A	N/A
T3	2.42	.047	.008	3.36	.036	.07	3.65	.027	.018
Patient activation									
T2	18.61	.004	.06	0.16	.687	<.01	28.75	.003	.07
T3	27.20	.004	.08	7.08	.027	.02	54.83	.002	.12
Theory of planned behavior									
T2	11.90	<.001	.057	2.14	.095	.016	22.74	<.001	.149
T3	17.21	<.001	.080	7.10	<.001	.052	33.04	<.001	.202
Attitudes toward pain									
T2	6.76	<.001	.022	3.62	.027	.018	13.46	<.001	.064
T3	11.02	<.001	.036	4.95	.008	.026	22.39	<.001	.102
Catastrophizing of pain									
T2	1.92	.174	<.01	N/A	N/A	N/A	N/A	N/A	N/A
T3	2.99	.069	.01	N/A	N/A	N/A	N/A	N/A	N/A

[a]Results from prevention-helping behaviors, patient activation, and catastrophizing of pain are from analysis of covariance models; all other results from multivariate analysis of covariance models.

[b]T2: post-intervention at 8 weeks after pre-test

[c]T3: post-intervention at 16 weeks after pre-test

[d]η^2=eta-square: measure of effect size with convention .01 small, .06 medium, large .14.

[e]N/A: not applicable; test not run because overall test not statistically significant.

Behavioral Outcome

For the Prevention-Helping behavioral measure, which assessed the level of engagement in behaviors intended to help or prevent back pain, the overall tests were significant at both T2 and T3. Both the treatment vs control comparison and the treatment vs alternative care comparison were statistically significant at both T2 and T3.

Worksite Outcomes

Regarding the Worker Productivity and the Presenteeism measures, the overall tests were significant at T3, but not at T2. Similarly, both the treatment vs control and treatment vs alternative care comparisons were significant at T3, but not T2.

Other Constructs

Patient Activation

The analyses of the Patient Activation Measure, which assessed the activation of patients to take responsibility for care for their own low back pain, found that the overall tests were significant at both T2 and T3. The treatment vs control follow-up comparisons were statistically significant at both T2 and T3. The treatment vs alternative care comparisons were statistically significant at T3, but not at T2.

Theory of Planned Behavior Constructs

The overall tests were significant at both T2 and T3. Both the treatment vs control and the treatment vs alternative care

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comparisons were statistically significant at T3, but only the treatment vs control comparison was significant at T2.

Attitudes Toward Pain

The overall tests were significant at both T2 and T3. Both the treatment vs control and the treatment vs alternative care comparisons were statistically significant at T2 and T3.

Catastrophizing of Pain

The overall tests for the Catastrophizing of Pain scale were not significant at either T2 or T3.

Process Analyses

User Satisfaction

Indices of user acceptance were all positive. Compared to the alternative care participants, FitBack program users had higher satisfaction ratings. The mean total score for FitBack participants was statistically greater at T2 (t_{380}=4.40, P<.001, d=.54) and T3 (t_{382}=3.51, P<.001, d=.37).

Website Usability

The System Usability Scale (SUS) score (mean 78.6, SD 15.7), when compared to normative data, is associated with "good" to "excellent" ratings and corresponds to a "B-" [65]. For comparison, across 3500 surveys within 273 studies on different platforms (Web, mobile phones, TV, etc), the average SUS score was approximately 70. For Web applications, the average SUS score was 68.2 [65].

Perception of Employer Survey

The summary analyses suggest that participants believed they would have a positive impression of employers who made the FitBack program available to employees. They felt that the company would care about them (mean 4.7, SD 1.1); they would feel more positive about the company (mean 4.6, SD 1.1); they would have greater commitment to the company (mean 4.1, SD 1.2); they would be more productive (mean 4.1, SD 1.2); and they would feel more job satisfaction (mean 4.0, SD 1.3).

Understanding and Implementation Survey

The results indicate that 96-98% of participants thought they understood the program recommendations for use of heat and ice, over-the-counter medications, exercising to deal with back pain, and relaxation techniques. Implementation of recommendations by participants was reported for relaxation activities (67.8%), exercises for prevention (78.2%), and dealing with pain occurrences (86%).

Discussion

Physical and Behavioral Outcomes

The major findings of the study were related to critical physical and behavioral outcomes. Users of the FitBack program were (1) significantly less likely to be experiencing current back pain at 4-month follow-up than either control (OR 1.7) or alternative care (OR 1.6) subjects, (2) significantly less likely to be experiencing back pain generally (ie, level, frequency, intensity, and duration of back pain) at 4-month follow-up than control subjects, (3) significantly more likely to have better functionality, quality of life, and well-being at both 2- and 4-month follow-up than control subjects, and (4) significantly more likely to be engaging in behaviors intended to help or prevent back pain at both 2- and 4-month follow-up than either control or alternative care subjects. In sum, the FitBack program's positive effects on physical and behavioral outcomes were consistent at 4-month follow-up comparisons with control subjects, and with 2 of 4 outcomes at 2-month follow-up. Given that the alternative care group received an intervention designed to prompt the use of 6 website links via 8 email reminders, it is not surprising that for some measures the FitBack effects were not significantly larger than the alternative care intervention. Nonetheless, alternative care users were 1.6 times more likely than the FitBack program users to be experiencing current back pain at 4-month follow-up and were significantly less engaged in prevention-helping behaviors at both 2- and 4-month follow-ups.

Worksite Outcomes

The above improvements in Physical and Behavior Outcomes translated to significant improvement in worker productivity and presenteeism at 4-month follow-up, but not at 2-month follow-up. It may take a longer time period for physical and behavioral changes to be detectable in worksite outcome measures. These worksite outcomes are central to making the case for the cost-effectiveness of online interventions such as FitBack.

Other Constructs

Patient Activation

This study is notable because it establishes in a randomized controlled trial that an online intervention that is designed to help users develop self-tailored strategies to treat NLBP occurrences and adopt behaviors to decrease future pain occurrences can improve the level of patient activation (ie, patients' taking responsibility for care for their low back pain) at 4-month follow-up.

Theory of Planned Behavior

This study indicated that an online intervention can effectively improve measures of constructs central to the TPB, specifically user knowledge, behavioral intentions, and self-efficacy.

Attitudes Toward Pain

Overview

Attitudes toward pain are connected by the TPB to self-efficacy and intentions to attempt behavioral remedies [40,41]. This study demonstrated that the FitBack program consistently improved both the extent to which a person believes he or she can control pain, and the extent to which a person believes his or her emotions affect the experience of pain.

Catastrophizing of Pain

The FitBack program did not affect the degree to which the user catastrophizes about back pain.

Process Outcomes

The measures of user satisfaction were positive. In addition, the FitBack program users had higher satisfaction ratings than

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alternative care participants. The FitBack program received "good" to "excellent" usability ratings. Last, FitBack users reported that they would have a positive impression of employers that made the FitBack program available to employees.

Online Recruitment

The research reported here adds to the literature on recruitment success of online research studies. A total of 3570 views of the informational website (Figure 2), led to 1932 respondents who submitted the online screening questionnaire (78.4%), which is substantially more than the 17.3% who submitted the online screening for an exercise study with sedentary older adults [37]. Also of potential interest to other researchers is the incidence of fraud reported here. Of 675 individuals who initially screened in as eligible, 12 (1.8%) were dropped because of fraudulent information, which is much less than the 9% dropped for fraud by Irvine and colleagues [37]. Across all our online studies, we have identified roughly 4% of those who initially qualify to be fraudulent because they supply inaccurate personal information to be accepted as a research subject. We believe that the potential for fraudulent participation in Internet research studies is an important issue, but few researchers report on it.

Limitations

The results reported here must be viewed cautiously because we believe this to be the first attempt to influence NLBP with an online intervention. We cannot gauge the importance of the email reminders on the results, which potentially could influence the response rate [70], and we only prompted the treatment group if they did not open the first message, which might have biased the response rate. Additionally, we cannot verify that participants provided accurate information on eligibility criteria, the surveys, and the 4-month follow-up period was somewhat limited. Perhaps 1-2-year follow-up studies, possibly combined with medical verification, would provide greater confidence in the intervention effects, as would research to tease out which aspects of FitBack were most effective. Also, we cannot determine whether social desirability bias might have influenced responses to assessment items, as has been reported elsewhere [71].

Research is needed to determine whether the results presented here generalize to other demographic categories. Participants tended to be employed, educated, with at least a middle-class income. Less educated, lower income, and rural populations might be less likely to have Internet in their homes [72], and FitBack would obviously be inapplicable for those who do not use computers or mobile phones.

Conclusions

The major conclusion of this study is that users of the FitBack program showed greater improvement compared to the control group in every comparison of the critical physical, behavioral, and worksite outcome measures at 4-month follow-up. In addition, the users of the FitBack program performed better than the alternative treatment group on presence of current back pain, behavioral, and worksite outcomes at 4-month follow-up. Further, the users of the FitBack program showed greater improvement compared to both the control group and the alternative treatment group at 4-month follow-up on patient activation, constructs of the Theory of Planned Behavior, and attitudes toward pain.

This research demonstrates that a theoretically based standalone responsive mobile-Web intervention that tailors content to users' preferences and interests can be an effective tool in self-management of low back pain. The results are promising considering that the FitBack intervention was neither supported by professional caregivers nor integrated within a larger health promotion campaign, which might have provided additional support and encouragement for the participants. When viewed from the RE-AIM perspective (ie, reach, efficacy/effectiveness, adoption, implementation fidelity, and maintenance) [73], one of the primary advantages of this type of self-guided intervention is its ability to increase reach at a low cost. This study supports the notion that there is considerable potential value in FitBack as a cost-effective tool that can reach large numbers of people. Still, more research is needed on how self-guided, mobile-Web interventions will be used over time and to understand factors associated with continuing user engagement.

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Conflicts of Interest

Blair Irvine was the grant Principal Investigator. Now retired, he was employed as a Research Scientist at ORCAS, a health care technology company that creates self-management programs to improve physical and emotional well-being. Software development was funded with a Small Business Innovation Research grant, which was designed to stimulate research and product development. Thus, improved versions of FitBack will be marketed. Dr Irvine and the other authors derived no financial benefit from sales or from publication of this research.

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Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [74].

[PDF File (Adobe PDF File), 1MB - jmir_v17i1e1_app1.pdf]

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Abbreviations

ACP: American College of Physicians
APS: American Pain Society
IRB: Institutional Review Board for protection of human subjects
MANCOVA: multivariate analysis of covariance
NLBP: nonspecific low back pain
PAM: Patient Activation Measure
SOPA: Survey of Pain Attitudes
SUS: System Usability Scale
TPB: Theory of Planned Behavior
WLQ: Work Limitations Questionnaire

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Original Paper

Virtual Intervention to Support Self-Management of Antiretroviral Therapy Among People Living With HIV

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Abstract

Background: Living with human immunodeficiency virus (HIV) necessitates long-term health care follow-up, particularly with respect to antiretroviral therapy (ART) management. Taking advantage of the enormous possibilities afforded by information and communication technologies (ICT), we developed a virtual nursing intervention (VIH-TAVIE) intended to empower HIV patients to manage their ART and their symptoms optimally. ICT interventions hold great promise across the entire continuum of HIV patient care but further research is needed to properly evaluate their effectiveness.

Objective: The objective of the study was to compare the effectiveness of two types of follow-up—traditional and virtual—in terms of promoting ART adherence among HIV patients.

Methods: A quasi-experimental study was conducted. Participants were 179 HIV patients on ART for at least 6 months, of which 99 were recruited at a site offering virtual follow-up and 80 at another site offering only traditional follow-up. The primary outcome was medication adherence and the secondary outcomes were the following cognitive and affective variables: self-efficacy, attitude toward medication intake, symptom-related discomfort, stress, and social support. These were evaluated by self-administered questionnaire at baseline (T0), and 3 (T3) and 6 months (T6) later.

Results: On average, participants had been living with HIV for 14 years and had been on ART for 11 years. The groups were highly heterogeneous, differing on a number of sociodemographic dimensions: education, income, marital status, employment status, and living arrangements. Adherence at baseline was high, reaching 80% (59/74) in the traditional follow-up group and 84% (81/97) in the virtual follow-up group. A generalized estimating equations (GEE) analysis was run, controlling for sociodemographic characteristics at baseline. A time effect was detected indicating that both groups improved in adherence over time but did not differ in this regard. Improvement at 6 months was significantly greater than at 3 months in both groups. Analysis of variance revealed no significant group-by-time interaction effect on any of the secondary outcomes. A time effect was observed for the two kinds of follow-ups; both groups improved on symptom-related discomfort and social support.

Conclusions: Results showed that both interventions improved adherence to ART. Thus, the two kinds of follow-up can be used to promote treatment adherence among HIV patients on ART.

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KEYWORDS

adherence; antiretroviral therapy, highly active; HIV-infected patients; human immunodeficiency virus; nursing; nursing informatics; Web-based intervention

Introduction

For over a decade, HIV infection has been considered a chronic disease thanks to the advent of antiretroviral drugs [1,2]. Living with HIV necessitates long-term health care follow-up particularly with respect to management of antiretroviral therapy (ART), which today entails daily medication intake for life. The latest guidelines recommend that ART initiation be offered to all upon HIV infection diagnosis [3]. Major developments in information and communication technologies (ICT) over the years have allowed diversification of the modalities and kinds of interventions available to support ART adherence or self-management. ICT can also facilitate access to a wide variety of interventions at a favorable cost-effectiveness ratio [4].

Recent literature reviews have reported the deployment of ICT-supported interventions for HIV patients. Pellowski and Kalichman [5] reviewed 12 studies, of which nine focused on adherence to HIV treatment subsequent to interventions delivered via different technologies, including short message service (SMS)/text messaging, cell phones, and computers. The systematic review realized by Saberi and Johnson [6] turned its attention to technology-based self-care approaches likely to improve ART adherence. According to these authors, a clear pattern of results emerged in favor of individually tailored interventions that used multi-function technologies allowing for periodic communications with health care providers instead of merely relying on electronic reminder devices. Moreover, recent reviews [7,8] have suggested that ICT-assisted interventions, such as sending text messages via mobile phone, had the potential to increase treatment adherence in sub-Saharan Africa. Pellowski and Kalichman [5] suggested that technology-delivered interventions held great promise across the entire continuum of HIV patient care but that further research was needed to properly determine and assess their effectiveness.

We developed a virtual intervention called HIV Treatment, Virtual Nursing Assistance and Education or VIH-TAVIE (from its French appellation, *Virus de l'immunodéficience humaine - Traitement assistance virtuelle infirmière et enseignement*) to empower HIV patients to manage their ART and their symptoms optimally. Based on theories of behavior change [9,10], VIH-TAVIE targets the development and consolidation of skills to enhance the individual's ability to act [11]. VIH-TAVIE consists of four interactive sessions at a computer, which are hosted by a virtual nurse who engages the user in a self-management skills-learning process [12]. Unlike conventional health-related websites that contain a library of information, VIH-TAVIE is a tailored intervention driven by a decision tree. What distinguishes this intervention from others is its mechanism of action, a tailored design that adapts content and messages to user profile and needs, the scientific rigor of its proposed content, and its flexibility of use. The intervention is the end point of a number of previous activities, which consisted of identifying predictors of treatment adherence [13], developing an intervention program aimed at promoting adherence [11], using innovative technology through the creation of a virtual intervention [12], and carrying out a preliminary validation among HIV patients [14].

As there is no cure for HIV infection, the number of chronically affected individuals is on the rise, placing growing demands on health care systems. Health resources need to be optimized in order to provide better support to service user groups living with various chronic health conditions. In this light, the aim of the present project was to compare the efficacy (value) of two kinds of health care follow-up—traditional and virtual (VIH-TAVIE)—on treatment adherence behavior among HIV patients on ART.

Methods

Study Design

A quasi-experimental study was conducted to evaluate the capacity of both kinds of follow-up to optimize medication adherence (primary outcome). Adherence is a behavioral indicator that can be predicted in part by cognitive and affective variables (secondary outcomes), particularly sense of self-efficacy and attitude toward drug intake [13], which in turn can be explained by perceived social support and absence of symptoms. The primary and secondary outcomes were selected on the basis of previously identified predictors of treatment adherence among HIV patients [13]. There were three measurement times: baseline (T0), 3 months (T3), and 6 months (T6) later. The study was approved by the Research Ethics Board of the Université de Montréal, the Research Centre of Centre Hospitalier de l'Université de Montréal, and the McGill University Health Centre.

Recruitment of Participants

Participants were recruited at two university hospitals that deliver specialized care and services to HIV patients in the same metropolitan area. The two sites share the same mission of care and services, teaching, and research in the field of HIV/AIDS. The HIV patients recruited had to be at least 18 years old and on ART for at least 6 months. Pregnant women, people with uncontrolled psychiatric conditions, and active intravenous drug users were not eligible for the study. It was estimated that an initial sample size of 186 participants was needed in order to detect a difference of 20 percentage points at 80% power and an alpha level of .05 for two-tailed chi-square tests.

Non-Random Assignment

Recruitment took place at the two university hospitals, one of which offered virtual follow-up in addition to traditional follow-up. Thus, one group was formed at each recruitment site: the traditional care group and the group with the adjunctive virtual intervention. Of the 179 participants, 99 were recruited

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at the site offering virtual follow-up adjunctive to traditional follow-up and 80 at the other site offering only traditional follow-up.

Follow-Up

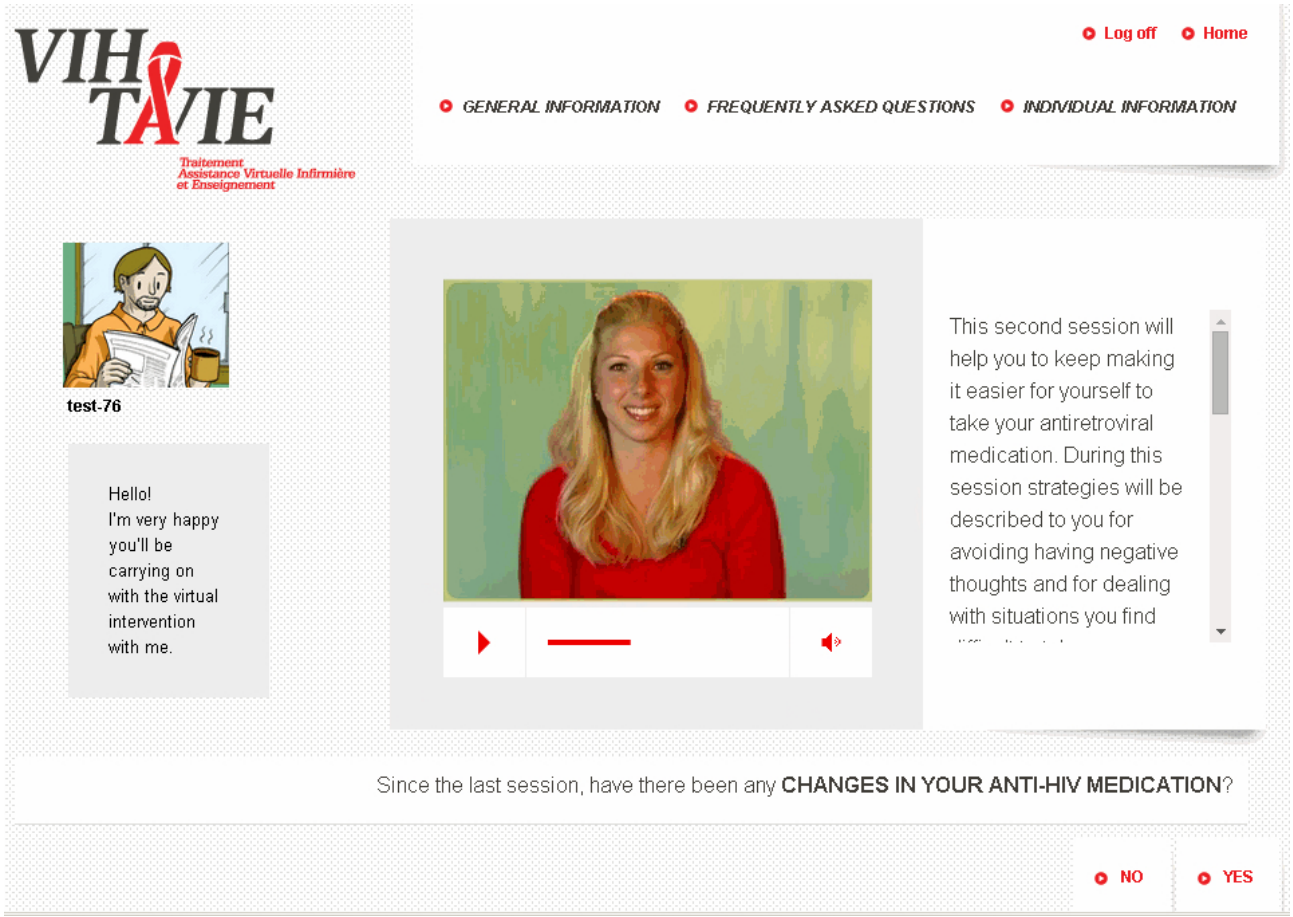
In virtual follow-up, the four VIH-TAVIE sessions, each 20-30 minutes long, were offered over an 8-week period following the baseline measurement. Each interactive session is distinct from the other in terms of messages, strategies, skills, questions, and data entry (for example, see Figure 1).

The sessions follow a predefined sequence in order to ensure a gradual conveyance of abilities. The first session focuses on developing self-assessment skills, reinforcing and developing motivational skills, such as associating a positive image with treatment, and managing undesirable and adverse effects. The second session deals with emotional management by learning to identify negative sentiments, recognizing their effects on behavior, and acquiring strategies to cope with them. It serves, also, to review the problem-solving process for dealing with situations where medication intake is awkward. The third session concerns how to establish, maintain, and strengthen social relations and interact with health professionals. In the final session, all the skills previously worked on are consolidated, as illustrated in Figure 2.

At the heart of the application is a virtual nurse who acts as coach interacting with the user asynchronously. Over the course of the sessions, approximately 140 video clips of the virtual nurse are presented, ranging in duration from 10 to 90 seconds. The virtual nurse provides feedback and positive reinforcement on the user's personal style and methods and on skills acquired. Aside from delivering tailored teaching, the virtual nurse also refers to the experiences of other HIV patients who have been able to cope successfully with situations similar to those of the user. The originality of this Web application lies in the process of interaction with the individual, which contrasts with standard health information websites where much of the content is passively presented and interaction with the user is minimal, if not nil. Participants who benefitted from VIH-TAVIE could also consult their regular health care teams.

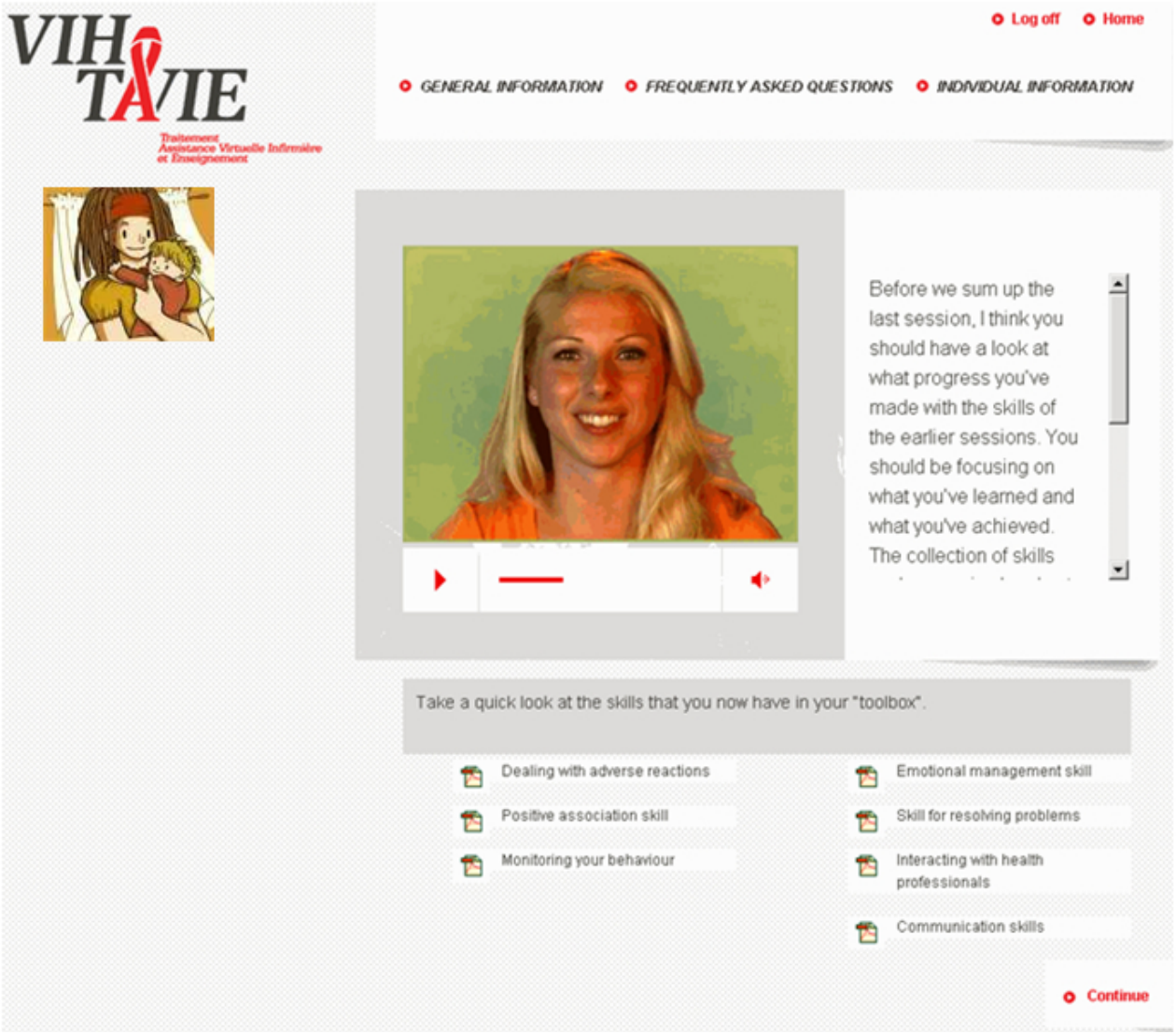
Traditional follow-up consisted of meeting with health care professionals over a period of 3 to 4 months. The meetings lasted 20 minutes and covered medication, symptoms, and problems encountered. Personalized health advice was given on these occasions.

Figure 1. Illustration of the first page of session 2 of VIH-TAVIE.



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Figure 2. Illustration of a page of session 4 of VIH-TAVIE.



Measures

Adherence, the study's primary outcome, was evaluated by means of a self-administered questionnaire developed and validated among HIV patients following the latest recommendations regarding the measure of therapy adherence [15]. The questionnaire comprised seven items serving to measure how often a person forgot to take their medication. It is designed to place the respondent in a context where events and situations could lead to lapses. The questionnaire's validity was demonstrated (sensitivity: 71%; specificity: 72%; correct classification: 72%; OR 6.15) using immunologic (CD4 count) and virologic (viral load) parameters as criteria. Adherence was defined as the intake of at least 90% of prescribed tablets. Though there is no clear minimum cut-off point defining what constitutes sufficient ART adherence for optimal treatment effectiveness [16], this is generally set at >90% to >95% [17].

Self-efficacy regarding medication intake was measured with 12 items rated on a 5-point Likert scale. These items were adapted from a scale developed by Godin et al [15] and previously used on a larger sample (N=399). To adapt the instrument to the present context, that is, ART medication intake, the items were reviewed by expert consensus on the basis of the results of a focus group, a literature review, and Bandura's theoretical model of self-efficacy. Content validation was carried out. A Cronbach alpha of .88 was obtained for this study.

Attitude toward medication intake was evaluated through six items rated on a 5-point Likert scale. These items emerged from focus groups of HIV patients on treatment. A preliminary version of the instrument was tested among 35 HIV patients. The scale was previously used on a large sample (N=399) [13], obtaining a Cronbach alpha of .83 and a test-retest reliability coefficient of .72. A Cronbach alpha of .86 was obtained for this study.

Symptom-related discomfort was measured with the Self-Completed HIV Symptom Index [18]. This 20-item instrument serves to determine whether symptoms are present on a scale of 0 to 4 (0=absence) and the degree of discomfort experienced (1, 2, 3, or 4). The instrument was validated among 188 HIV patients, demonstrating acceptable psychometric properties, including good construct validity. A Cronbach alpha of .93 was obtained for this study.

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Social support was evaluated using the Medical Outcome Survey [19,20]. One dimension of social support was measured by the emotional support (8 items) subscale. Items are rated on a 5-point Likert scale. The instrument has demonstrated good content validity and appreciable internal consistency. A Cronbach alpha of .97 was obtained for this study.

Stress was measured with the stressfulness subscale (4 items) of the Stress Appraisal Measure developed by Peacock and Wong [21]. A Cronbach alpha of .90 was obtained for this study.

Immunologic and viral indicators were captured through CD4 count and viral load, respectively. This information was garnered from the participants' medical files.

Statistical Analyses

Descriptive statistics (frequency tables, means, and standard deviations) were summarized at each time point. Student's *t* tests or chi-square tests were performed for each sociodemographic and baseline psychological variable to verify group equivalence. A generalized estimating equations (GEE) analysis was run to test differences in adherence over time (baseline, 3 months, and 6 months) between kinds of follow-up (traditional vs virtual: dichotomous variable). For the analysis, an intention-to-treat approach was applied. Thus, all available data for each participant were used in the analysis model. To test changes in continuous variables (attitudes, self-efficacy, symptoms, stress, and social support) over 6 months for both groups, we compared measures of change at T3 and T6 separately with two *t* tests. Then, we compared the two measures of change using a two-factor (time and group) repeated-measures analysis of variance (ANOVA). Finally, we ran the same analysis controlling for the measure at T0. In all cases, the ANOVAs were based on a generalized linear model (GLM) and no allocation technique (no imputation of missing data) was used.

Results

Sample Characteristics

The sample included 23 women and 153 men and had a mean age of 48 years (SD 8.4, range 23-73). On average, participants had been living with HIV for 14 years and had been on treatment for 11 years. The groups were highly heterogeneous, differing on a number of sociodemographic dimensions. For instance, compared with participants in the virtual follow-up group, those in the traditional follow-up group had more years of formal education ($P<.001$), earned more ($P<.003$), had more children ($P<.035$), and were more likely to be married ($P<.001$) and living with a spouse ($P<.001$). A high percentage of participants in each group had an undetectable viral load and maintained a CD4 level within reasonable limits. A higher proportion of participants in the virtual follow-up group reported having ceased taking anti-HIV medication in the 3 months prior to the study, compared with those in the traditional follow-up group ($P<.030$). Also, the virtual group had a lower CD4 count compared with the traditional follow-up group ($P<.021$). Table 1 presents the sociodemographic and clinical characteristics of the participants in both groups.

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Table 1. Demographic and clinical characteristics of the participants in both groups.

Variables		Traditional follow-up (n=80)	Virtual follow-up (n=99)	*P* value
Gender, n (%) [a]				.151[b]
	Female	7 (8.8)	16 (16.2)	
	Male	71 (88.8)	82 (82.8)	
Age (years), mean (SD)		49 (9.2)	47 (7.6)	.062[c]
Ethnicity, n (%)				<.001[b]
	Canadian	41 (51.2)	89 (89.9)	
	Other	39 (48.8)	10 (10.1)	
Marital status, n (%)				<.001[b]
	Single	41 (51.2)	80 (80.8)	
	Married or living as couple	31 (38.8)	7 (7.1)	
	Divorced/widowed	8 (10.0)	12 (12.1)	
Employment status, n (%)				<.001[b]
	Working/student	37 (46.2)	14 (14.1)	
	Insurance/retired	16 (20.0)	9 (9.1)	
	Welfare	19 (23.8)	64 (64.6)	
	Other	8 (10.0)	12 (12.1)	
Education levels, n (%)				.001[b]
	Primary	5 (6.2)	7 (7.1)	
	Secondary	27 (33.8)	54 (54.5)	
	College	23 (28.7)	29 (29.3)	
	University	25 (31.2)	9 (9.1)	
Annual income, CAD, n (%) [a]				.003[b]
	<$14,999	33 (41.2)	67 (67.7)	
	$15,000 - $34,999	20 (25.0)	21 (21.3)	
	$35,000 - $54,999	10 (12.6)	5 (5.0)	
	>$55,000	11 (13.8)	3 (3.0)	
Years of HIV infection, mean (SD)		14.4 (7.3)	13.4 (7.7)	.365[c]
Years on antiretroviral therapy, mean (SD)		11.6 (6.6)	9.9 (6.5)	.077[c]
Treatment interruption 3 months before baseline T0, n (%)		4/79 (5.1)	15/99 (15.2)	.03[b]
Viral load less than 50 copies, n (%)		60/67 (89.6)	67/82 (81.7)	.179[b]
CD4 count (cells/µl), mean (SD)		540 (293)	441 (237)	.021[c]

[a]Subgroups do not always add up to totals owing to missing data.

[b]Chi-square test.

[c]Student's *t*-test.

Engagement and Participation in Virtual and Traditional Follow-Up

Of the 99 participants in the virtual follow-up group, 73 completed all four VIH-TAVIE sessions, three completed three, seven completed two, 12 completed only one, and four completed none. The computer sessions took place every 2 weeks at the hospital/clinic over a period of 6 to 8 weeks. The time required to complete session 1 varied from 20 to 30 minutes, sessions two and three took 20 minutes to complete, and session 4 required about 10 minutes. Participants in the virtual follow-up group could also consult their regular health care teams during the study's 6-month period. Of the 80 participants in the traditional follow-up group, 60% (48/80) met

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with their medical teams twice and the remaining 40% (32/80) met three times.

Effect on Adherence Behavior

Adherence at baseline was high, reaching 80% (59/74) for the traditional follow-up group and 84% (81/97) for the virtual follow-up group. Given the inter-group differences at baseline in terms of sociodemographic characteristics, a GEE analysis was run controlling for age, living alone, income, symptoms, and employment status. A time effect was observed, whereby the two groups improved on adherence over time but did not differ. Improvement at 6 months was significantly greater than at 3 months for both groups. No significant group-by-time interaction was noted. Table 2 shows the GEE results for kind of follow-up effect on medication intake adherence (≥90%).

Table 2. Effect of follow-up type on medication adherence (% of adherence ≥90%) using generalized estimating equations (GEE)[a].

Type of follow-up	Baseline (T0) % adherence ≥90	3 months (T3) % adherence ≥90	6 months (T6) % adherence ≥90
Traditional follow-up (n=80)	79.7	85.7	92.7
Virtual follow-up (n=99)	83.5	90.4	89.6

[a]Group x Time interaction, Z=−1.36, P=.1743; time effect, Z=−1.96, P=.0496.

Effect on Cognitive and Affective Variables

Overall, participants reported on symptoms in terms of quantity and perceived discomfort. They also expressed positive attitudes, a high sense of self-efficacy, a low level of stress, and a moderate level of perceived social support. Nonetheless, at baseline, the virtual follow-up group reported more symptoms, a higher level of stress, and less perceived social support, compared with the traditional follow-up group. Table 3 gives a description of the cognitive and affective variables relative to the participants in each group.

Statistical analyses revealed no significant group x time interaction on self-efficacy, attitude toward medication intake, symptom-related discomfort, stress, or social support. A time effect was observed for both kinds of follow-up on symptom-related discomfort and social support. Both groups improved over time with respect to these variables. ANOVA results regarding type of follow-up effect on cognitive and affective variables are presented in Table 4. These ANOVAs were based on a GLM with no data imputation technique used. Participants lost to attrition at T3 and T6 were considered missing at random. To verify our strategy, analyses were run to compare characteristics at T0 based on presence/absence of participants at T6. Differences emerged in terms of age, having children (yes/no), income, and ART drug intake cessation. Accordingly, there were more losses among younger participants, those with no children, those with lower income, and those who had ceased taking ART medication 3 months prior to the study. However, these differences were not of the sort to call into question the analysis strategy used. Moreover, as attrition was higher in the traditional follow-up group, use of the last observation carried forward (LOCF) allocation method would have contributed to obtain the desired results (difference of evolution between groups) by generating a larger number of stable participants in the traditional follow-up group compared with the virtual follow-up group.

Table 3. Cognitive and affective variables of the participants in both groups.

Cognitive and affective variables	Traditional follow-up (n=80) mean (SD)	Virtual follow-up (n=99) mean (SD)	P value[a]
Symptoms count[b]	9.85 (7.17)	12.57 (6.91)	.011
Symptoms bother[c]	21.16 (17.19)	29.07 (18.23)	.004
Attitude[d]	23.90 (5.32)	23.46 (4.69)	.554
Stress[e]	6.23 (3.67)	7.45 (4.04)	.037
Self-efficacy[f]	1246.25 (206.22)	1192.89 (196.89)	.079
Social support[g]	70.23 (21.61)	60.77 (20.03)	.003

[a]Student's t test.

[b]Possible range 0-24.

[c]Possible range 0-96.

[d]Possible range 6-30.

[e]Possible range 4-20.

[f]Possible range 0-1400.

[g]Possible range 19-95.

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Table 4. Effect of follow-up type on cognitive and affective variables using ANOVA.

Variables/type of follow-up		Group x time interaction *F*, *P* value	Time effect *F*, *P* value
Symptoms count			
	Virtual (n=67)	*F*=0.322, *P*=.572	*F*=4.166, *P*=.044
	Traditional (n=31)		
Symptoms bother			
	Virtual (n=67)	*F*=0.562, *P*=.455	*F*=4.127, *P*=.045
	Traditional (n=31)		
Attitude			
	Virtual (n=67)	*F*=3.759, *P*=.056	*F*=1.069, *P*=.304
	Traditional (n=29)		
Stress			
	Virtual (n=68)	*F*=0.871, *P*=.353	*F*=1.915, *P*=.170
	Traditional (n=32)		
Self-efficacy			
	Virtual (n=68)	*F*=0.268, *P*=.606	*F*=1.416, *P*=.237
	Traditional (n=32)		
Social support (total score)			
	Virtual (n=68)	*F*=0.184, *P*=.669	*F*=5.647, *P*=.019
	Traditional (n=32)		

Discussion

Principal Results

The objective of the study was to compare the effectiveness of two kinds of follow-up—traditional and virtual—in promoting adherence behavior among HIV patients on ART. We expected virtual follow-up to produce greater adherence on account of the use of an innovative tool, VIH-TAVIE, designed to empower HIV patients to self-manage their ART. Results showed that the two groups improved in adherence at 6 months but did not differ in this regard. Hence, neither type of follow-up proved better than the other in terms of treatment adherence.

The two groups or cohorts studied had been living with HIV for 14 years, had been under therapy for 10 years, reported many symptoms, but maintained a high adherence level that far exceeded percentage levels reported in the literature. In this regard, a recent meta-analysis of 84 studies from 20 countries [17] showed that only 62% of participants reported 90% or better ART adherence. Despite a high percentage at baseline that left little room for improvement, the two groups still managed to improve over time. The two groups also improved in terms of symptom-related discomfort and perceived social support. Sense of self-efficacy and attitude toward ART medication intake, which were high at baseline, remained unchanged.

It is worth noting that with both types of follow-up—virtual and traditional—individuals improved in adherence over the 6-month period. This is a significant clinical outcome given the consequences of non-adherence on treatment's effectiveness to stop viral replication and the individual's subsequent state of health. As it is documented, poor adherence remains a major risk factor for virologic failure and the development of resistance [22] and has major implications regarding future viral transmission.

Notwithstanding our results, Hersch and colleagues [23] reported that the adherence rate of participants in their Web-based adherence program did not improve but actually decreased slightly, whereas the adherence rate in the control group declined from about 85% to 66%.

Such differences in reported findings can be attributed to the difficulty of observing improvement in adherence among HIV patients. This was observed by Mathes et al [24]. In their systematic review, they pointed out that the likelihood of finding only slight differences between groups is limited by a ceiling effect (high baseline adherence) and the fact that comparison groups benefit from adherence-enhancing components in their usual follow-up. Also, the meta-analysis by de Bruin and colleagues [25] showed that standard adherence care (traditional follow-up) had a large impact on HIV treatment effectiveness and adherence. In fact, these authors found these HIV patients in the experimental and the comparison groups (standard adherence care) of ART adherence intervention trials were exposed to effective adherence care that explained up to 55% of treatment success rates.

At present, comparisons with previous studies remain difficult given the scant literature on interventions similar to VIH-TAVIE. Most of the published studies concern interventions using mobile phones [26-28] or SMS/text

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messaging [8,28-33]. To date, only Fisher and colleagues [34] and Hersch and colleagues [23] have evaluated Web-based HIV medication adherence interventions comparable to VIH-TAVIE. Fisher et al [34] conducted a large randomized controlled trial (RCT) to evaluate or test the efficacy of a computer-administered ART adherence support intervention. Though an intention-to-treat analysis (n=594) revealed no significant impact on medication adherence compared with usual interventions (standard care), a protocol analysis (n=328) that considered only participants who completed all planned sessions showed a significant increase in self-report adherence for the computer-based intervention group. Hersch and colleagues [23], for their part, tested a Web-based program intended to improve medication adherence among adult HIV patients. For the purpose, 168 participants were randomized into either the Web-based program or a wait-list control condition. Those who benefitted from the Web-based program had a significantly higher ART medication adherence rate than did patients in the control group over a 9-month period. As stated by the authors, the adherence rate of participants in the Web-based program did not improve, while the adherence rate of the control group declined substantially. The work conducted by León and colleagues [35] is very innovative and instructive as well. These researchers developed an Internet-based homecare model—Virtual Hospital—that covers management of chronic HIV-infected patients in full. It offers four main services: virtual consultations, telepharmacy, virtual library, and virtual community. In an RCT, 42 patients were followed through Virtual Hospital and 41 through standard care. Results showed Virtual Hospital to be a feasible and safe tool. In fact, the groups did not differ in terms of clinical parameters such as viral load, CD4 count, and treatment adherence.

Although ICT-assisted interventions have shown promise as an effective means of maintaining and improving medication adherence, more research is needed to determine their efficacy with larger trials and adequate statistical power. According to Pellowski and Kalichman [5], no definite conclusions can be drawn from existing research as only pilot studies with insufficient statistical power to detect even modest-sized effects have been carried out to date. In their systematic review of the literature, Linn et al [36] concluded that ICT-assisted interventions showed promising results as a means of enhancing patient adherence to prescribed long-term medication but since this constituted a relatively new field of endeavor, high-quality studies were required in the future to establish more robust evidence of the effectiveness of this type of intervention.

Limitations

Our study is not without limitations. Above all, the absence of randomization and a deep selection bias led to the formation of highly heterogeneous groups in terms of sociodemographic characteristics and affective and cognitive variables. Statistical adjustments were necessary to correct for this. In addition, conservative statistical strategies were used to address the problem of attrition within the traditional follow-up group at T3 and T6. Unfortunately, randomization was not feasible in our clinical context and study setting. Given that group assignment was non-random, the risk for bias in the study was high.

Future Research and Spin-Offs

In our study, VIH-TAVIE was evaluated in a hospital setting as an adjunct to usual care. Users did not need to own a computer in order to participate in the study as one was provided at the health care center. We thus managed to involve a wider range of participants than is normally reached by Web-based interventions. Indeed, three-quarters of our participants were in a precarious socioeconomic condition, collecting welfare benefits and living on annual income of less than CAD $15,000. We are presently conducting a large online trial to evaluate VIH-TAVIE's capacity to optimize adherence among participants with Internet access [37]. Other applications developed on the basis of the TAVIE platform are currently under evaluation. These include TRANSPLANT-TAVIE (a virtual nurse intervention intended to support transplant recipients in managing their treatment) and TAVIE@coeur (a virtual nurse intervention intended to support persons with a heart condition in managing their treatment). SOULAGE-TAVIE has been field-tested with persons in the pre-operative phase of heart surgery to help them with pain management; results so far are very promising [38].

Future Implications and Conclusions

We developed and tested an innovative intervention for providing follow-up care to HIV patients, particularly by helping patients manage their ART. This virtual tool is easy to implement and could constitute a complementary service in support of existing specialized services. Given the current short supply of specialized resources in health care and in the area of HIV-related services, VIH-TAVIE offers clinicians an additional instrument to support their professional practice and meet the needs of their clientele with a minimum investment in human resources. As it consists essentially of simulated interactions with a virtual nurse, all that is needed is to provide minimal remote computer support services in the event the user encounters technical problems. The computer platform affords the system administrator the flexibility to add and modify page models without always having to resort to a Web programmer. This reduces system costs and facilitates the implementation of solutions over the long term in a normal context of clinical practice.

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We wish to thank the participants who contributed to this research. We are grateful also to the professionals at the clinics for their help with participant recruitment.

Conflicts of Interest

Granting of licensing options for marketing VIH-TAVIE will follow study completion.

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Abbreviations

ANOVA: analysis of variance
ART: antiretroviral therapy
GEE: generalized estimating equations

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GLM: generalized linear model
HIV/AIDS: human immunodeficiency virus/acquired immune deficiency syndrome
ICT: information and communication technologies
LOCF: last observation carried forward
RCT: randomized controlled trial
SMS: short message service
VIH-TAVIE: HIV Treatment, Virtual Nursing Assistance and Education (Virus de l'immunodéficience humaine - Traitement assistance virtuelle infirmière et enseignement)

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Original Paper

The Effect of Social Support Features and Gamification on a Web-Based Intervention for Rheumatoid Arthritis Patients: Randomized Controlled Trial

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Abstract

Background: Rheumatoid arthritis (RA) is chronic systematic disease that affects people during the most productive period of their lives. Web-based health interventions have been effective in many studies; however, there is little evidence and few studies showing the effectiveness of online social support and especially gamification on patients' behavioral and health outcomes.

Objective: The aim of this study was to look into the effects of a Web-based intervention that included online social support features and gamification on physical activity, health care utilization, medication overuse, empowerment, and RA knowledge of RA patients. The effect of gamification on website use was also investigated.

Methods: We conducted a 5-arm parallel randomized controlled trial for RA patients in Ticino (Italian-speaking part of Switzerland). A total of 157 patients were recruited through brochures left with physicians and were randomly allocated to 1 of 4 experimental conditions with different types of access to online social support and gamification features and a control group that had no access to the website. Data were collected at 3 time points through questionnaires at baseline, posttest 2 months later, and at follow-up after another 2 months. Primary outcomes were physical activity, health care utilization, and medication overuse; secondary outcomes included empowerment and RA knowledge. All outcomes were self-reported. Intention-to-treat analysis was followed and multilevel linear mixed models were used to study the change of outcomes over time.

Results: The best-fit multilevel models (growth curve models) that described the change in the primary outcomes over the course of the intervention included time and empowerment as time-variant predictors. The growth curve analyses of experimental conditions were compared to the control group. Physical activity increased over time for patients having access to social support sections plus gaming (unstandardized beta coefficient [B]=3.39, P=.02). Health care utilization showed a significant decrease for patients accessing social support features (B=–0.41, P=.01) and patients accessing both social support features and gaming (B=–0.33, P=.03). Patients who had access to either social support sections or the gaming experience of the website gained more empowerment (B=2.59, P=.03; B=2.29, P=.05; respectively). Patients who were offered a gamified experience used the website more often than the ones without gaming (t_{91}=–2.41, P=.02; U=812, P=.02).

Conclusions: The Web-based intervention had a positive impact (more desirable outcomes) on intervention groups compared to the control group. Social support sections on the website decreased health care utilization and medication overuse and increased empowerment. Gamification alone or with social support increased physical activity and empowerment and decreased health care utilization. This study provides evidence demonstrating the potential positive effect of gamification and online social support on health and behavioral outcomes.

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Trial Registration: International Standard Randomized Controlled Trial Number (ISRCTN): 57366516; http://www.controlled-trials. com/ISRCTN57366516 (Archived by webcite at http://www.webcitation.org/6PBvvAvvV).

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KEYWORDS

social support; gaming; experimental games; eHealth; rheumatoid arthritis; randomized controlled trial; multilevel analysis; patient empowerment; physical activity; health care utilization

Introduction

Background

Rheumatoid arthritis (RA) is a chronic systemic disease that affects the joints, connective tissues, muscles, tendons, and fibrous tissue [1]. The disease predominantly targets adults aged between 20 and 40 years and it is more prevalent in women than in men [1]. Because RA affects people during an especially productive economic period of their lives, it is considered a serious public health problem globally. In Switzerland, up to 1% of the population suffers from RA. Its estimated cost to Swiss society reaches €23,982 per patient a year [2]. The impact of RA goes beyond physical and economic aspects; it affects patients psychologically and emotionally, making them suffer severe consequences and losses [3].

The fast adoption and use of the Internet during the last decade and the proliferation of Web-based apps (eg, wikis, blogs, forums, chat rooms, social networking, and video sharing) with the emergence of Web 2.0 has made health care providers realize the importance and potentials of the medium to target patients [4]. As Internet penetration has been increasing—the share of the population using the Internet was estimated to be 63.2% in Europe and 78.6% in North America as of June 2012 [5]—the Internet has become a necessity and part of people's daily life. In April 2012, 82% of all American adults older than 18 years used the Internet or email at least occasionally [6] and 70% of Internet users aged 65 and older used the Internet on a typical day.

The health care domain, like many other fields, benefits from this technological advancement; people tend to seek online health information, virtual communities, and Web-based apps, and many other forms of online health services have started to emerge to satisfy people's needs.

The basic idea behind informative eHealth offers issued by official or medical institutions is to help patients better cope with chronic conditions, primarily by providing correct and up-to-date information [7]. The goals include knowledge gain, better health-related quality of life, behavior change beneficial to patients' health, and less unnecessary utilization of the health system.

To attain these goals, several interventions and self-management programs were developed and their efficacy for helping patients to achieve these goals tested. Many of these interventions emphasized empowerment and self-management [8-13]. The aim of empowering patients is to enable them to use the health information they acquire for making decisions and judgments that help them manage their disease. The effectiveness of more physical activity [14-16] and self-management [17-19] has been long established in treating arthritis-related pain and disabilities. One of the first Internet-based interventions was created and studied by Van Den Berg and colleagues [20] to increase physical activity of patients with RA. They compared 2 versions of an Internet-based intervention; the first included a physical activity program with individual/tailored guidance, a bicycle ergometer, and group contacts, and the second consisted of only general information on exercises and physical activity. They found that the proportion of RA patients who reported meeting the physical activity recommendations was significantly higher in the first program than in the second.

Along the same lines, another experiment done by Lorig and colleagues [9] tested the efficacy of delivering their developed arthritis self-management program through an Internet-based intervention. The intervention improved health status measures at 1 year, presenting an alternative to the conventional small-group arthritis self-management program.

In addition to the provision of information, the Internet has more to offer to attain these goals; in particular, health websites can be designed to provide social support to their users. Social support is an important factor because it has been shown that seeking and receiving assistance from other people is vital to chronically ill persons and it is associated with an increase in empowerment and self-management skills [21-24]. Consequently, the online health communities providing online social support become an essential resource for patients searching for others with similar health concerns [25].

Two forms of social support can be distinguished: structural support (availability of support givers) and functional support (perception of support) [26]. Both can help chronically ill patients to cope emotionally and practically [27,28]. There is strong empirical evidence that the support patients receive from their social environment can help them face the challenges and improve their self-management of chronic disease [29]. Our focus, as in most of the research, is on the structural support that usually comes from family, friends, and significant others [30-31], but we shift the perspective to structural social support delivered online by other website users, be they experts, physicians, or other patients.

Many studies, predominantly qualitative studies, analyzed post comments and messages published on bulletin boards or forums for patients with chronic diseases [32-37] and categorized the types and themes of online social support. There is no consensus on the order or importance of types of support, but a recurring categorization across studies distinguishes informational, emotional, and practical (or instrumental) support [38].

Literature reviews, such as Eysenbach et al [21] and more recently Griffiths et al [39], investigated the evidence of an

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effect of online peer-to-peer interactions on users/patients and Internet support groups (ISGs) in the area of depressive symptoms. According to Eysenbach et al [21], virtual communities cannot harm people; however, there was no evidence of benefit either, which suggests more research is needed to understand for whom and under which conditions social support could work [21]. For the Griffiths et al review [39], there was little high-quality evidence dealing with the efficacy of ISGs on coping with depression, suggesting a need for high-quality randomized controlled trials (RCTs) in this domain.

The concept of "gamification" has emerged recently. It is described as the application of game design elements in a nongame context to motivate or influence participation [40-42] and sometimes also refers to designing new serious games [43]. Significant knowledge increase by, and high users' appreciation of, gamified apps are shown in studies on gamifying laboratory experience for undergraduate microbiology students [44], evaluating a 3D serious game for advanced life support retraining [45], and major incident triage training [46]. However, much of the evidence for an influence of gamification on people's mind and behavior is anecdotal, with only 1 very recent systematic literature review [47] as discussed by Cugelman [48]. The review included 24 studies for final evaluation, which examined the relationship between motivation affordances (eg, points, badges, leaderboards, reward) and behavioral (use of the system/application and intentions surveyed through questionnaires) and psychological outcomes (motivation, attitude, and enjoyment) using evaluative interviews or questionnaires [47]. Only 1 study [43] from the review of Hamari el al [47] used validated psychometric measurements and its context was health/exercise. The predominant context of gamification studies was education or learning and their participants were students [41-44] or they were conducted in crowdsourcing systems (ie, Amazon Mturk) [47].

Do social support features and gamification elements affect the attainment of the goal of health websites, provided they do have effects? Given the dearth of hard evidence for the effect of gamification and a conflicted or at most modest evidence for the effect of online social support of Web-based health interventions on health outcomes, we decided to conduct an experimental study that included both. The intervention used in this study is ONESELF, a Web-based intervention designed and operated for chronically ill patients with RA [49].

ONESELF has informational and online support features and a gamified user experience, but access to these features was manipulated for the different experimental groups. We developed ONESELF in collaboration with the doctors of the Swiss Rheumatology Association. The ONESELF website is compliant with the Health on the Net (HON) Foundation guidelines and is HON certified.

ONESELF Overview

ONESELF began in late 2004 (early prototype and development) as a project to test the efficacy of an online tool (using the Internet as a medium) to enhance the self-management of chronic low back pain patients in the Italian-speaking population of Switzerland [50]. The results of the pilot study (June 2004 to June 2005) were promising; the patients' experiences and feedback obtained helped to improve and redesign the website. As a result, another study [51] with a larger sample (129 patients who filled in pre- and postuse questionnaires) was conducted between June 2006 and May 2007. The results confirmed the pilot study with patients reporting decreased painkiller intake and an increase in knowledge of back pain. Moreover, there was an acknowledgment of the benefits for improving the communication with doctors and family and colleagues. The qualitative analysis done in the same study [51] and in another by Zufferey et al [52] reported that patients experienced positive effects on self-management attitudes and behaviors with regard to their chronic low back pain condition. The design principles followed in developing ONESELF content (patient centeredness and rich information), monitoring by health professionals, and providing a tailored experience to patients proved to be a promising, viable tool for helping patients enhance and develop their self-management of chronic low back pain. This was true especially for patients who were engaged in the process of self-management or were inclined to self-manage [51,52].

The research on ONESELF was extended to target other chronic patients when another release of ONESELF took place in June 2008, which included a new section for patients with fibromyalgia syndrome. A first cross-sectional study took place in the same period, for which 209 patients were recruited to evaluate the effectiveness of the Internet-based education intervention built on principles of personalization and participatory design [53]. An a priori model was tested that included the patients' self-reported use of the website, health knowledge, self-management behavior, and health outcomes. The results showed that using the tailored functionalities that were the result of end users' involvement and participation in the design and development process improved patients' health knowledge and, in turn, improved the self-management skills that can decrease the effects of fibromyalgia syndrome and eventually lead to reaching better health outcomes. The online gymnasium for patients with fibromyalgia syndrome [54] was 1 of the many examples of personalization and tailoring done on ONESELF [53]. A final experiment was conducted on ONESELF before its most recent version was released [55]. The goal was to investigate and test the role of functional interactivity on patients' knowledge, empowerment, and health outcomes. It was a pretest-posttest experimental design in which 165 patients suffering from fibromyalgia syndrome were randomly allocated to 3 groups corresponding to different levels of functional interactivity. The study reported a model-driven evaluation that tested whether health knowledge and empowerment mediated a possible relationship between the availability of interactive features and individuals' health outcomes. Functional interactivity did not affect empowerment or knowledge; however, knowledge and some dimensions of the empowerment positively affected the health outcomes.

Research Aims

Because of the importance of the impact of knowledge and empowerment on health outcomes [55], the goal in this study was to target these constructs and enhance their effects. Inspired by the model-driven approach presented by Camerini and Schulz [55], the current RCT aimed at testing the new experimental

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manipulation (online social support and gamification) in a similar approach. The primary outcomes studied were patients' physical activity, health care utilization, and prescription medication overuse. Moreover, we considered secondary outcomes (empowerment, knowledge), which were also included as predictors of the primary ones. To our knowledge, this is 1 of the first RCT studies that includes gamification as part of experimental manipulation and studies its effect on cognitive and behavioral outcomes of patients diagnosed with RA.

The main part of this study looks into the effects of social support features and gamification on the primary outcomes, expecting beneficial effects (more exercise, less health care utilization, less medication overuse) for the former, and treating the direction of an effect of gamification as an open research question. In a side analysis, the effect of gamification on website use will be addressed.

Methods

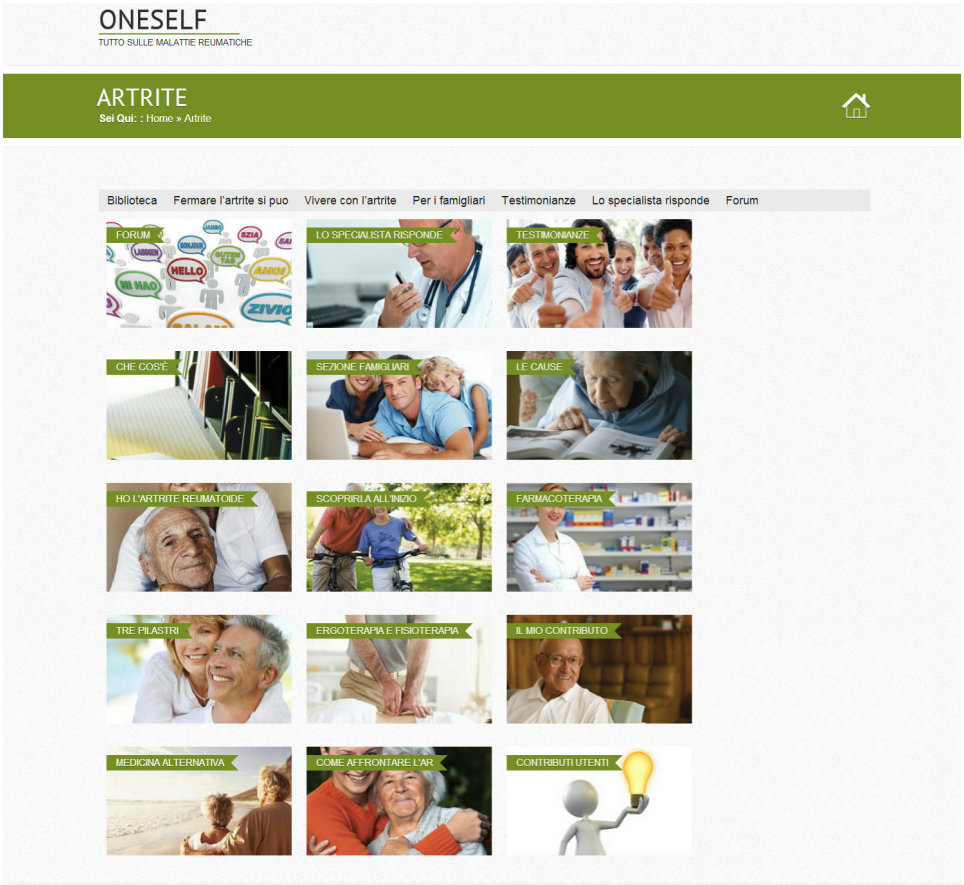
Overview

The study was conducted as an RCT experiment with RA patients in Ticino (Italian-speaking part of Switzerland). Data (assessment of the intervention) were collected from the last week of February 2013 until July 2013.

A new independent section about RA was created and added to the other 2 sections of the ONESELF website, which were completely rewritten in Drupal [56]. Drupal was chosen because of its flexibility and scalability to develop features and functionalities through writing custom modules that would integrate with the other core modules available from the system. For this study, multiple custom modules were written that took care of the experimental manipulation, the gamification of many of the functionalities of the website, and many other tailored features specifically for the conducted experiment as described in the following sections. Moreover, it is a well-documented open source content management system (CMS) that has a vibrant and active development community making it a reliable CMS.

The single-blinded experiment tested, in a repeated-measure design, the effect of website sections and features offering social support and a corresponding gaming experience compared to a standalone informative version of the website. Participants were randomly allocated to the parallel experimental groups, unaware of any manipulation, and blinded to one other. Each group had access to different sections and features of the website, including a control group with no access at all. Participants filled in questionnaires at 3 occasions: baseline, posttest 2 months later, and a follow-up after another 2 months. The study was approved by the Ethical Committee of Canton Ticino (the Italian-speaking part of Switzerland). Figure 1 presents the complete RA section of the website.

Figure 1. Screenshot of the complete rheumatoid arthritis section on the ONESELF website.



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Website Sections and Features

The original purpose of ONESELF was to provide information that promotes good health outcomes. Building on the past and learned experiences in developing the ONESELF website and its content and following the principle of patient centeredness, patients' needs were translated into material and content prepared with the help of health professionals, providing the right reading level, in the right language, using culturally appropriate images [51]. ONESELF was designed to target the declarative knowledge, the procedural knowledge, and the integration of knowledge toward a behavioral response [51].

The main sections and features were:

1. One section included informative webpages about RA and served to improve the declarative knowledge of the patients by using simple layperson language to present and describe arthritis, covering its main aspects and the issues around it.
2. Three sections included articles and videos prepared in collaboration with physiotherapists, ergotherapists, and doctors. They explained methods and techniques that helped in coping with RA especially in one's everyday life. These sections served to minimize the negative impact of the disease on patients' lives at home and at the workplace. Treatment options such as medications and alternative therapies were also discussed in these sections. The goal was to target the procedural knowledge of the patients by explaining the steps and actions that contribute to better disease management.
3. The testimonies section included video interviews with patients speaking about their experience with the disease and the way they dealt with it.
4. Another section offered video interviews with doctors about different therapies and the ways for handling the pain and getting over the obstacles presented by RA.
5. A forum and chat room were implemented and made available to the patients. During the course of the intervention, 9 prescheduled sessions were offered in the chat room. Patients were able to see the agenda of the planned sessions and the topic that would be addressed by each doctor. In each session, a different doctor participated in the chat with the patients, moderated by the research team. Patients discussed their questions and concerns with the doctor. The discussion was visible to all participants in the chat room.
6. A patients' blog was a tool for patients to contribute to the website. They were allowed to write anything and attach files and materials accessible to other patients.
7. Gamification was added to encourage and motivate the patients to use the platform more. Participants' actions and contributions to the platform were rewarded by points that allowed for collecting different badges and gaining various medals. Points were given according to patients' contributions and interaction with different features of the website. We differentiated between immediate and delayed rewarding. Points were immediately rewarded for posting, commenting/replying in the forum, writing and publishing in the patients' blog, and answering 1 of the quizzes correctly that were attached to the different webpages. Delayed rewarding was given for visiting and exploring the different webpages and sections and for participating in the chat room sessions. Points were automatically calculated and distributed at midnight (Swiss time). A section called "My Points" (Figures 2 and 3) was available in which patients could see their rank and statistics for their performance in collecting points, badges, and medals. The same section contained a leadership board that showed the top 5 users from among the same experimental group and gave information about their points collected in the different categories. The rules of the game and the explanation of how to earn points, badges, and medals were included in the same section that announced a real prize for the top 5 users at the end of the intervention.

Sections 1 and 2 offered information primarily, whereas the other sections provided social support to users, including emotional, practical, and informational support from different parties: RA patients for testimonies, physicians and doctors for video interviews, and both for the forum and chat room. For additional information and presentation of different features and sections implemented in the platform, refer to Multimedia Appendix 1.

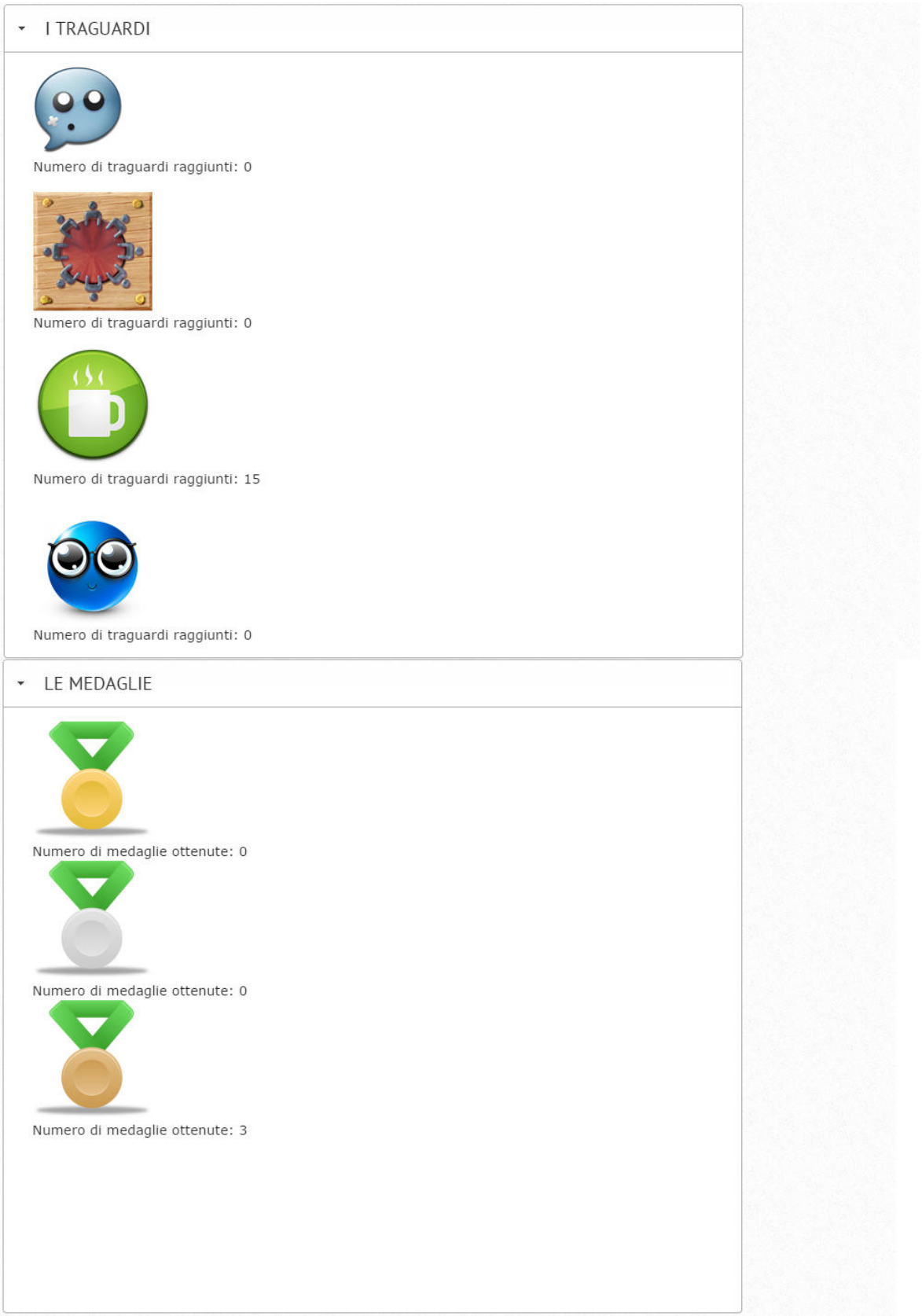
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Figure 2. Screenshot of My Points section of the ONESELF website displaying statistics of the collected points for every action in each category and leadership board of top 5 users.



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Figure 3. Screenshot of My Points section of the ONESELF website displaying the badges and medals achieved during the intervention.



Recruitment and Participants

Recruitment of participants lasted from November 2012 until February 2013. Patients were introduced to the experiment through brochures left with health care providers (rheumatologists, physiotherapists, ergotherapists, and psychologists). There was a continuous collaboration between the research team and the health care providers who helped in the recruitment process at their corresponding clinics and rehabilitation centers. In this way, we were assured that

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prospective participants received a diagnosis of RA from their doctor and had not participated in another experiment or research study before. Moreover, the screening process included predefined inclusion criteria the patients had to meet to participate in the study: (1) received a diagnosis for RA from a doctor, (2) had sufficient competence to use the website effectively (self-reported ability to navigate the Internet and browse websites for health information), (3) did not have any other major chronic illness (eg, cancer, diabetes), (4) had Internet access, (5) was willing to use the website for at least 1 hour per week, and (6) was fluent in the Italian language. If they met these criteria, patients were given a brochure with a brief description of the study and a contact and consent form to be signed and sent back to the research team (see Multimedia Appendix 2).

Experimental Groups

Patients were randomly allocated to 1 of 4 experimental groups or a control group with no access to the website. The randomization of the patients was based on a computerized random number generator that handled the patients' assignment to different groups.

One group of patients had access to informational sections only, another group additionally had access to the social support sections but not to the gaming section, a third group had access to the gaming but not the social support sections, and a final group had access to everything. Table 1 illustrates the experimental design.

Table 1. Overview of experimental conditions.

Group access	No access to information sections		Access to informational sections	
	No access to social support features	Access to social support features	No access to social support features	Access to social support features
No access to gaming feature	Control group		Information group	Support group
Access to gaming feature			Gaming group	Support plus gaming group

Procedure

Once patients were randomly allocated to 1 of the experimental groups, a researcher with the help of a student assistant contacted the patients (via email or phone) to inform them of further instructions. They also contacted the patients when questionnaires were ready at later assessment points.

Patients who were to use the ONESELF website were given a brief explanation of the study and provided with further instructions to access the website through generated accounts with unique user IDs. By following the instructions, patients were able to log in to the website and edit their user profile by choosing a new username and password. The first time patients signed in to the platform, they were prompted to fill in an online baseline questionnaire. Access to the website was blocked until the patients finished it. After that, patients were free to explore the different sections and features of the website available to their experimental group. On the patient profiles, a paragraph called "ethical consideration" was clearly visible, which stated that the study was approved by an ethical committee and participation was voluntary and that they could revoke the consensus they had given and quit the study without any need for justification or reason at any time.

During the experiment, the website was updated frequently and we notified the patients continually by email. The updating and notification mechanism allowed for presenting communication messages in modal windows (modal dialogs blocking the interaction with other elements and windows on the website) to the patients when they accessed the website. In addition, they were also redirected to different pages after closing these messages for checking the new published content. Moreover, a ticker was displayed on the different sections of the website showing the latest messages addressing the patients. In addition to sending emails, patients who had access to social support features were also notified by short message service (SMS) text message about the chat room appointments, inviting them to participate. A researcher from the research team played the role of moderator during the chat room sessions in addition to coordinating the interaction and communication on the forum between the patients and invited health professionals throughout the intervention. The researchers and the student assistant mentioned previously did not participate in the data analysis.

Two months after the beginning of the intervention, the posttest was presented again in a modal window and patients had to complete it if they wished to continue using the site. The final follow-up questionnaire was filled in 2 months after the posttest. Patients were contacted by email and/or telephone when the online questionnaire was ready. A maximum of 2 phone calls were made as a reminder to fill in the questionnaires.

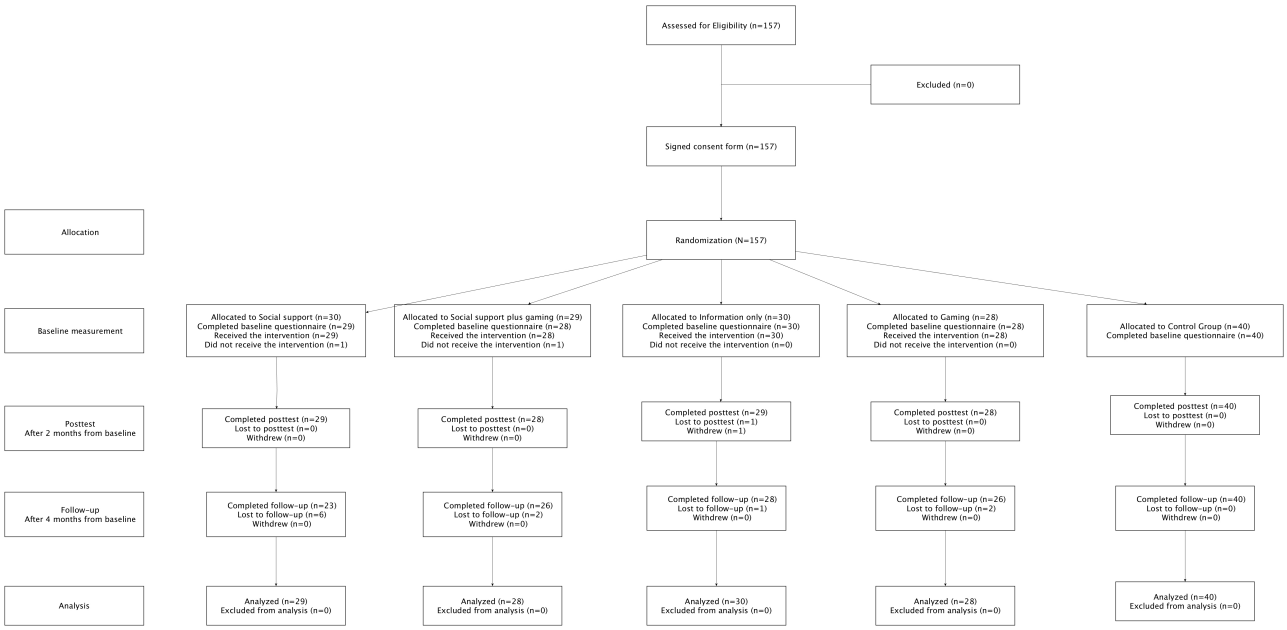
For the control group, they were instructed to fill out a paper-and-pencil version of the questionnaire that was sent by mail to their contact address, having been informed that we were interested in collecting general information about RA with the aim of developing an online platform that would be accessible to the public at a later date.

Figure 4 shows the flow diagram summarizing the recruitment, randomization, attrition, and measurements at the 3 time points [57].

When the experiment was finished, participating patients were invited to a press conference [58] held at the university where the researchers presented the preliminary results of the study and the real research goals of the experiment in the presence of collaborating health professionals and the local media reporters. Moreover, all participating patients were contacted (via email or phone) and were informed that the website was publicly accessible.

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Figure 4. CONSORT flow diagram of participants.



Measures

Overview

The baseline questionnaire, the posttest, and the follow-up used the same questions and exact wording. The study used the following measures.

Primary Outcomes

1. Physical activity: 6 items based on the Exercise Behaviors Scale [59]. The items measured the time spent on physical activity in the last week on a scale from 0=never to 5=more than 3 hours per week. More specifically, it measured for the entire week the time spent on each of the following exercise categories: (1) stretching or strengthening exercises, (2) walk for exercise, (3) swimming or aquatic exercise, (4) bicycling, and (5) other aerobic exercise equipment (eg, rowing, skiing) and other specified aerobic exercise. The scoring of each item as reported by the original scale estimated the number of minutes spent on exercise from 0 to 180 minutes. The average sum of the items represented the mean minutes spent on exercise by each patient. The test-retest reliability of the measure in the original reference was .72
2. Health care utilization: 5 items based on Health Care Utilization Scale [60]. They were used to measure the self-reported outpatient visits to physicians, emergency room visits, nights in the hospital, chiropractic visits, and physical therapy visits. The mean number of visits indicated the health care utilization measure. The test-retest reliability of the measure in the original reference ranged from .76 to .97 for each of the 5 items.
3. Prescription medication overuse: 6 items based on the Prescription Opioid Misuse Index [61]. Each item was a yes/no question. Items were scored 1=yes and 0=no, and the sum of the items' score was mapped to a final score ranging from 0 to 100, where the higher the score (ie, 100=full score), the more medication overuse is indicated. The items asked about RA medications and primarily pain medications. By using the Kuder-Richardson 20 coefficient (KR-20) for dichotomous variables [62], the internal consistency of the scale measured at each assessment point range from .66 to .69.

Secondary Outcomes

1. Rheumatoid arthritis knowledge: 15 multiple-choice questions based on the Patient Knowledge Questionnaire in RA [63]. The total sum score of the 15 items was the final measure. The test-retest reliability of the measure in the original reference was r=.81 and the internal consistency measured by KR-20 was .72
2. Empowerment: 12 items adapted for RA, based on the empowerment scale proposed by Spreitzer [64]. It included 4 subdimensions: meaning, competence, self-determination, and impact. Each item in the scale was measured on a 7-point Likert scale from 1=very strongly disagree to 7=very strongly agree. The internal consistency of the scale measured using Cronbach alpha at each assessment point had values ranging from .95 to .96.

Predictors

The predictor variables were time of measurement and experimental condition, and additionally for the models of the primary outcomes the secondary outcomes (knowledge, empowerment). Time of measurement was coded 0=baseline, 2=posttest after 2 months, and 4=follow-up after 4 months from baseline. Experimental condition was coded as 4 dummy variables for the 4 experimental groups with the control group with no access to the site as reference. Therefore, all analyses of experimental condition were in comparison to the control group.

Control Variables

For sociodemographic information, patients' age (in years), gender (1=male, 2=female), coded level of education (1=elementary school, 2=middle school, 3=high school,

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4=university), working status (1=yes, 2=no), and nationality (1=Swiss, 2=other) were measured. In addition, patients indicated (in years) the duration of their arthritis disease from diagnosis and the time from the first symptoms to first diagnosis. The demographic measures were included only in the baseline questionnaire.

Data Analysis and Model Building

Overview

Data were analyzed using a multilevel linear modeling technique in which the 3 measurement occasions were on the first level and the patients on the second level. Multilevel modeling was chosen because it is well suited for the analysis of repeated measurements allowing for correct inferences because standard errors of the estimated model parameters will not be underestimated and consequently reduces the risk of inflation of type I errors. It is known to be robust for unbalanced and missing data [65-67]. This approach is known as growth curve modeling; it studies growth trajectories over time, examining the pattern of change and taking into account the correlation between the measurement occasions for each patient by considering random effects of the parameters and additionally estimating the error variance-covariance matrix of the repeated measurements.

The approach models the within-patients change/growth trajectory in the outcome measure by presenting 2 kinds of submodels, both consisting of linear regressions. A level 1 submodel was computed for each participant based on 3 cases; namely, the 3 measurement points. The outcome measure was regressed on time and any potential time-variant covariate (empowerment and knowledge in our case). Because there were 3 primary outcomes and 155 participants, the total number of computed regressions was 465. The level 1 model parameters defined the shape of the individual's growth curve or change in the outcome measure over time. The intercept indicates an individual's initial value on the outcome variable. The slope coefficient of the time variable indicates the rate of change in the primary outcome net of the secondary outcomes, and the slope coefficients of the secondary outcome variables indicate their contribution to the primary outcome net of time.

For the level 2 submodels, the parameters from level 1 were each made dependent variables in new regressions based on the 155 participants as cases. Each parameter of the level 1 submodel was regressed on the experimental condition and the sociodemographic control variables to analyze between-patient differences in the change trajectories of the measured outcome and their effect on this change. The combined submodels (levels 1 and 2) formed the final composite model that represented the multilevel model used and evaluated for each primary and secondary outcome in this study. The approach followed a previously explained modeling procedure [68,69]. We conducted an intention-to-treat analysis that considered all patients (N=155) who filled in the baseline questionnaire and it assumed missing data were missing at random. Recent research [70] showed that for all types of missing data (missing completely at random, missing at random, and missing not at random), multiple imputation is not necessary before performing longitudinal mixed model analysis.

Primary Outcomes

The starting point was the unconditional means model with no predictors at any level to evaluate the intraclass correlation coefficient (ICC), which identifies the share of variance between patients among the total variance and validates the relevance of using multilevel analysis. The shares were 77.3%, 72.8%, and 61.0% for the 3 outcome measures (physical activity, health care utilization, medication overuse), confirming that multilevel modeling was an appropriate method of data analysis.

Then we constructed a series of composite "full-controlled" multilevel models. At level 1, various combinations of time and time-variant explanatory variables were used; the level 2 submodels always included the experimental conditions and sociodemographic variables. Therefore, the number of full-controlled multilevel models depended on the number of combinations that could be formed from choosing level 1 explanatory variables. Given that we had 2 explanatory variables (empowerment, knowledge) in addition to time, 4 combinations were possible: a multilevel model that included only time, or time and empowerment, or time and knowledge, or all 3 variables together. A likelihood ratio test was used to assess the multilevel model fit (the composite model of both level 1 and level 2 submodels) and track the best-fit model. In addition, Akaike information criterion (AIC) was used for comparing nonnested models. The models were full controlled (ie, adjusted) because they included all measured sociodemographic variables. This was done to investigate the net effect of the experimental condition on the outcome measure in a situation in which some of the groups, in spite of randomization, differed from others in the sociodemographic variables (ie, gender, age, and education as described subsequently). After investigating different model specifications (fixed and random effects and error variance-covariance matrix structure, such as unstructured, autoregressive order 1, etc), the final reported best-fit models in addition to the fixed effects, they included a random intercept and a first-order autoregressive structure with heterogeneous variance error variance-covariance matrix. Maximum likelihood estimation was used for estimating model parameters in which the time-variant predictors and covariates were centered at their grand mean.

For making sense of the estimated parameters, the intercept indicated the average initial level of the dependent variable in the control group. Regression parameters for the experimental condition indicated differences between the groups and the control group; most importantly, the coefficients for the interaction of condition by time signaled any condition-specific trajectories, which were the major focus of this study. Parameters for the interaction of condition by secondary outcome indicated condition-specific influences of these secondary outcomes on the primary ones.

Secondary Outcomes

In a similar approach, we looked at the change in the secondary outcomes by regressing them on time for each patient (level 1 submodels). All sociodemographic plus experimental group variables were used again in the level 2 submodels, as done with the primary outcomes. The goal, also similar, was to investigate the effect of the experimental conditions on both

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empowerment and knowledge by studying the change over time of each of the latter variables and explore whether there were systematic differences between the experimental conditions and the control group after controlling for all sociodemographic variables.

Website Usage

For testing the effect of gamification, the usage of the website was indicated by the sum of the logged visits to each of the sections 1-6 of ONESELF, which were registered in the access log table of the website's database. When a section was entered, a new visit was counted. To look at the effect of gamification on usage, we grouped patients who had access to gaming (social support plus gaming and gaming groups) and those who did not (social support and information groups). For comparison, *t* tests and Mann-Whitney *U* tests were employed.

The models' estimated parameters for the primary and secondary outcomes and the test statistics for website usage were considered significant at $P \leq .05$. All analyses were conducted using SPSS 20 (IBM Corporation, Armonk, NY, USA).

Results

Patients' Baseline Demographics

A total of 155 people participated (information: n=30; social support: n=29; gaming: n=28; social support plus gaming: n=28; control: n=40). In all, 54.2% (84/155) were males and 45.8% (71/155) females. The mean age was 57.95 (SD 12.29) years; 85.2% (132/155) were Swiss nationals and 14.8% (23/155) were another nationality. Mean time since first diagnosis was 11.89 (SD 11.47) years. For level of education, 7.1% (11/155) had elementary school, 16.8% (26/155) had middle school, 67.7% (105/155) had high school, and 8.4% (13/155) had a university degree; 43.2% (67/155) of the patients were working. Baseline information about the sociodemographic measures for each group are reported in Table 2. Multimedia Appendix 3 reports descriptive statistics about the primary and secondary outcomes for each experimental group at every assessment point.

Table 2. Descriptive characteristics of the 5 experimental groups (N=155).

Self-reported measures	Information (n=30)	Social support (n=29)	Gaming (n=28)	Social support plus gaming (n=28)	Control (n=40)
Age (years), mean (SD)	55.10 (10.48)	53.17 (13.29)	54.50 (12.01)	53.46 (9.96)	69.33 (6.35)
Gender (male), n (%)	17 (57)	26 (90)	24 (86)	15 (54)	2 (5)
Education level, n (%)					
Elementary school	2 (7)	1 (4)	1 (4)	0 (0)	7 (18)
Middle school	2 (7)	6 (21)	5 (18)	2 (7)	11 (28)
High school	24 (83)	18 (64)	18 (64)	23 (82)	19 (49)
University	1 (3)	3 (11)	4 (14)	3 (11)	2 (5)
Work status (working), n (%)	17 (57)	19 (66)	13 (46)	14 (50)	4 (10)
Nationality, n (%)					
Swiss	21 (70)	24 (83)	26 (93)	27 (96)	34 (85)
Other	9 (30)	5 (17)	2 (7)	1 (4)	6 (15)
Duration of RA from first diagnosis (years), mean (SD)	9.90 (9.34)	10.52 (9.83)	8.89 (8.22)	10.43 (8.42)	18.11 (15.93)

Website Usage

On average, participants paid a mean 53.68 (SD 93.07) visits to the various sections of ONESELF during the period of data collection. Participants offered the gaming experience (social support plus gaming and gaming groups) visited the website a mean 66.81 (SD 112.44) times, whereas participants not offered the gaming experience visited the site less frequently (mean 26.15, SD 27.11 visits). As a result, there was a significant difference between the groups (t_{91}=–2.41, P=.02; U=812, P=.02). This suggests that groups who were offered the gamified experience used the website more often than groups denied this experience.

Multilevel Model Evaluation

Primary Outcomes

For the best-fit multilevel models, the estimated fixed effects parameters (the interactions between time-variant covariates and experimental groups) are reported for the 3 outcome measures in Table 3. For a better overview, only the significant parameters are shown. The complete regression tables, including *P* values, standard errors, etc, are available in Multimedia Appendix 4.

Physical activity was best predicted by a model that included time and empowerment. Looking at the trajectory of the control group, initially the mean number of minutes spent on exercise at baseline was significant (unstandardized beta coefficient [B]=57.55, P<.001) and there were no differences at baseline

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between the experimental groups and the control group. There was a significant influence factor: mean minutes spent on exercise increased over time for patients with access to the social support sections and gaming (B=3.39, *P*=.02), indicating that patients with access to the complete website features (social support plus gaming group) became more physically active as the experiment progressed in comparison to the group with no access to the site.

Change in health care utilization was best predicted by a model that included time and empowerment. At baseline, there was, on average, significant utilization of the health care system (B=2.79, *P*=.02) and there were no differences between the experimental conditions and the control group. As time passed, the average rate of change in health care utilization showed a significant decrease for patients in the social support group (B=–0.41, *P*=.01) and patients in the social support plus gaming group (B=–0.33, *P*=.03).

Prescription medication overuse was best predicted by a model that included time and empowerment. At baseline, the control group showed a significant medication overuse (B=12.06, *P*=.03), with no differences found between the control group and patients in the social support group or the gaming group. However, there were differences in the initial status between the control group and patients in the social support plus gaming group (B=9.51, *P*=.03) and patients in the information-only group (B=10.06, *P*=.02). When considering time, the mean monthly rate of change in medication overuse showed a decrease (marginally significant) only for patients in the social support group (B=–1.61, *P*=.056).

Table 3. Estimates of regression coefficients for predicting change in primary outcomes.

Predictors	Primary outcomes,[a] B		
	Physical activity	Health care utilization	Medication overuse
Intercept	57.55[b]	2.79[c]	12.06[c]
Group			
Social support	NS	NS	NS
Social support plus gaming	NS	NS	9.51[c]
Information	NS	NS	10.06[c]
Gaming	NS	NS	NS
Time	NS	NS	NS
Social support × time	NS	–0.41[c]	–1.61[c]
Social support plus gaming × time	3.39[c]	–0.33[c]	NS
Information × time	NS	NS	NS
Gaming × time	NS	NS	NS
Empowerment	NS	NS	NS
Social support × empowerment	NS	NS	NS
Social support plus gaming × empowerment	NS	NS	NS
Information × empowerment	NS	NS	NS
Gaming × empowerment	NS	NS	NS

[a] NS: not significant

[b] *P*<.001

[c] *P*≤.05

Secondary Outcomes

A significant change in empowerment without differences between the experimental conditions in the initial status is visible in the significant intercept (B=51.56, *P*<.001) and the absence of significant parameters for the experimental groups (Table 4). Generally, the mean rate of change for the control group did not increase over time as indicated by an insignificant parameter of the time variable. However, the interaction of 2 of the experimental conditions and time indicates that for these 2 groups the increase in empowerment became larger over time (B=2.59, *P*=.03; B=2.29, *P*=.05; respectively). The 2 groups were the social support and gaming groups that had access also to the informative sections of course. This means that users of the website with access to either social support sections or the gaming experience, both in addition to the informative parts, gained more empowerment than patients without access to the website at all.

The control group initially had a significant level of RA knowledge (B=5.89, *P*<.001) because there were no differences in the initial status between the experimental and the control group. Moreover, the effect of time was not significant where all the experimental conditions were comparable and had an

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average rate of change similar to the control group (equal to zero; null hypothesis was retained). This indicated that knowledge did not change significantly during the entire intervention for any of the experimental conditions.

Table 4. Estimates of regression coefficients for predicting change in secondary outcomes.

Predictors	Secondary outcome,[a] B	
	Empowerment	RA knowledge
Intercept	51.56[b]	5.89[b]
Group		
Social support	NS	NS
Social support plus gaming	NS	NS
Information	NS	NS
Gaming	NS	NS
Time	NS	NS
Social support × time	2.59[c]	NS
Social support plus gaming × time	NS	NS
Information × time	NS	NS
Gaming × time	2.29[c]	NS

[a] NS: not significant

[b] $P<.001$

[c] $P\leq.05$

Discussion

Principal Findings

The study included cognitive and behavioral measures. It tested the effect of online social support and gamification on health outcomes (health care utilization and medication overuse), patients' behavior (physical activity), empowerment, and knowledge for patients with RA.

Empowerment levels changed over time, more so in groups having access to online social support or a gamified experience of the website. The study suggests that online social support plays an essential role in improving patients' level of empowerment. This observation contrasts with the results of the earlier study done by Camerini and Schulz on ONESELF [55], which did not find any effect for functional interactivity on empowerment. This might be because we considered all 4 dimensions of empowerment together, whereas the previous study treated each dimension as a single variable. Moreover, our study included gamification, which was not included in Camerini and Schulz [55], in which functional interactivity was primarily about access to social support features (forum and chat room). Lastly, this study had 3 assessment points targeting RA patients, whereas the previous study was a pre-post test design targeting fibromyalgia syndrome patients. In addition, our comparisons were always with a control group without access to the website; the previous study did not have a real control group [55].

In contrast, there were no changes of RA knowledge levels over time for any of the experimental conditions. This result shares the findings of Camerini and Schulz [55] in which functional interactivity did not have a direct impact on knowledge of patients. This was additionally observed in this study by the absence of RA knowledge as a predictor in any of the best-fit models. The fact that knowledge did not change during the entire intervention for any of the experimental groups would explain the absence of its effect on the primary outcomes and not being part in any best-fit model, in contrast to empowerment. Given the familiarity of the participants in this study with their RA condition (mean time since first diagnosis was 11.89 years), their knowledge was sufficient to a certain extent and one would not expect significant change. The effect of knowledge might be visible if participants were much younger and recently diagnosed with RA. It would be an interesting idea for further research to test similar experiments with much earlier diagnosed patients.

Gamified experience of the website showed to increase website usage as defined by the number of access times to meaningful website sections. Because the main goal of gamifying systems is to engage users and increase their participation [40,48,71], a gamified health website such as ours also attracts and encourages patients to use and interact with the platform more. This adds empirical evidence to the validity of the motives behind gamification in the medical field. Moreover, gamification as implemented and designed for this experiment showed to increase empowerment over time. Patients' participation in a competition-like environment where their actions, contributions, and usage of the website were rewarded might have increased their motivation and confidence in acquiring and processing the disease-related information they found on ONESELF, eventually improving or creating the sense of empowerment in dealing with RA. Because empowerment and its importance were celebrated throughout the literature [10], having an association between gamification and empowerment provides additional

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evidence of its benefits. Further experiments are needed to better understand the mechanisms and the relation in greater detail of how presenting health information in an environment using gaming elements would eventually affect empowerment levels in managing a chronic disease.

Gamification and online social support was also associated with increased physical exercise over time. Looking to this effect from the gaming part, the increased physical activity aligns with a similar observation reported by Hamari et al [43] for a gamified platform in the context of fitness and exercise websites. From the online social support part, the increase in patients' self-reported physical activity echoes the effect that tested an Internet-based physical activity program with individually tailored supervision, exercise equipment, and group contacts compared to a control group that had access to Internet-based program offering general information on exercises and physical activity [20]. The combined effect of online social support and the gaming experience suggests that advice and information received by patients in the social support plus gaming group helped them cope with their disease and promoted exercises suitable for them, allowing the patients to follow and adhere more to the information and advice especially when they were presented in a gaming context. That is also evident in the case of health care utilization where a significant decrease was associated with gamification.

In the same line, this was also true for patients having access to online social support. The contribution of the information exchanged through the forum and chat room, which were the major features in the social support group, seems to improve patients' ability to self-manage their condition and eventually reduce the need to use the physical health care system. In other words, sharing the experiences and raising questions with other RA patients and health care professionals online substituted for the need to overly use the real health care system. Something similar happened in the case of medication overuse, in which patients accessing online social support features witnessed a decrease (marginally significant) compared to the control group. This complements and adds to the experiment done by Lorig et al [9] that looked into the effects of delivering an Internet-based arthritis self-management program compared to a usual care, small-group, self-management program by providing evidence of the role of Web-based delivered programs in decreasing health care utilization and medication overuse for RA patients.

For this study, we cannot conclude which is better: online social support or gamification. In fact, the relation between both components should not be represented as an exclusive OR as much as a complimentary relation. As shown in the growth curve models for each measured outcome except knowledge, patients with access to either of them (social support or gaming) or both of them (social support plus gaming) had an improvement leading to a better health or behavioral outcome.

Limitations

The study, as many others on Web-based interventions, used self-reported measures to assess changes in behavioral and health outcomes. More objective measures could be utilized to study the efficacy of gamification and social support that would complement the results presented. This is especially pertinent for the case of measuring physical activity, for which other studies did not find differences when physical equipment (ie, activity monitor) was used to measure the participants' physical exercise or activity [20,71].

Moreover, a 4-month period might not be sufficient to explore the longitudinal effect of the experimental condition on the changes in measured outcomes. A longer period with more measurement points would result in more precise estimates of the effect of the experimental manipulation on the growth curves that might take different functional forms than the linear one used in this study.

Although they did not have access to ONESELF, we cannot guarantee that the control group in the current study did not use other online tools and platforms on their own that provide information or any other support for patients with RA.

In addition, the study did not include a formal measure for computer skills or the ability and confidence to navigate and browse the Internet. It was only self-reported by patients and it would be interesting to include a formal measure (ie, e-literacy scale) in further studies to understand and identify patterns of intervention use among patients with different levels of computer skills.

Finally, another important aspect to keep in mind is the context in which the study was conducted. It was in the Italian-speaking part of Switzerland (Canton Ticino). However, we do not see this as a limitation as much as a call for more research in this area in different sociocultural contexts to be able to generalize the current study findings.

Conclusions

The Web-based intervention had a positive impact (more desirable outcomes) on intervention groups compared to the control group. Social support sections on the website decreased health care utilization and medication overuse and increased empowerment. Gamification alone or with social support increased physical activity and empowerment and decreased health care utilization. The information-only condition did not differ from the control group. For the other measures, all groups were comparable to the control group.

In conclusion, this study pointed to the positive potential and the promising desirable effects of online social support and especially gamification on patients' behavioral and health outcomes when included in an eHealth intervention. Hence, more research on the efficacy of gamification applied in different situations (ie, patients diagnosed with different diseases, different targeted platforms such as mobile apps) is needed to understand which gamification strategies would help the most in benefiting the patients and meeting the objectives and goals of health platforms. Moreover, the concept of patient empowerment as operationalized and measured in this study showed to be an important construct in the best-fit models predicting and representing the change in patients' health and behavioral outcomes. In addition, the study showed that patients who had access only to informational webpages were similar to the control group who had no access to the website. This might suggest that eHealth Web-based interventions would

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benefit from including social support features or gamification in their platforms compared to informative sections alone.

Lastly, the choice of gamifying a website (as in this study) and incorporating game design elements and corresponding mechanisms instead of designing a new game from scratch has high practical implications. Because many health-related websites exist and contain already a substantial amount of health information, they can rapidly benefit from the gamification done in this study. By adjusting their Web-based platforms and redefining their users' experience on the website through the inclusion of gaming elements (ie, badges, points, rewards, incentives) and presenting challenges and competition or an action-reward environment, owners of health websites will be able to create a new type of interaction between online users and the already existing health information found on their websites.

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Conflicts of Interest

The author Ahmed Allam is the developer of the new version of ONESELF.

Multimedia Appendix 1

Video Demos that demonstrate various aspects of the RCT (various sections and features of the ONESELF intervention, types of access by experimental groups and the implemented gamification mechanism).

[ZIP File (Zip Archive), 32MB - jmir_v17i1e14_app1.zip]

Multimedia Appendix 2

The brochure and the consent form that were distributed to the patients.

[PDF File (Adobe PDF File), 16MB - jmir_v17i1e14_app2.pdf]

Multimedia Appendix 3

Descriptive statistics about the primary and secondary outcomes for each experimental group in every assessment point.

[PDF File (Adobe PDF File), 84KB - jmir_v17i1e14_app3.pdf]

Multimedia Appendix 4

Primary and secondary outcomes multilevel models (fixed and random-effect estimated parameters, error variance-covariance matrix, standard errors, p-values and 95% confidence intervals in addition to model fit measures).

[PDF File (Adobe PDF File), 187KB - jmir_v17i1e14_app4.pdf]

Multimedia Appendix 5

CONSORT-EHEALTH checklist V1.6.2 [57].

[PDF File (Adobe PDF File), 995KB - jmir_v17i1e14_app5.pdf]

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Abbreviations

AIC: Akaike information criteria
CMS: content management system
HON: Health on the Net
ICC: intraclass correlation coefficient
ISG: Internet support group
NS: not significant
RA: rheumatoid arthritis
RCT: randomized controlled trial

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Original Paper

A Mobile App to Aid Smoking Cessation: Preliminary Evaluation of SmokeFree28

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Abstract

Background: Little is known about the effectiveness of mobile apps in aiding smoking cessation or their validity for automated collection of data on smoking cessation outcomes.

Objective: We conducted a preliminary evaluation of SF28 (SF28 is the name of the app, short for SmokeFree28)—an app aimed at helping smokers to be smoke-free for 28 days.

Methods: Data on sociodemographic characteristics, smoking history, number of logins, and abstinence at each login were uploaded to a server from SF28 between August 2012 and August 2013. Users were included if they were aged 16 years or over, smoked cigarettes at the time of registration, had set a quit date, and used the app at least once on or after their quit date. Their characteristics were compared with data from a representative sample of smokers trying to stop smoking in England. The percentage of users recording 28 days of abstinence was compared with a value of 15% estimated for unaided quitting. Correlations were assessed between recorded abstinence for 28 days and well-established abstinence predictors.

Results: A total of 1170 users met the inclusion criteria. Compared with smokers trying to quit in England, they had higher consumption, and were younger, more likely to be female, and had a non-manual rather than manual occupation. In total, 18.9% (95% CI 16.7-21.1) were recorded as being abstinent from smoking for 28 days or longer. The mean number of logins was 8.5 (SD 9.0). The proportion recording abstinence for 28 days or longer was higher in users who were older, in a non-manual occupation, and in those using a smoking cessation medication.

Conclusions: The recorded 28-day abstinence rates from the mobile app, SF28, suggest that it may help some smokers to stop smoking. Further evaluation by means of a randomized trial appears to be warranted.

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KEYWORDS

smoking cessation intervention; mobile; smartphone; apps; PRIME theory

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Introduction

Face-to-face and telephone-based behavioral support for smoking cessation can be effective [1,2]. However, uptake of these interventions is low even when they are offered free and are readily accessible [3]. Evidence suggests that Internet-based [4-7] and text messaging interventions [8,9] can be effective in aiding smoking cessation. Mobile devices have even greater potential as a flexible and cost-effective means of delivering smoking cessation interventions because of their ability to run apps that can be tailored to users' needs and be available when needed [10,11]. Apps also have the capacity to upload data automatically onto a server for data analysis, thus making data gathering highly efficient. To date, there is only a small published study evaluating the effectiveness of a smoking cessation app [12]. This paper reports a preliminary evaluation of an app designed on the basis of a broad theory of motivation specifically designed to underpin behavior change interventions. It also examines the characteristics of users and evaluates the validity of automated data gathering as a way of screening apps for further development and evaluation.

Currently, there are more than 23,000 apps available on iTunes under the "health and fitness" or "medical" categories [13], and more than 200 of these purport to be for smoking cessation. Two recent content analyses of smoking cessation apps found that these apps did not typically adhere to evidence-based principles for smoking cessation or contain behavior change techniques (BCTs) that have been found effective in face-to-face support [14,15]. One small randomized controlled trial (RCT) has compared an app containing short messages to a text messaging system. That study found that the text messaging system produced slightly higher abstinence on one of the outcome measures than did the mobile phone app. However, it is possible that the app's effect was masked due a small sample size (N=102) [12].

SF28 (SF28 is the name of the app, short for SmokeFree28) is an app that focuses on BCTs that would be expected from theory [16] and evidence [17] to aid smoking cessation (see Figure 1). The theory adopted was PRIME theory (Plans, Responses, Impulses, Motives, and Evaluations). It aims to explain and predict the impact on behavior of interventions that address higher level cognitions involving personal goals, identity, and beliefs about the harms of smoking as well as lower level drive mechanisms such as cravings, as well as the interactions between the two [18].

PRIME theory recognizes that all behavior arises "in the moment" out of the strongest of potentially competing impulses and inhibitions acting at that time. It charts potential sources of these impulses and inhibitions from learned stimulus-impulse associations, through "wants" (arising from feelings of anticipated pleasure or satisfaction) or "needs" (arising from anticipated relief from discomfort) to beliefs and self-conscious plans. It proposes that plans, such as the intention not to smoke, have to translate into sufficiently powerful wants or needs "in the moment" in order to control behavior. One factor in this is setting up clear boundaries around what is acceptable and being rewarded for staying within those boundaries. Another is doing everything possible to reduce the strengths of the wants, needs, and impulses driving the unwanted behavior.

Thus, the core of SF28 involves setting a highly salient target of becoming 28 days smoke-free and monitoring progress towards that target using the app. Maintaining abstinence for 28 days on average increases the chances of lasting success at stopping more than five-fold as cigarette cravings and nicotine withdrawal symptoms are substantially reduced in most smokers after this period [19]. The app also provides a "toolbox" of evidence-based BCTs for smokers to help them achieve the goal, including advice on the use of stop-smoking medication and licensed nicotine products, inspirational stories and videos of smokers going through the process of quitting, a distraction game, and advice on matters such as reducing exposure to smoking cues. A fuller description, including a BCT analysis of the components of the app is given in Multimedia Appendix 1 [17,20-23].

SF28 involves a registration process in which smokers provide information about themselves and their smoking history, select a quit date, and indicate whether or not they intend to use a stop-smoking medicine or licensed nicotine product. They are encouraged to open the app each day from the quit date onwards for at least 28 days. The app continues to be available after that time, but the material after that does not change. It automatically uploads users' data including each login and whether or not they indicate that they are still abstinent. Following initial testing and gauging of user reactions, it was decided that they should be permitted up to two "lapses" and still progress towards their target during the 28 days. In this study, a "lapse" was defined as a report of having smoked any time during the intervention, "even a puff". The app did not include any push notifications to prompt users to log in; it relied on their remembering to do so.

SF28 was developed for iPhone and made available free of charge to users via iTunes. No promotion was undertaken, so usage depended on iPhone users finding it through searches or through word of mouth. The app requested users' consent for the use of their information in research, which is anonymous and not traceable to the participants.

Before moving to a costly randomized trial of an intervention such as a mobile app, it is important to establish prima facie evidence for its effectiveness and appeal [24]. It is also useful to be able to identify the characteristics of those who elect to use it. The fact that the app uploads data automatically offers the prospect of undertaking this exercise at minimal cost, as long as the data can be relied on. Data from prospective studies of unaided cessation and surveys of smokers who have tried to stop smoking suggest that among smokers in England (the primary target for SF28), about 15% could be expected to manage 28 days' abstinence following their quit attempt [25-27]. This includes smokers who buy nicotine replacement therapy (NRT) over-the-counter rather than getting it from a health professional. For these smokers, the success rates are similar to unaided cessation, possibly because of inadequate usage [28]. Other evidence shows that overall abstinence rates in England in smokers who try to stop are as high as or higher than in other major English-speaking countries [29]. Therefore, one could

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set an a priori goal that an app should achieve a significantly higher abstinence rate than 15% for the purposes of establishing the prima facie case for further development and evaluation.

In accordance with the principles set out in the Russell Standard [30], there are grounds for specifying that the 28-day abstinence number in those using the app involve all those trying to quit, counting participants who no longer use the app as having resumed smoking. This may underestimate the quit rate if smokers who continue to abstain using the app because they do not feel they need it. However, the main alternative of including only those whose outcome is known would almost certainly overestimate success rates. The conservative approach is preferable because of the need for at least a moderate level of confidence in effectiveness before expending significant further resources on product development.

It is desirable, and in some cases essential, for evaluation of effectiveness of smoking cessation interventions to involve some form of biochemical confirmation [30]. This is because in some cases there may be significant pressure to claim abstinence falsely. In the case of the data automatically recorded from SF28, it is judged unlikely that users would log into the app so as to misreport abstinence. There would have been no human contact during the process and no social contract to pressurize a false abstinence claim. Therefore, an argument can be made that self-reported abstinence rates in an app of this kind are unlikely to be a substantial overestimate.

Given that automated outcome assessment using self-report has not been used to evaluate smoking cessation interventions before, it would be useful to assess its validity. One way to do this is to examine how closely this variable is associated with a basket of other variables that are known from previous studies to be associated with actual rates of smoking cessation. In essence, this is a measure of construct validity [31]. This approach has been used previously to identify an appropriate threshold for validating claims of abstinence using expired air carbon monoxide [32]. Variables known to be associated with abstinence are age, occupational group, and cigarette dependence [33], as well as the use of a stop-smoking medication [34].

An important variable in the evaluation of a mobile app is the extent of engagement. A simple measure of this is the number of times users open the app. There are no benchmarks for this kind of measure in smoking cessation apps, but previous research on mobile health apps has found that about one-third of app users open it no more than once and three-quarters open the app fewer than 10 times [35]. Our study could help establish a reference point for evaluation of future apps of this kind.

It is important to understand the characteristics of smokers who would be interested in using stop-smoking apps to inform further development and assess reach for different sectors of the population. One study has examined the characteristics of smokers who indicated that they would be interested in using an app for smoking cessation [36]. In that study, Internet use was not associated with social grade but was associated with being younger, more highly motivated to stop smoking, more cigarette dependent, having attempted to quit recently, having regular Internet and handheld computer access, and having recently searched for online smoking cessation information and support. This suggests that apps may have differential reach towards more dependent and younger smokers. Good data for comparison are available from a large ongoing study on characteristics of smokers in England who make quit attempts. This study, the Smoking Toolkit Study, involves monthly household surveys of nationally representative samples of people aged 16 and up [37].

From all the above considerations, the following research questions were identified: (1) Is the proportion of SF28 app users, who begin their quit attempt and record their smoking abstinence, greater than 15% (ie, is the lower bound of the 95% confidence greater than 15%)?, (2) What is the construct validity of abstinence automatically recorded for 28 days in terms of its association with variables known to be associated with success of quit attempts?, (3) What is the mean number of times the app is opened?, and (4) How do the characteristics of users of SF28 compare with smokers who made a quit attempt in the past year in a large representative sample of smokers in England?

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Figure 1. SF28 homescreen.



Methods

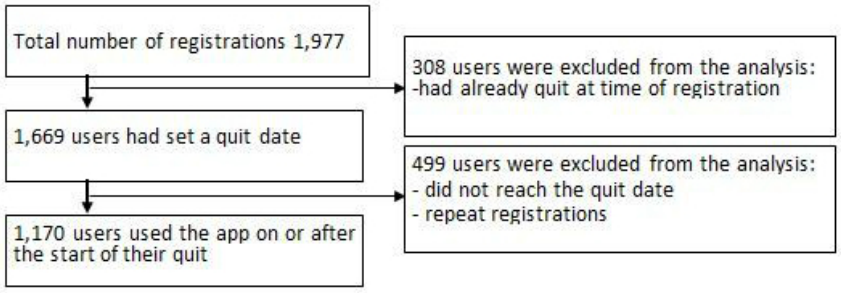
Study Design

This was an observational study involving automated data collection from SF28 users between August 2012 and August 2013. Ethical approval was granted by the University College London ethics committee.

Participants

Figure 2 shows the participant flow in the study. A total of 1977 registrations were recorded. Participants were included in the analysis (N=1170) if they met the following criteria: adults aged 16 years or over, smoked cigarettes at the time of registration, set a quit date, and used the app at least once on or after their preferred quit date. Those users who had already started their quit attempt at the time of registration were excluded, and if users registered more than once, only data from the first registration was used.

Figure 2. Participant flow.



Intervention

The app could be found by searching while searching for stop-smoking apps in iTunes store. Once a potential user downloaded SF28 onto their mobile device, the app would seek permission for data to be collected and used for research purposes. Each time users logged in, SF28 routinely collected data from the session. No identifying information was collected apart from the device identification (to identify multiple registrations). The terms and conditions stated “Information will be gathered concerning your use of SF28 but it shall be anonymous and not traceable to you. The information will only be used for research purposes with a view to developing improved ways of helping smokers to stop”.

When the app was downloaded for the first time, users were presented with a tutorial lasting up to 5 minutes about how to use the app. Participants were then asked to choose a quit date and to answer questions on their demographic and smoking characteristics. Each consecutive day of abstinence was “rewarded” by the app with the addition of a star on the home screen and every week with a heart. Progress towards the goal of 28 days’ abstinence was visualized on the home screen as progress down a road through the countryside towards a rainbow arch. Information on money saved to date was activated by tapping on an image of a bird sitting on a road sign saying how

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many days of abstinence had been achieved. More information on the app is presented in Multimedia Appendix 2.

Measures

The primary outcome measure was the proportion of users who continued to use the app for at least 28 days (though not necessarily every day), and recorded abstinence for the full period with no more than two lapses. At the start of each session, users were asked "Have you smoked since you last used SF28" to which they responded "No, not a puff" or "Yes". Users who opened the app at least 28 days after the declared quit date and reported abstinence up to that point with no more than two lapses having been reported prior to that were considered as meeting the criteria for success. All other users were considered to have resumed smoking. Thus the abstinence measure was a form of continuous abstinence for at least 28 days allowing for up to two reports of having lapsed.

The other variables measured were age (16-29, 30-49, or 50+), gender, occupational group (manual, non-manual, or other), number of cigarettes smoked per day as a proxy for cigarette dependence (1-9, 10-19, or 20+), time since the most recent quit attempt (never, over a year ago, or in last year), weekly expenditure on cigarettes (£1-£9, £10-£19, £20-£29, £30-£39, or £40+), and choice of medication option (none, nicotine replacement therapy, Champix—recoded as none versus any). We did not include Zyban as an option because its use in England is very rare [38]. Users then set a quit date that could be any date in the preceding 2 weeks or up to 2 weeks hence. In our analysis, users who had already started with their quit attempt at the time of registration were excluded. The number of times users browsed the app was recorded. The percentage of missing data ranged between 4 (0.3%) and 26 (2.2%).

Analysis

A total of 1170 participants were included in the analysis. Abstinence for 28 days was calculated as a percentage with 95% confidence intervals. Construct validity of the abstinence measure was assessed by logistic regression of this measure on to the following predictors shown in previous studies to be linked to abstinence: age (positive), non-manual occupational group (positive), daily cigarette consumption (negative), and use of a stop-smoking medication (positive). Each predictor was evaluated separately because the purpose was not to model the outcome but to assess how each predictor individually was associated with it. "Usage" was defined by the mean number of times the users opened the app.

In our sample of 1170 participants, 819 (70.00%) of the SF28 users were from the United Kingdom, followed by 199 (17.01%) from the United States. We were able to compare the characteristics of SF28 users with those obtained from the smokers in England, who had tried to stop smoking in the past 12 months in the Smoking Toolkit Study (STS) [37]. The STS is an ongoing surveillance project assessing smoking and smoking cessation patterns in England. It involves a series of monthly household surveys using a sampling procedures designed to maximize representativeness. Percentages of SF28 users with particular characteristics were compared with those from the STS using chi-square tests.

Results

The self-reported smoking cessation rate for 28 days or longer was 18.9% (95% CI 16.7-21.1). Recorded abstinence was significantly associated with older age, non-manual occupational group, and use of a stop-smoking medicine but not with daily cigarette consumption (Table 1).

Table 1. Associations between smoker characteristics and recorded abstinence (all odds ratios are unadjusted).

Predictor	Odds ratio (CI)	*P* value
Age category (older age)	1.66 (1.30-2.13)	<.001
Non-manual occupational group (vs manual)	1.45 (1.08-1.95)	.013
Cigarette consumption category	1.16 (0.95-1.43)	.152
Intended use of stop-smoking medicine	1.56 (1.16-2.12)	.003

From a total of 1170 participants, 977 (83.50%) had set a quit date on the day of registration and 193 (16.50%) had set their quit date after the day of registration. The mean number of times SF28 users opened the app was 8.5 (SD 9.0) occasions. Of all 1170 users who set a quit date, 782 users (66.84%) used the app for 2 days or more from the start of their quit date; 470 (40.17%) used it for 7 days or more; 347 (29.66%) used it for 14 days or more; 277 (23.68%) used it for 21 days or more; and 226 (19.32%) used it for 28 days or more. As would be expected, a strong positive association was found between number of times the app was opened and 28-day abstinence (OR 1.17, 95% CI 1.15-1.19, *P*<.001).

No significant associations were found between the mean number of logins between men 8.4 (SD 8.9) and women 8.5 (SD 9.0). The mean number of logins was higher for smokers aged 30-49 years (9.5, SD 9.8), non-manual occupation (9.2, SD 9.7), smokers who were taking stop-smoking medication (9.7, SD 9.8), heavy smokers (8.9, SD 9.4), and smokers who were spending £40 or more per week (8.8, SD 9.0) as compared to other users in their respective cohorts. Post-hoc analyses (using Tukey's test) revealed that the mean number of logins was higher for smokers: (1) in the 30-49 years age group (*P*=.001) than for those in 16-29 years age group, (2) in non-manual occupations (*P*=.032) than for those in other occupational groups (retired, unemployed, and students), (3) who made a quit attempt over a year ago (*P*=.002) than for those who never made a quit attempt, and (4) who used stop-smoking medication (*P*=.001) than for those who did not use any stop-smoking medication.

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Table 2 shows that compared with smokers who had tried to quit in the past year in England, SF28 users were more likely to be younger, have a non-manual occupation, be female, smoke more cigarettes per day, and spend more money on cigarettes. They were less likely to intend to use a stop-smoking medicine.

Table 2. Characteristics of participants compared with nationally representative sample of smokers in England who had tried to quit in the past year (all differences apart from varenicline use are statistically significant by chi-square test, $P<.01$).

Characteristics	SF28 users (N=1170)[a] % (n)	Smoking Toolkit Study sample (N=13,706) % (n)
Gender		
Female	64.49 (752)	49.44 (6776)
Age, years		
16-29	50.43 (590)	34.38 (4710)
30-49	45.38 (531)	41.23 (5649)
50+	4.19 (49)	24.39 (3342)
Occupation		
Non-manual occupation	45.64 (523)	41.86 (5738)
Previous quit attempt(s)		
Tried to quit in past year	37.76 (435)	34.75 (4763)
Medication use		
Nicotine replacement therapy	28.03 (328)	39.54 (5419)
Varenicline	5.21 (61)	5.88 (806)
Weekly expenditure on cigarettes, £		
1-9	8.72 (102)	20.41 (1529)
10-19	15.56 (182)	27.74 (2078)
20-29	19.66 (230)	21.80 (1633)
30-39	18.97 (222)	16.50 (1236)
40+	37.09 (434)	13.56 (1016)
Cigarettes smoked per day		
1-9	19.32 (226)	32.56 (4399)
10-19	45.90 (537)	41.26 (5574)
20+	34.79 (407)	26.18 (3537)

[a]The percentage per variable was calculated after excluding those with missing data; thus, the "valid %" approach was used (missing data: gender n=4; occupation n=24; previous quit attempts n=18).

Discussion

Principal Findings

Recorded abstinence rates among users of SF28 were slightly but significantly higher than might have been expected from unaided cessation. Recorded abstinence showed expected associations with predictors of abstinence identified in previous studies with the exception of daily cigarette consumption. Compared with smokers in England who try to stop, SF28 users were younger and had higher daily cigarette consumption. They were also less likely to use a stop-smoking medication. Although the proportion with a non-manual occupation was higher than in the general population of smokers trying to stop, the difference was small.

The fact that the app was typically not used daily suggests that there is room for improvement with regard to user engagement. Users received no prompts, and it seems likely that introducing these could improve usage rates. The rate of discontinuation of app usage followed the classic relapse curve, and it seems likely that relapse was a primary driver of discontinuation. Thus, the proportion of users who logged in on or after day 28 was nearly identical to the number reporting abstinence. This would be expected given the focus of SF28, but it raises the question as to whether or not the app could be made more effective by attempting to help users recover from lapses.

It is noteworthy that the large majority of users set their quit date as the same day that they downloaded the app. Thus, it seems that apps of this kind need to be aware that many users want to get on with their quit attempt immediately, leaving minimal opportunity for planning or obtaining medication in

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preparation for quitting. It remains to be seen whether or not encouraging smokers to wait before quitting so that they could plan ahead would be beneficial, but it should be noted that other research has found that quit attempts made with no pre-planning are at least as likely to succeed as those that are planned in advance [39].

The overall abstinence rate among users of the app suggests that it may have helped some to achieve abstinence. The estimated effect is small, but given the extremely low unit cost of the app, it could still be cost-effective. The data provide sufficient encouragement to develop the app further and test it using a comparative trial. From the usage data, one obvious potential area for improvement would be to include push notifications to prompt users to open it every day. In addition, we did not collect data on which parts of the app were accessed. It would be useful to include this information in the next version to allow further improvements to be made. Focusing on complete abstinence for 28 days is clearly a core feature of the app, and it is not known how far this may detract from ability to help users after they have lapsed. The rationale for it was to try to set as high a bar for initial lapse as possible, but this could have come at a cost of losing users after lapse who could have been helped. This is something that merits further examination. The fact that intended medication use was lower than is found in smokers in England who try to quit may reflect the fact that many users of apps like this download them on impulse. Given the potential for such apps to support users to use medication more effectively, more attention could be given to this in future versions.

If, in the next phase of the research, it can be demonstrated in a comparative study that the app improves success rates over and above whatever else smokers might be using, this would provide a kind of “base camp” from which a program of “theory-based A-B testing” (making theory-informed changes and establishing whether this improves or worsens success rates) could be conducted as part of iterative optimization [40].

The associations between recorded abstinence and the basket of predictors mostly confirmed the validity of our outcome measure. The exception was the failure of daily cigarette consumption to predict recorded abstinence. This may have been partly because of the range restriction: the fact that the range of cigarette consumption among users of SF28 was smaller than is found in the general population, with a skew towards heavier smokers. It is also possible that the association was mitigated by the fact that medication use was more prevalent in heavier smokers (data not shown). It is conceivable that heavier smokers may be more motivated to quit, as they are more likely to experience smoking-related adverse health effects, whereas light smokers might feel less motivated to quit because of perceived lower personal risk. It would be worthwhile in future studies of this kind to identify more robust measures of nicotine dependence. Time from waking to the first cigarette of the day and strength of rated urges to smoke are two potential candidates [41].

The positive association between amount of usage and outcome is consistent with the hypothesis that the app is helpful in aiding cessation but equally could be due to smokers ceasing to use the app if they resume smoking. The association between usage and outcome should, however, be treated with caution. The problem with this association is of reverse causality, that is, smokers who resume smoking would stop using the app, and those who are performing better in terms of managing their cravings would log in more frequently.

The demographic and smoking profile of the app users may provide a useful comparator for future app evaluations. It should be noted that the app was not promoted, and so those using it had to discover it through searching on iTunes. Different user profiles would be expected with different types of iPhones and in different contexts. The tendency for users to be younger and heavier smokers was expected. It was not predicted that there would be a preponderance of women, but previous research has shown that women are more likely than men to seek support for stopping smoking and that may partly account for this result. The proportion of smokers with non-manual occupations was only slightly higher than in the general population of smokers trying to stop, which suggests that, contrary to what might have been expected, the app may have appeal across the social spectrum. The social gradient in app usage is something that merits further investigation.

Limitations

This study had several limitations. First, there was no direct comparison condition so evaluation of whether the app helped any users to stop is based on comparison with expected unaided quit rates. However, on the conservative assumption that every user who did not log in to the app for the full 28 days had resumed smoking, the abstinence rate was slightly higher than would have been expected for unaided cessation. On the other hand, approximately a third of app users said they intended to use a stop-smoking medicine, mainly NRT, which would be expected to increase the quit rate that would have been expected had they not been using the app. Against this, it has been found that NRT, when bought over-the-counter and used without any professional support, may not improve success rates outside of clinical trials [28]. Taking all this into consideration, it seems reasonable to consider that the app may have helped some users and would have provided a useful basis for further development and for a comparative evaluation.

Another limitation is that smokers were followed up for only 28 days. It is possible that there might have been a higher rate of relapse after that point, given that the 28-day target was prominent. This will need to be addressed in a future stage of development and evaluation.

The lack of biochemical verification is another limitation. We argued in the introduction that it is implausible that users would log in to the app to record abstinence when they were smoking, and it is noteworthy that almost no one logged in and reported smoking. However, this assumption will need to be tested when it comes to a full-scale comparative trial.

The comparison of app users with other smokers trying to stop was limited to smokers in England. However, these comprised 70% of the users, and most of the remainder were from the United States where figures are broadly similar [42].

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A further limitation was reliance on daily cigarette consumption as a measure of dependence. Future studies could include the heaviness of smoking index as a 2-item measure [43] or the "urges to smoke" scale [44] or both.

Conclusions

This study provided preliminary evidence that SF28 may help some smokers to stop and that automated data collection using an app of this kind has potential to provide useful information in the early screening stage of app development. This represents a first step in an iterative process of app development and evaluation, working towards a full-scale randomized comparative evaluation of an app with a realistic expectation that the app would assist the process of smoking cessation.

Acknowledgments

RW is funded by Cancer Research UK and is a member of the UK Centre for Tobacco and Alcohol Studies. The app design and programming was undertaken by British Websites.

Conflicts of Interest

RW has undertaken research and consultancy for companies that develop and manufacture smoking cessation medications. RW has a share of a patent for a novel nicotine delivery device. DK received an unrestricted grant from Pfizer for a smoking cessation trial.

Multimedia Appendix 1

BCT analysis of the components of SF28.

[PDF File (Adobe PDF File), 268KB - jmir_v17i1e17_app1.pdf]

Multimedia Appendix 2

SF28: a mobile application to aid smoking cessation.

[PDF File (Adobe PDF File), 26KB - jmir_v17i1e17_app2.pdf]

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Abbreviations

BCTs: behavior change techniques
RCT: randomized controlled trial
SF28: SmokeFree28

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Original Paper

Short- and Medium-Term Efficacy of a Web-Based Computer-Tailored Nutrition Education Intervention for Adults Including Cognitive and Environmental Feedback: Randomized Controlled Trial

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Abstract

Background: Web-based, computer-tailored nutrition education interventions can be effective in modifying self-reported dietary behaviors. Traditional computer-tailored programs primarily targeted individual cognitions (knowledge, awareness, attitude, self-efficacy). Tailoring on additional variables such as self-regulation processes and environmental-level factors (the home food environment arrangement and perception of availability and prices of healthy food products in supermarkets) may improve efficacy and effect sizes (ES) of Web-based computer-tailored nutrition education interventions.

Objective: This study evaluated the short- and medium-term efficacy and educational differences in efficacy of a cognitive and environmental feedback version of a Web-based computer-tailored nutrition education intervention on self-reported fruit, vegetable, high-energy snack, and saturated fat intake compared to generic nutrition information in the total sample and among participants who did not comply with dietary guidelines (the risk groups).

Methods: A randomized controlled trial was conducted with a basic (tailored intervention targeting individual cognition and self-regulation processes; n=456), plus (basic intervention additionally targeting environmental-level factors; n=459), and control (generic nutrition information; n=434) group. Participants were recruited from the general population and randomly assigned to a study group. Self-reported fruit, vegetable, high-energy snack, and saturated fat intake were assessed at baseline and at 1- (T1) and 4-months (T2) postintervention using online questionnaires. Linear mixed model analyses examined group differences in change over time. Educational differences were examined with group×time×education interaction terms.

Results: In the total sample, the basic (T1: ES=–0.30; T2: ES=–0.18) and plus intervention groups (T1: ES=–0.29; T2: ES=–0.27) had larger decreases in high-energy snack intake than the control group. The basic version resulted in a larger decrease in saturated fat intake than the control intervention (T1: ES=–0.19; T2: ES=–0.17). In the risk groups, the basic version caused larger decreases in fat (T1: ES=–0.28; T2: ES=–0.28) and high-energy snack intake (T1: ES=–0.34; T2: ES=–0.20) than the control intervention. The plus version resulted in a larger increase in fruit (T1: ES=0.25; T2: ES=0.37) and a larger decrease in high-energy snack intake (T1: ES=–0.38; T2: ES=–0.32) than the control intervention. For high-energy snack intake, educational differences were found. Stratified analyses showed that the plus version was most effective for high-educated participants.

Conclusions: Both intervention versions were more effective in improving some of the self-reported dietary behaviors than generic nutrition information, especially in the risk groups, among both higher- and lower-educated participants. For fruit intake, only the plus version was more effective than providing generic nutrition information. Although feasible, incorporating environmental-level information is time-consuming. Therefore, the basic version may be more feasible for further implementation,

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although inclusion of feedback on the arrangement of the home food environment and on availability and prices may be considered for fruit and, for high-educated people, for high-energy snack intake.

Trial Registration: Netherlands Trial Registry NTR3396; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=3396 (Archived by WebCite at http://www.webcitation.org/6VNZbdL6w).

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KEYWORDS

cognitive feedback; environmental feedback; self-regulation; computer tailoring; nutrition education; fruit consumption; vegetable consumption; fat consumption; snack consumption

Introduction

Promoting healthy diets remains an important public health target because unhealthy dietary intake patterns are highly prevalent in most Western countries [1-3]. Of Dutch adults, only 3%-14% comply with the guideline of consuming 200 grams of vegetables a day and only 4%-26% comply with the guideline of 2 pieces of fruit a day [4]. Furthermore, 88%-92% have a higher habitual intake of saturated fat than the recommended 10 energy percent (E%) [4]. Because high-energy snacks often contain a lot of saturated fat [5], decreasing high-energy snack intake could result in a considerable decrease in the intake of saturated fat. The intake of fruit, vegetables, and saturated fat is even more unfavorable among lower-educated people compared to higher-educated people [4,6-8], making this an important target group for nutrition education interventions. Not complying with dietary guidelines is an important risk factor for multiple chronic diseases, such as cancer, cardiovascular diseases (CVD), and type 2 diabetes mellitus [9]. Therefore, it is important to improve the intake of fruit, vegetables, high-energy snacks, and saturated fat, especially among people who do not comply with dietary guidelines (ie, risk groups).

To modify dietary intake patterns in large population groups, intervention techniques that can reach large numbers of people and that can be tailored to individual dietary intake patterns are required. Computer tailoring is a suitable technique that can reach a large number of people at relatively low cost [10]. In computer-tailored nutrition education, health information is adapted to the specific needs and characteristics of a person [11,12]. Several reviews have shown that Web-based computer-tailored interventions can be effective in improving the self-reported intake of fruit, vegetables, and fat compared to generic or no information [10,13-15], also among lower-educated people [16,17]. The effect sizes (ES) of existing computer-tailored nutrition education interventions are, however, often small [10,13,15]. Therefore, it is important to find ways to increase the size of the effects, (eg, by targeting “new” determinants or behavior change processes). Until now, nutrition education interventions have primarily targeted motivational determinants, such as attitude and self-efficacy. Although motivation is an important first step in the behavior change process, it is not likely that motivation alone will lead to sustained behavior change [18-20]. This approach neglects important volitional [18,20] and self-regulation processes, such as goal setting and action planning, which focus on translating intention into action and facilitate actual changes.

Self-regulation skills, such as planning and monitoring, are shown to predict dietary behavior [21]. Using intervention techniques that foster self-regulation, such as goal setting and providing feedback on performance, is associated with larger improvements in dietary outcomes [22]. In addition, a meta-regression by Michie and colleagues [23] showed that including the self-regulatory technique self-monitoring of behavior in combination with other self-regulation behavior change techniques (ie, prompt intention formation, prompt specific goal setting, provide feedback on performance, and prompt review of behavioral goals) is likely to increase the efficacy of interventions aimed at promoting healthy nutrition. Self-regulation processes such as goal setting and action planning were shown to be feasible to apply in interventions targeting weight maintenance [24], weight loss among young adults [25], and diabetes management [26], but the additional effect of targeting self-regulation processes in computer-tailored interventions has yet to be established.

In addition to individual-level factors, environmental-level factors may play a role as drivers of behaviors [27,28]. The evidence regarding environmental-level determinants for dietary behaviors is, however, not compelling yet and more studies are needed to examine which environmental-level determinants may be most important [29-31]. Environmental-level factors that were found to be related to dietary behaviors are physical environmental-level factors, such as the availability at home [32-35] and perceived availability in the neighborhood [36,37], and economic environmental-level factors, such as the perception of price [7,34,36]. Environmental-level factors have shown to be more important (eg, price [8,38]) and more unfavorable [7,34,35] among lower-educated people. Because computer-tailored interventions are traditionally targeted at individual-level factors, environmental-level factors are only addressed to a limited extent and mostly in the form of perceived barriers to be overcome. Modern technology makes it possible to provide more sophisticated feedback on environmental-level factors, such as objectively assessed availability of healthy products in the local food environment. Adding this type of feedback can potentially increase the efficacy of computer-tailored nutrition education interventions because an important category of determinants is addressed. The efficacy of adding environmental-level feedback on the availability and prices of healthy food products and the arrangement of the home food environment in computer-tailored interventions has yet to be established because there is no existing evidence so far. There is, however, some evidence from the physical activity domain,

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but the evidence for the additional value of environmental-level feedback is still inconclusive [39-42].

To test the added value of targeting environmental-level factors in a computer-tailored nutrition education intervention, we developed 2 versions of a Web-based computer-tailored nutrition education intervention. One version addresses individual cognitions and self-regulation processes (the basic version) and the other version additionally addresses environmental-level factors (the plus version). The main aim of this study was to establish the efficacy of both intervention versions at 1- and 4-months postintervention on the intake of fruit, vegetables, high-energy snacks, and fat, compared to generic nutrition information. The efficacy is evaluated in both the total study sample and among people who do not comply with the guidelines for fruit, vegetables, high-energy snacks, or fat at baseline because these people should particularly benefit from the intervention. Another aim was to explore potential educational differences in intervention effects.

We hypothesized that both intervention versions would result in a larger increase in fruit and vegetable intake and a larger decrease in high-energy snack and fat intake compared to generic nutrition information and that the effects would be more prominent in the risk groups. In addition, we hypothesized that the intervention version that targets environmental-level factors would be more effective for lower-educated participants than for higher-educated participants because environmental-level factors are suggested to be more strongly related to behavior among lower-educated people.

Methods

Overview

A detailed description of the study protocol has been published elsewhere [43]; therefore, a summary of the methodology and protocol is described subsequently. The trial was registered in the Dutch Trial Registry (NTR3396) and was approved by the Medical Ethics Committee of the Erasmus Medical Centre in Rotterdam, the Netherlands (NL35430.078.11 / MEC-2010-408).

Study Design

A 3-group randomized controlled trial (RCT) was conducted from March 2012 to December 2013 in the Netherlands. Participants were randomly assigned to the basic intervention group (n=456), the plus intervention group (n=459), or the control group (n=434). Fruit, vegetable, high-energy snack, and fat intake were assessed at baseline (T0), 1-month postintervention (T1), and 4-months postintervention (T2). The whole study was conducted online.

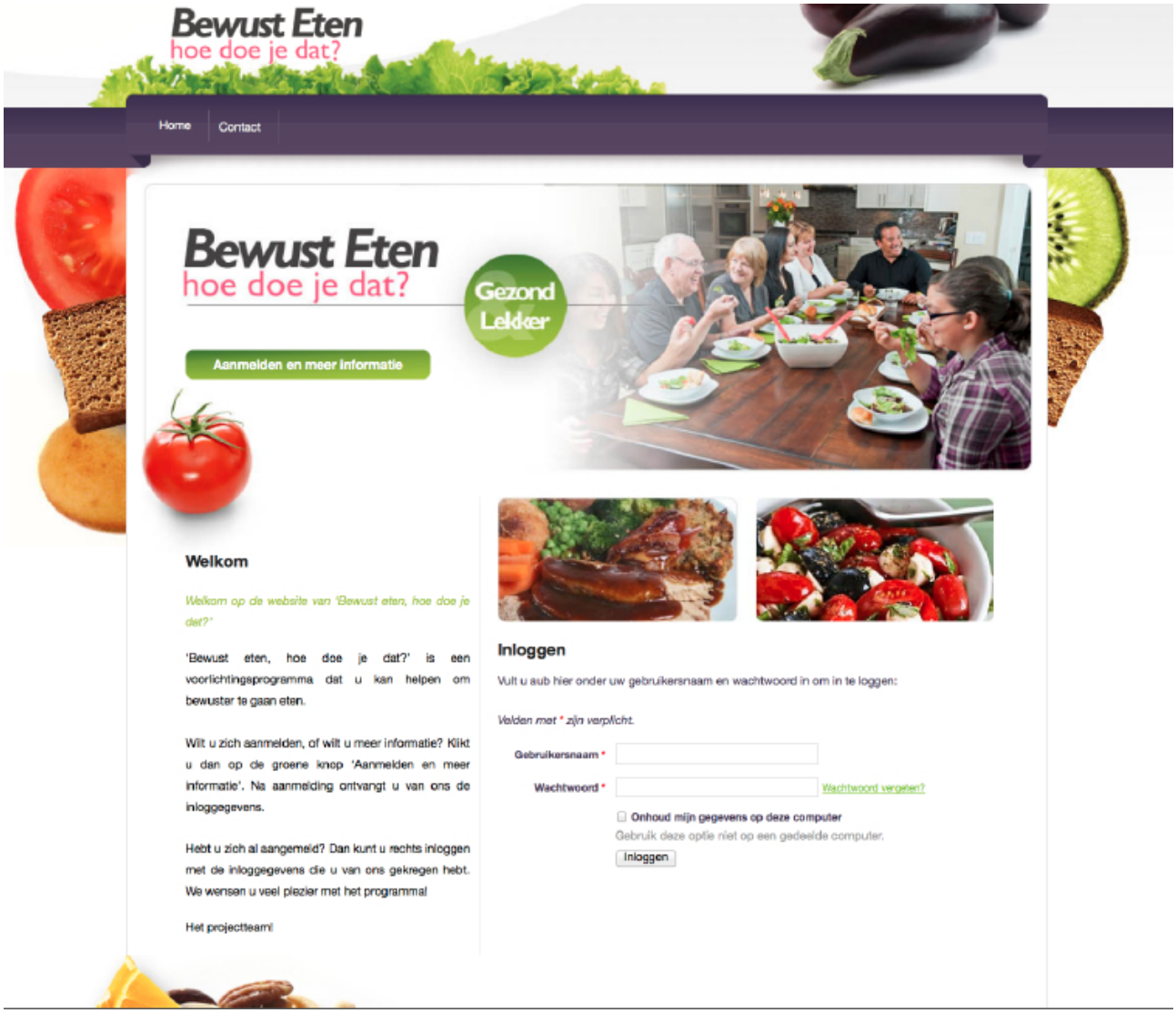
Study Procedure

Participants

The target group for this trial were adults aged 20 to 65 years. A power calculation [43] (power=.80; significance level α=.05) showed that 1400 participants would be sufficient to detect a small intervention effect (ES<0.30). To account for dropout between each measurement and a potential higher dropout among the lower educational group, 2000 people needed to be recruited. Participants were recruited between March and October 2012 from the general population in 5 cities in the South of the Netherlands, primarily via personal mailings sent to 26,402 random home addresses. These addresses were obtained via municipalities. Additionally, Facebook advertisements, advertisements in local newspapers, local television, and promotion activities in shopping malls (ie, distribution of flyers and talking to people) were used for recruitment. People received a flyer with information about the goal, procedure, and incentives for the study. Participants could sign up for the study by phone, email, or via the study website (Figure 1). Participants were included in the study if they were aged between 20 and 65 years, had a sufficient understanding of the Dutch language (in reading and writing), and had access to a computer that was connected to the Internet. Exclusion criteria were being on a diet prescribed by a physician or dietician, having a medical condition that implied restrictions in eating behavior (eg, CVD or bowel disease), and not willing to sign an informed consent.

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Figure 1. Screenshot of the study website.

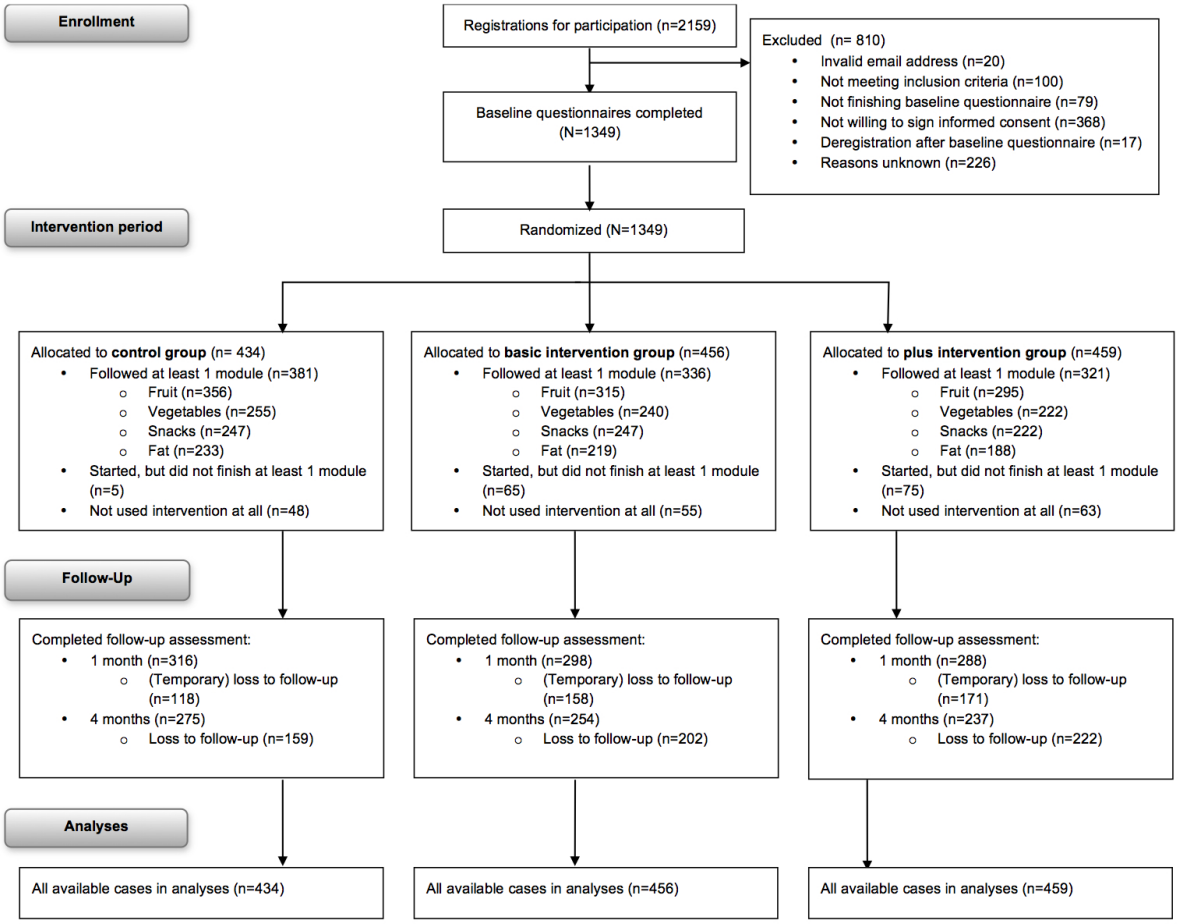


Procedure

After signing up for the study, a link to the online baseline questionnaire was sent via email. One email reminder to fill out the baseline questionnaire was sent 2 weeks after the initial invitation. The baseline questionnaire started with assessing the inclusion and exclusion criteria. People who met the inclusion criteria were asked to give online informed consent before they could continue with the baseline questionnaire. Additionally, a written informed consent form was sent via postal mail or email and people were asked to sign and return the form. Only people who signed and returned the written form were included in the study. One month after completing the baseline questionnaire, participants could start with the intervention program. Randomization took place just before participants received the invitation to access the website. Individual participants were randomly assigned to 1 of the study conditions in a computer-determined sequence. Participants received a log-in code and password through email, which gave them access to the allocated intervention program on the study website (Figure 1). Participants were asked to visit the website at least 3 times during a 2-month period. Email reminders to visit or revisit the intervention were sent every 2 weeks. At 1 and 4 months after the 2-month intervention period, participants were asked by email to fill out online questionnaires again. Email reminders were sent 2 and 4 weeks after the initial invitation. Twenty iPads and 500 gift vouchers of €20 were allotted among participants who completed all questionnaires. To improve the response, 1 extra iPad and 25 extra gift vouchers were allotted for filling out the first and second follow-up questionnaires, respectively. The study procedure, including the enrollment of participants and the distribution of the questionnaires and interventions, is shown in Figure 2.

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Figure 2. Overview of the study procedure and measurements.



Intervention

Overview

The objective of the Web-based computer-tailored nutrition education intervention [43] was to increase fruit and vegetable intake and decrease high-energy snack and saturated fat intake. The 2 intervention versions were developed in a systematic way following the steps of the Intervention Mapping protocol [44] and were partly based on existing interventions [45,46]. Both versions consisted of 4 modules (ie, fruit, vegetables, high-energy snacks, and fat), each containing 3 sessions that could be worked through during 6 consecutive weeks. Two weeks after each intervention visit, email reminders were sent to prompt returning to the intervention to evaluate progress toward achieving the behavioral goal or to receive feedback on another target behavior. Completion of the entire intervention took approximately 160 minutes. The first session took approximately 20 to 30 minutes to complete per module, and the second and third sessions approximately 10 to 20 minutes per module. The information was written at grade level 4-6 (ie, years of education) to make the information comprehensible for lower-educated people as well. The intervention was delivered via a website that participants could log into. A pretest among both higher- (n=45) and lower-educated (n=20) people showed that both intervention versions were appreciated by the target group and that the information was usable and comprehensible, but there was also some room for improvement. Based on this pretest, some small adaptations were made (eg, decreasing the length of the text). Both intervention versions are described briefly subsequently, but a detailed description is published elsewhere [43].

Basic and Plus Versions of the Intervention

Both intervention versions were based on self-regulation theory [47], the Theory of Planned Behavior [48], and the Precaution Adoption Process Model [49], and targeted knowledge, awareness, intention, attitude, self-efficacy, goal setting, and action and coping planning. All 4 modules had a similar structure, except for the fat module that did not contain methods to target attitude and self-efficacy in the first session to limit participant burden because the assessment of fat intake was quite long. The 3 sessions were arranged according to the self-regulation phases preaction, action, and evaluation of the behavior change [50,51].

Participants could choose which behavior(s) they wanted to receive feedback and guidance on. After choosing a target behavior, the first session started with providing information to increase knowledge about the chosen behavior [52]. Subsequently, participants could assess their behavior. Based on this assessment, tailored personal, normative, and comparative feedback was provided to increase awareness [44]. Attitude was targeted by providing feedback on self-selected

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advantages and disadvantages [44,53]. Feedback on self-selected potential barriers and difficult situations was provided to increase self-efficacy [44,52,53]. At the end of the first session, participants could set a goal and formulate an implementation intention for when, where, and how to make the behavior change [44,52,54-56]. After the first session, participants could start enacting their plans and initiate performing their new behavior for 2 weeks.

The second and third sessions provided the opportunity to evaluate the progress of the behavior change. Participants first monitored their goal achievement in the past week and were provided with feedback on their progress [52,57,58]. When the goal was not achieved, attitude and self-efficacy were targeted to stimulate participants to take a second attempt. All participants were stimulated to formulate coping plans for expected difficult situations [56]. If necessary, goals could be adapted to make them more achievable or more challenging. The third session additionally provided information on how to maintain the behavior change over time. This information was based on the 3 self-regulation phases [50,51] and described the different self-regulation steps participants could follow (eg, "what to do when your plan isn't successful?" or "what can you do when you relapse to your old habit?").

Plus Version of the Intervention

The content of the plus version was identical to the basic version, but the first session additionally included environmental-level feedback on the availability and prices of healthy food products in the supermarket where the participant usually does his or her shopping and on the availability and location of food products in the home food environment. The second and third sessions were identical to the basic version.

Before receiving feedback on dietary intake levels, participants could state for each target behavior at which supermarket they buy their food products (eg, fruit). The tailored feedback that was provided contained the availability and price of products in this specific supermarket. The feedback on the availability and price of food products in the specific supermarket was incorporated into the feedback on attitude and self-efficacy. After selecting relevant disadvantages or barriers (eg, "fruit is expensive"), participants received objective environmental-level information presented as a list of selected food products available in the supermarket, with the price of the products if relevant for the disadvantage or barrier. This environmental-level feedback was also provided in a separate section. Before stating a goal and action plan, participants could review the list with the availability and prices of selected food products in their supermarket, relevant for the target behavior (eg, in the module on fruit, only information about fruit was provided). Subsequently, participants could use this information to set goals and make action plans. The availability and prices of selected food products were collected by observing participating supermarkets (n=31) in the 5 cities where the study was conducted. For supermarkets that did not provide permission for these observations (n=27), more general information on availability and prices for this supermarket was provided. The information on availability was based on information that was available via websites or flyers of the supermarket, if possible (n=13). When no information was available on websites or in flyers (n=14), general information on availability of the selected food products (ie, which products are available in most supermarkets) was provided to the participants. For price, only general information (ie, which products are usually least expensive in supermarkets) was provided for supermarkets that did not provide permission for observations.

In addition, the arrangement of the home food environment was targeted. Participants could fill out whether they always have fruit, vegetables, or high-energy snacks available at home and where they store fruit, vegetables, or high-energy snacks. Subsequently, participants received feedback on possible improvements in availability and storage of products (eg, "make sure you always have fruit available and store the fruit in a visible place, like in a fruit bowl"). Participants could use this information to create a more supportive home environment. This feedback consisted of approximately 8 to 10 lines of text. This section about the home food environment was incorporated in the intervention before the objective information on availability and prices in supermarkets.

Because of the extra information that was provided in the first session of the plus version, the extra time to work through the first session of this version took approximately 5 to 10 minutes per module (ie, 20 to 40 minutes extra when the whole intervention was used).

Control Condition

The generic information for the control group also consisted of 4 modules, each consisting of 3 sessions that could be worked through in 6 consecutive weeks. Participants could choose which behavior(s) they wanted to get information about and received nontailored information about fruit, vegetables, high-energy snacks, and/or saturated fat, which was derived from general information that is available from the Netherlands Nutrition Centre [59] and the Dutch Vegetable and Fruit Centre [60]. For example, information was provided about the importance of complying with guidelines, how people can eat more fruit, and how people can maintain eating less fat. The control program had the same name and was provided via the same website and in the same layout as the intervention. Similar reminders for visiting or revisiting the program were sent to the participants.

Measures

Overview

Online questionnaires were used to collect self-reported data on the intake of fruit, vegetables, high-energy snacks, and saturated fat.

Vegetable and Fruit Intake

Vegetable and fruit intake were measured with a validated food frequency questionnaire [61,62]. Four items were used to measure vegetable intake in average grams per day. Participants were asked on how many days per week they usually consume cooked and raw vegetables or salads (ranging from 0-7 days per week) and how many tablespoons of cooked and raw vegetables or salads they usually eat on these days (ranging from 1 to ≥6). One tablespoon of cooked vegetables represented 50 grams of vegetables and 1 tablespoon of raw vegetables or

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salads represented 25 grams of vegetables. Grams of vegetables per day were calculated by multiplying the frequency by the amount of tablespoons multiplied by grams and dividing by 7 (days a week).

Six items were used to assess fruit intake in average number of pieces of fruit per day. Participants were asked on how many days per week they usually consume citrus fruit, other fruit, or (unsweetened) fruit juices (ranging from 0-7 days per week), and how many pieces of citrus fruit and other fruit or glasses of fruit juices they usually consume on these days (1 to ≥7). Daily amount of fruit was calculated by multiplying the frequency by the amount of pieces or glasses of juice and dividing by 7 (days a week).

Fat Intake

Saturated fat intake was measured with a validated food frequency questionnaire (the "fat list") aimed to assess the frequency and quantity of a variety of food items eaten in the past week [63]. Participants were asked to report on how many days per week they usually consume a selection of food items during or between meals. If applicable, the quantity and kind of products (eg, low-fat or full-fat milk) were also assessed. Based on this questionnaire, fat points were calculated, which represent grams of saturated fat. The total "fat score" was based on 35 questions, assessing food products in the following categories: dairy products (n=11), butter (n=1), gravy (n=3), sandwich fillings (n=6), meat and cheese eaten at dinner (n=4), and snacks (n=10). Based on the frequency and amount of intake and the kind of product, fat points were assigned for each product group, ranging from zero (lowest fat intake) to a maximum of 2-5 (highest fat intake, depending on how much fat a product group contains). The fat points for each product group were summed up to create a total fat points measure. In total, a maximum of 80 fat points could be obtained.

Intake of High-Energy Snacks

To measure snack intake, the questions on frequency of high-energy snack intake from the fat list questionnaire [63] were used, in combination with extra items to measure the number of snacks eaten per occasion. A total of 21 items measured high-energy snack intake, such as fried products, candy bars, cookies, and chocolate. High-energy snack intake was calculated as the mean number of high-energy snacks eaten per day by multiplying the frequency per week by the quantity and dividing by 7 (days a week).

Demographic Factors

Sex (male vs female), age (in years), place of residence (What is your place of residence?: Heerlen, Roermond, Weert, Venlo, Venray), ethnicity, and educational level were assessed in the baseline questionnaire. To assess educational level, participants had to indicate their highest attained educational level [64]. Educational level was first divided into 3 groups: high educated (higher vocational education and university), moderate educated (intermediate vocational education and higher secondary or preuniversity education), and low educated (no education to lower general secondary education). Because differences in intake levels between low- and moderate-educated people are reported to be small [4], educational level was dichotomized into 2 groups: (0) high educated and (1) lower educated (low and moderate educated). Ethnicity (non-Western and Western) was defined according to the procedures of Statistics Netherlands [65]; a participant was considered to be of Western ethnicity if both parents were born in Europe (except for Turkey), North America, Oceania, Indonesia, or Japan. If at least 1 parent was born elsewhere, the participant was considered to be of non-Western ethnicity.

Statistical Analyses

Descriptive statistics were used to describe the study groups at baseline. Multiple logistic regression analyses were conducted to test for selective dropout from the study. Demographics (ie, gender, age, ethnicity, educational level, place of residence), study group, and intake of fruit, vegetables, high-energy snacks, and fat at baseline were regressed on dropout (yes=1; no=0) at first and second follow-up measurements. To study equality of the study groups at baseline, 3 multiple logistic regression analyses were conducted with study group as dependent variable and age, gender, ethnicity, educational level, place of residence, and intake of fruit, vegetables, high-energy snacks, and fat at baseline as independent variables.

Repeated measures analyses were conducted to study the intervention effects on the intake of fruit, vegetables, high-energy snacks, and saturated fat. General linear mixed models with time as a repeated statement and an unstructured covariance structure were used to study differences in changes over time between the 3 study groups (group×time interaction). Using a linear mixed model allowed for inclusion of cases with missing data; therefore, all randomized participants are included [66]. No clustering of observations of participants within cities was found so including place of residence as an extra level was not indicated. The linear mixed model analyses were only adjusted for place of residence.

Separate analyses were conducted for the 4 outcome measures. In each analysis time, group, and a group×time interaction were entered as independent variables and the group×time interactions were interpreted. Place of residence and variables that differed between 2 or more groups at baseline or that were predictors for dropout were entered as covariates. The type III Wald test was used to test overall statistical significance of the group×time effects. When this overall test statistic for the group×time interaction (ie, F test) was significant ($P \leq .05$), in-depth results for group differences were examined and reported (ie, unstandardized regression coefficients that represent the difference in change over time between 2 groups). Both intervention groups were compared to the control group and to each other. To make comparisons with previous studies and between different intervention modules, ES were calculated by dividing the unstandardized regression coefficient representing the difference in change over time between 2 groups by the square root of the variance at the corresponding time point (eg, unstandardized regression coefficient/$\sqrt{\text{variance}_{T1}}$ for T1). An ES <0.30 was considered small, an ES between 0.30 and 0.80 was considered moderate, and an ES >0.80 was considered large [67].

Before running the main analyses, we explored for each outcome measure whether educational level moderated the intervention

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effects, by adding a group×time×education interaction term to the repeated measures analyses. If these interaction terms were statistically significant ($P \leq .05$), stratified analyses were conducted.

The repeated measures analyses were conducted in both the total sample and the risk groups for each dietary outcome (ie, participants who, at baseline, consumed <200 grams of vegetables, <2 pieces of fruit, >2 pieces of high-energy snacks, or did not comply with gender- and age-specific guidelines for fat intake).

Depending on the distribution of the outcome variable, the original or the log-transformed value was used in the repeated measures analyses. All tests were 2-sided and alpha levels were set at .05. All analyses were performed with SPSS version 22.0 (IBM Corp, Armonk, NY, USA).

Results

Participant Characteristics at Baseline

A total of 1349 participants were included in the analyses. The mean age of the participants was 49.05 years (SD 10.62), 35.43% (478/1349) were male, 1.34% (18/1348) had a non-Western ethnic background, and 45.66% (616/1349) were in the high-educated group (Table 1). The mean daily vegetable intake was 159.12 grams (SD 69.24), daily fruit intake was 1.85 pieces (SD 1.29), daily high-energy snack intake was 3.34 pieces (SD 2.98), and mean saturated fat intake was 17.91 fat points (SD 6.07). The sizes of the risk groups were as follows: 1014 participants (75.17%) did not comply with the recommendation of 200 grams of vegetables a day, 803 participants (59.53%) did not comply with the guideline of 2 pieces of fruit per day, 808 participants (59.90%) consumed more than 2 high-energy snacks per day, and 627 participants (46.48%) did not comply with the age- and gender-specific guidelines for maximum fat intake. The plus group was significantly younger than the control group (OR 0.99, 95% CI 0.97-0.99, $P=.04$) and the plus group consisted of more lower-educated people than the basic group (OR 1.33, 95% CI 1.01-1.74, $P=.04$). Hence, age and education were included in the repeated measures analyses as covariates in addition to place of residence.

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Table 1. Participant characteristics at baseline.

Characteristic	Total n=1349	Control n=434	Basic n=459	Plus n=456	Group comparison, OR (95% CI)[a] Basic vs control	Plus vs control	Plus vs basic
Background characteristics							
Age (years), mean (SD)	49.05 (10.62)	50.01 (10.40)	48.63 (11.10)	48.54 (10.30)	0.99 (0.98, 1.00)	0.99 (0.97, 0.99)	0.99 (0.99, 1.01)
Gender, n (%)							
Male	478 (35.43)	145 (33.4)	165 (36.2)	168 (36.6)	1.00	1.00	1.00
Female	871 (64.57)	289 (66.6)	291 (63.8)	291 (63.4)	0.80 (0.60, 1.08)	0.80 (0.59, 1.07)	1.00 (0.75, 1.34)
Ethnicity (n=1348), n (%)							
Western	1330 (98.66)	425 (98.2)	451 (98.9)	454 (98.9)	1.00	1.00	1.00
Non-Western	18 (1.34)	8 (1.8)	5 (1.1)	5 (1.1)	0.50 (0.16, 1.60)	0.49 (0.16, 1.55)	0.98 (0.28, 3.44)
Educational level, n (%)							
High	616 (45.66)	184 (42.4)	232 (50.9)	200 (43.6)	1.00	1.00	1.00
Lower	733 (54.34)	250 (57.6)	224 (49.1)	259 (56.4)	0.77 (0.58, 1.01)	1.02 (0.77, 1.34)	1.33 (1.01, 1.74)
Place of residence (ie, cities in the Netherlands), n (%)							
Heerlen	323 (23.94)	103 (23.7)	113 (24.8)	107 (23.3)	1.00	1.00	1.00
Roermond	217 (16.09)	69 (15.9)	78 (17.1)	70 (15.3)	1.04 (0.68, 1.59)	1.00 (0.65, 1.54)	0.95 (0.62, 1.44)
Weert	251 (18.60)	77 (17.7)	82 (18.0)	92 (20.0)	1.01 (0.67, 1.54)	1.19 (0.79, 1.79)	1.17 (0.79, 1.75)
Venlo	304 (22.54)	104 (24.0)	93 (20.4)	107 (23.3)	0.82 (0.56, 1.22)	1.01 (0.69, 1.49)	1.23 (0.83, 1.81)
Venray	254 (18.83)	81 (18.7)	90 (19.7)	83 (18.1)	1.05 (0.70, 1.59)	1.04 (0.68, 1.57)	0.98 (0.65, 1.46)
Dietary intake							
Vegetable intake (grams)							
Mean (SD)	159.12 (69.24)	157.73 (64.54)	162.68 (72.76)	156.91 (69.94)	1.00 (0.99, 1.00)	1.00 (0.99, 1.00)	1.00 (0.99, 1.00)
Not complying, n (%)	1014 (75.17)	330 (76.0)	338 (74.1)	346 (75.4)			
Fruit intake (pieces)							
Mean (SD)	1.85 (1.29)	1.80 (1.23)	1.92 (1.36)	1.81 (1.27)	1.07 (0.97, 1.20)	1.03 (0.92, 1.15)	0.95 (0.85, 1.05)
Not complying, n (%)	803 (59.53)	261 (60.1)	263 (57.7)	279 (60.8)			
High-energy snack intake (pieces)							
Mean (SD)	3.34 (2.98)	3.19 (2.74)	3.30 (2.94)	3.51 (3.24)	1.04 (0.98, 1.10)	1.05 (0.99, 1.11)	1.02 (0.96, 1.07)
Not complying, n (%)	808 (59.90)	251 (57.8)	275 (60.3)	282 (61.4)			
Saturated fat intake (fat points) (n=1348)							
Mean (SD)	17.91 (6.07)	17.99 (6.07)	17.60 (6.09)	18.13 (6.05)	0.98 (0.96, 1.01)	0.99 (0.96, 1.02)	1.01 (0.98, 1.04)
Not complying, n (%)	627 (46.47)	197 (45.4)	203 (44.5)	227 (49.5)			

[a] Logistic regression model with age, gender, ethnicity, educational level, place of residence, fruit intake, vegetable intake, high-energy snack intake, and fat intake as independent variables.

Loss to Follow-Up

A total of 1349 participants filled out the baseline questionnaire, 902 participants filled out the complete first follow-up questionnaire (33.14% dropout), and 766 participants completely filled out the second follow-up questionnaire (43.22% dropout) (Figure 2). Younger participants were more likely to drop out between baseline and T1 (OR 1.02, 95% CI 1.01-1.03, *P*=.002) and T2 (OR 1.03, 95% CI 1.02-1.04, *P*<.001) compared to older participants. Dropout between baseline and T1 was higher in the basic (34.6%, 158/456; OR 1.42, 95% CI 1.07-1.90, *P*=.02) and the plus group (37.3%, 171/459; OR 1.55, 95% CI 1.17-2.07, *P*=.003) than in the control group (27.2%, 118/434). Dropout between baseline and T2 was also higher in the basic

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(44.3%, 202/456; OR 1.36, 95% CI 1.04-1.80, *P*=.03) and plus group (48.4%, 222/459; OR 1.58, 95% CI 1.20-2.07, *P*=.001) than in the control group (36.6%, 159/434).

Assessment of Moderation by Educational Level

No significant interaction effects with educational level were found in the total sample and risk groups for fruit, vegetable, and saturated fat intake. Therefore, stratified analyses by educational level were not indicated for these behaviors. For high-energy snack intake, the interaction with education was borderline significant in both the total sample ($F_{4,932.32}$=2.34, *P*=.053) and risk group ($F_{4,533.59}$=2.37, *P*=.051). Therefore, stratified analyses by educational level were performed as additional analyses for high-energy snack intake.

Intervention Effects

Fruit Intake

Even though fruit intake increased over time ($F_{2,953.39}$=38.44, *P*<.001), there was no difference in change over time between the 3 groups ($F_{4,1151.24}$=1.09, *P*=.36) in the total sample (Tables 2 and 3).

Among participants who consumed less than 2 pieces of fruit at baseline (n=803), a significant difference in change over time was found between the groups ($F_{4.523.71}$=3.61, *P*=.007). The plus group had a significantly larger increase in fruit intake than the control group, between baseline and both T1 (plus vs control: ES =0.25, *P*=.01) and T2 (plus vs control: ES =0.37, *P*=.001). At medium term, the plus version also resulted in a larger increase in fruit intake than the basic version (plus vs basic: ES =0.22, *P*=.04) (Tables 4 and 5).

Table 2. Estimated marginal means at baseline and 1- and 4-month follow-ups and changes over time for the total sample (N=1349).[a]

Time point	Fruit (pieces)		Vegetables (grams)		High-energy snacks (pieces)		Saturated fat (fat points)	
	Mean (SE)	Mean change (95% CI)[b]	Mean (SE)	Mean change (95% CI)[b]	Mean (SE)	Mean change (95% CI)[b,c]	Mean (SE)	Mean change (95% CI)[b]
Baseline								
Control	1.81 (0.06)	NA	158.93 (3.31)	NA	3.21 (0.14)	NA	17.96 0.29)	NA
Basic	1.94 (0.06)	NA	163.24 (3.22)	NA	3.29 (0.14)	NA	17.60 (0.29)	NA
Plus	1.83 (0.06)	NA	158.96 (3.23)	NA	3.50 (0.14)	NA	18.09 (0.29)	NA
1-month follow-up								
Control	2.05 (0.07)	0.24 (0.12, 0.36)	164.30 (3.71)	5.37 (–1.12, 11.86)	3.06 (0.13)	–0.15 (–0.39, 0.09)	17.62 (0.31)	–0.33 (–0.80, 0.14)
Basic	2.25 (0.07)	0.32 (0.19, 0.44)	180.34 (3.76)	17.10 (10.44, 23.67)	2.42 (0.13)	–0.86 (–1.11, –0.62)	16.17 (0.31)	–1.43 (–1.91, –0.95)
Plus	2.22 (0.07)	0.39 (0.27, 0.52)	170.63 (3.81)	11.66 (4.92, 18.43)	2.66 (0.13)	–0.84 (–1.08, –0.59)	17.36 (0.31)	–0.73 (–1.21, –0.25)
4-month follow-up								
Control	2.00 (0.08)	0.19 (0.04, 0.33)	158.67 (3.76)	–0.27 (–6.94, 6.41)	2.84 (0.13)	–0.37 (–0.62, –0.12)	17.13 (0.30)	–0.83 (–1.33, –0.33)
Basic	2.14 (0.08)	0.20 (0.05, 0.34)	173.28 (3.81)	10.03 (3.18, 16.89)	2.50 (0.13)	–0.79 (–1.04, –0.53)	15.84 (0.31)	–1.77 (–2.82, –1.25)
Plus	2.17 (0.08)	0.35 (0.20, 0.50)	167.61 (3.92)	8.66 (1.60, 15.72)	2.50 (0.13)	–1.00 (–1.26, –0.74)	16.67 (0.31)	–1.42 (–1.95, –0.89)

[a] Based on linear mixed model including place of residence, age, education, study group, time, and group×time.

[b] As compared to T0.

[c] Significance tests based on natural logarithm of high-energy snacks.

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Table 3. Results of linear mixed model analyses for the total sample (N=1349).

Outcome measure	*F* (*df*)	B[a] (95% CI)	*P*	ES
Fruit intake				
Group×time×education[b]	0.49 (4, 1015.26)	—	.74	—
Group×time[c]	1.09 (4, 1151.24)	—	.36	—
Time[d]	38.44 (2, 953.39)	—	<.001	—
Differences in change over time after 1 month (T1)				
Basic vs control[c]	—	NA	NA	NA
Plus vs control[c]	—	NA	NA	NA
Plus vs basic[c]	—	NA	NA	NA
Differences in change over time after 4 months (T2)				
Basic vs control[c]	—	NA	NA	NA
Plus vs control[c]	—	NA	NA	NA
Plus vs basic[c]	—	NA	NA	NA
Vegetable intake				
Group×time×education[b]	1.40 (4, 904.08)	—	.23	—
Group×time[c]	1.97 (4, 905.49)	—	.10	—
Time[d]	16.69 (2, 906.08)	—	<.001	—
Differences in change over time after 1 month (T1)				
Basic vs control[c]	—	NA	NA	NA
Plus vs control[c]	—	NA	NA	NA
Plus vs basic[c]	—	NA	NA	NA
Differences in change over time after 4 months (T2)				
Basic vs control[c]	—	NA	NA	NA
Plus vs control[c]	—	NA	NA	NA
Plus vs basic[c]	—	NA	NA	NA
High-energy snack intake [e]				
Group×time×education[b]	2.34 (4, 932.32)	—	.053	—
Group×time[c]	5.77 (4, 933.35)	—	<.001	—
Time[d]	54.81 (2, 1310.46)	—	<.001	—
Differences in change over time after 1 month (T1)				
Basic vs control[c]	—	–0.71 (–1.06, –0.37)	<.001	–0.30
Plus vs control[c]	—	–0.69 (–1.04, –0.34)	.001	–0.29
Plus vs basic[c]	—	0.03 (–0.32, 0.37)	.36	0.01
Differences in change over time after 4 months (T2)				
Basic vs control[c]	—	–0.42 (–0.77, –0.06)	.006	–0.18
Plus vs control[c]	—	–0.63 (–0.99, –0.27)	.002	–0.27
Plus vs basic[c]	—	–0.21 (–0.58, 0.15)	.75	–0.09
Saturated fat intake				

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Outcome measure	*F* (*df*)	B[a] (95% CI)	*P*	ES
Group×time×education[b]	1.64 (4, 919.05)	—	.16	—
Group×time[c]	3.02 (4, 919.65)	—	.02	—
Time[d]	39.29 (2, 919.57)	—	<.001	—
Differences in change over time after 1 month (T1)				
Basic vs control[c]	—	–1.10 (–1.77, –0.42)	.001	–0.19
Plus vs control[c]	—	–0.40 (–1.07, 0.28)	.25	0.07
Plus vs basic[c]	—	0.70 (0.02, 1.38)	.045	0.12
Differences in change over time after 4 months (T2)				
Basic vs control[c]	—	–0.94 (–1.66, –0.22)	.01	–0.17
Plus vs control[c]	—	–0.59 (–1.32, 0.14)	.11	–0.11
Plus vs basic[c]	—	0.35 (–0.39, 1.09)	.36	0.06

[a] B=unstandardized regression coefficient for difference in change over time between groups.

[b] Based on linear mixed model including place of residence, age, education, study group, time, group×time, time×education, group×education, and group×time×education.

[c] Based on linear mixed model including place of residence, age, education, study group, time, and group×time.

[d] Based on linear mixed model including place of residence, age, education, study group, and time.

[e] Repeated measures analyses on natural logarithm of high-energy snacks; estimates based on original variable.

Table 4. Estimated marginal means at baseline and at 1- and 4-month follow-ups and changes over time for the risk groups.[a]

Time point	Fruit (pieces) (n=803)		Vegetables (grams) (n=1014)		High-energy snacks (pieces) (n=808)		Saturated fat (fat points) (n=627)	
	Mean (SE)	Mean change (95% CI)[b]	Mean (SE)	Mean change (95% CI)[b]	Mean (SE)	Mean change (95% CI)[b,c]	Mean (SE)	Mean change (95% CI)[b]
Baseline								
Control	1.04 (0.03)	NA	130.53 (2.21)	NA	4.75 (0.19)	NA	22.98 (0.30)	NA
Basic	1.04 (0.03)	NA	128.99 (2.18)	NA	4.77 (0.18)	NA	22.65 (0.30)	NA
Plus	1.03 (0.03)	NA	127.27 (2.16)	NA	5.03 (0.18)	NA	22.82 (0.28)	NA
1-month follow-up								
Control	1.56 (0.07)	0.52 (0.38, 0.66)	146.11 (3.66)	16.08 (9.34, 22.82)	4.10 (0.18)	–0.65 (–1.01, –0.28)	21.13 (0.42)	–1.85 (–2.57, –1.13)
Basic	1.67 (0.08)	0.64 (0.49, 0.78)	157.78 (3.84)	28.79 (21.65, 35.94)	3.26 (0.18)	–1.51 (–1.87, –1.15)	19.35 (0.42)	–3.30 (–4.03, –2.56)
Plus	1.80 (0.08)	0.78 (0.63, 0.92)	152.72 (3.82)	25.45 (18.35, 32.56)	3.41 (0.18)	–1.62 (–1.98, –1.25)	20.78 (0.41)	–2.04 (–2.75, –1.33)
4-month follow-up								
Control	1.41 (0.08)	0.37 (0.22, 0.52)	143.25 (3.61)	12.72 (6.01, 19.43)	3.80 (0.18)	–0.94 (–1.32, –0.57)	20.55 (0.41)	–2.43 (–3.17, –1.69)
Basic	1.56 (0.09)	0.53 (0.36, 0.69)	153.20 (3.79)	24.21 (17.11, 31.32)	3.32 (0.18)	–1.46 (–1.83, –1.08)	18.83 (0.42)	–3.82 (–4.57, –3.60)
Plus	1.80 (0.09)	0.77 (0.60, 0.94)	148.03 (3.86)	20.76 (13.53, 28.00)	3.28 (0.19)	–1.75 (–2.14, –1.37)	19.58 (0.43)	–3.24 (–4.03, –2.46)

[a] Based on linear mixed model including place of residence, age, education, study group, time, and group×time.

[b] As compared to T0.

[c] Significance tests based on natural logarithm of high-energy snacks.

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Table 5. Results of linear mixed model analyses for the risk groups.

Outcome measure	*F* (*df*)	B[a] (95% CI)	*P*	ES
Fruit intake (n=803)				
Group×time×education[b]	0.64 (4, 522.34)	—	.64	—
Group×time[c]	3.61 (4, 523.71)	—	.007	—
Time[d]	136.31 (2, 523.62)	—	<.001	—
Differences in change over time after 1 month (T1)				
Basic vs control[c]	—	0.12 (–0.08, 0.32)	.25	0.11
Plus vs control[c]	—	0.26 (0.06, 0.46)	.01	0.25
Plus vs basic[c]	—	0.14 (–0.06, 0.35)	.18	0.12
Differences in change over time after 4 months (T2)				
Basic vs control[c]	—	0.16 (–0.07, 0.38)	.16	0.14
Plus vs control[c]	—	0.40 (0.18, 0.63)	.001	0.37
Plus vs basic[c]	—	0.25 (0.01, 0.48)	.04	0.22
Vegetable intake (n=1014)				
Group×time×education[b]	1.21 (4, 679.32)	—	.31	—
Group×time[c]	2.15 (4, 671.86)	—	.07	—
Time[d]	72.11 (2, 654.00)	—	<.001	—
Differences in change over time after 1 month (T1)				
Basic vs control[c]	—	NA	NA	NA
Plus vs control[c]	—	NA	NA	NA
Plus vs basic[c]	—	NA	NA	NA
Differences in change over time after 4 months (T2)				
Basic vs control[c]	—	NA	NA	NA
Plus vs control[c]	—	NA	NA	NA
Plus vs basic[c]	—	NA	NA	NA
High-energy snack intake [e] (n=808)				
Group x time x education[b]	2.37 (4, 533.59)	—	.051	—
Group x time[c]	4.30 (4, 534.96)	—	.002	—
Time[d]	144.93 (2, 535.40)	—	<.001	—
Differences in change over time after 1 month (T1)				
Basic vs control[c]	—	–0.86 (–1.38, –0.35)	<.001	-0.34
Plus vs control[c]	—	–0.97 (–1.49, –0.45)	.001	-0.38
Plus vs basic[c]	—	–0.11 (–0.62, 0.41)	.90	-0.04
Differences in change over time after 4 months (T2)				
Basic vs control[c]	—	–0.51 (–1.04, 0.02)	.02	–0.20
Plus vs control[c]	—	–0.81 (–1.34, –0.28)	.008	–0.32
Plus vs basic[c]	—	–0.30 (–0.83, 0.24)	.74	–0.12
Saturated fat intake (n=627)				

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Outcome measure	*F* (*df*)	B[a] (95% CI)	*P*	ES
Group×time×education[b]	0.90 (4, 425.13)	—	.46	—
Group×time[c]	2.99 (4, 441.26)	—	.02	—
Time[d]	112.02 (2, 419.08)	—	<.001	—
Differences in change over time after 1 month (T1)				
Basic vs control[c]	–	–1.45 (–2.48, –0.42)	.006	–0.28
Plus vs control[c]	–	–0.19 (–1.20, 0.83)	.72	–0.04
Plus vs basic[c]	–	1.26 (0.24, 2.28)	.02	0.24
Differences in change over time after 4 months (T2)				
Basic vs control[c]	—	–1.38 (–2.44, –0.33)	.01	–0.28
Plus vs control[c]	—	–0.81 (–1.89, 0.27)	.14	–0.16
Plus vs basic[c]	—	0.58 (–0.51, 1.66)	.30	0.12

[a] B=unstandardized regression coefficient for difference in change over time between groups.

[b] Based on linear mixed model including place of residence, age, education, study group, time, group×time, time×education, group×education, and group×time×education.

[c] Based on linear mixed model including place of residence, age, education, study group, time, and group×time.

[d] Based on linear mixed model including place of residence, age, education, study group, and time.

[e] Repeated measures analyses on natural logarithm of high-energy snacks; estimates based on original variable.

Vegetable Intake

Vegetable intake increased over time in the total sample ($F_{2,906.08}$=16.69, *P*<.001), but there was no difference in change over time between the 3 groups ($F_{4,905.49}$=1.97, *P*=.10) (Tables 2 and 3). The same results were found in the risk group: vegetable intake increased over time ($F_{2,654.00}$=72.11, *P*<.001), but no difference between the 3 groups was found ($F_{4,671.86}$=2.15, *P*=.07)(Tables 4 and 5).

High-Energy Snack Intake

High-energy snack intake had a very skewed distribution and, therefore, was log-transformed. The significance tests were based on the log-transformed variable, but the unstandardized regression coefficients and ES were based on the original variable.

In the total sample, there was a significant difference in decrease of high-energy snacks between the groups ($F_{4,933.35}$=5.77, *P*<.001). Both intervention groups had a significantly larger decrease in high-energy snack intake than the control group between baseline and both T1 (basic vs control: ES =–0.30, *P*<.001; plus vs control: ES =–0.29, *P*=.001) and T2 (basic vs control: ES =–0.18, *P*=.006; plus vs control: ES =–0.27, *P*=.002) (Tables 2 and 3).

Stratified analyses showed that for lower-educated participants both the basic and plus version resulted in a larger decrease than the control intervention between baseline and T1 (basic vs control: ES =–0.33, *P*<.001; plus vs control: ES =–0.23, *P*=.02). Between baseline and T2, only the basic version resulted in a larger decrease than the control intervention (basic vs control: ES =–0.23, *P*=.009). For high-educated participants, both intervention groups had a larger decrease than the control group between baseline and T1 (basic vs control: ES =–0.31, *P*=.006; plus vs control: ES =–0.38, *P*=.01). Between baseline and T2, the plus version resulted in a larger decrease than the control intervention (plus vs control: ES =–0.53, *P*<.001) and basic version (plus vs basic: ES =–0.32, *P*=.04).

Also in the risk group (n=808), significant differences in change over time were found ($F_{4,534.96}$=4.30, *P*=.002). Both intervention groups had a significant larger decrease than the control group between baseline and T1 (basic vs control: ES =–0.34, *P*<.001; plus vs control: ES =–0.38, *P*=.001) and T2 (basic vs control: ES =–0.20, *P*=.02; plus vs control: ES =–0.32, *P*=.008) (Tables 4 and 5).

Stratified analyses showed that among lower-educated participants only the basic version resulted in a larger decrease in high-energy snack intake than the control intervention between baseline and both T1 (basic vs control: ES =–0.40, *P*=.002) and T2 (basic vs control: ES =–0.26, *P*=.03). For higher-educated participants, both intervention groups had a larger decrease than the control group between baseline and T1 (basic vs control: ES =–0.34, *P*=.02; plus vs control: ES=–0.50, *P*=.001). Between baseline and T2, the plus version resulted in a larger decrease than the control intervention (plus vs control: ES =–0.64, *P*<.001) and basic version (plus vs basic: ES =–0.38, *P*=.03).

Fat Intake

Differences in change over time between the groups were found ($F_{4,919.65}$=3.02, *P*=.02) in the total sample. The basic group had a larger decrease in saturated fat intake than the control group between baseline and both T1 (basic vs control: ES =–0.19, *P*=.001) and T2 (basic vs control: ES =–0.17, *P*=.01). In addition, the decrease between baseline and T1 was significantly

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smaller for the plus group compared to the basic group (plus vs basic: ES =0.12, *P*=.045) (Tables 2 and 3).

Also in the risk group (n=627), differences in change over time between the groups were found ($F_{4,441.26}$=2.99, *P*=.02). The basic group had a significantly larger decrease in saturated fat intake than the control group between baseline and both T1 (basic vs control: ES=–0.28, *P*=.006) and T2 (basic vs control: ES=–0.28, *P*=.01). Between baseline and T1, the decrease was lower for the plus group than for the basic group (plus vs basic: ES =0.24, *P*=.02) (Tables 4 and 5).

Discussion

Principal Findings

An RCT was conducted to evaluate the short- (1 month) and medium-term (4 months) efficacy and educational differences in efficacy of a cognitive (basic) and an environmental feedback (plus) version of a Web-based computer-tailored nutrition education intervention [43] on self-reported intake of fruit, vegetables, high-energy snacks, and saturated fat compared to a generic nutrition information control group, in both the total sample and risk groups that did not comply with guidelines for fruit, vegetables, high-energy snacks, or fat at baseline.

In both the total sample and risk group, the basic version was more effective than generic nutrition information in changing saturated fat intake; in the short term, this version was also more effective than the plus version. The plus version was more effective than generic nutrition information in changing fruit intake among participants who did not comply with guidelines for fruit intake. At the medium term, this version was also more effective in improving fruit intake than the basic version. Both intervention versions were not more effective than generic nutrition information in increasing vegetable intake. Both intervention versions were effective in decreasing high-energy snack intake in both the total sample and risk group, although educational differences were found. In the short term, the basic version was effective among both high- and lower-educated participants and the plus version was effective among lower-educated participants in the total sample and high-educated participants in both the total sample and risk group. In the medium term, however, only the basic version was effective for lower-educated participants, whereas for high-educated participants the plus version was more effective than both the control intervention and basic version. No educational differences were found for the other behaviors indicating that the intervention can be equally effective among high- and lower-educated people. As expected, the effects were more prominent and ES were slightly larger in risk groups, which is an important finding because people who do not comply with dietary guidelines are most in need of improving their diets. These results show that, except for fruit intake in the risk group and high-energy snack intake among high-educated participants, the plus intervention version did not clearly outperform the basic version.

The results of this study add favorably to the evidence base of positive effects of Web-based computer-tailored nutrition education interventions on fruit and fat intake [10,13-15] and more prominent effects in risk groups [17,45,68]. The results on vegetable intake, however, compare unfavorably to those of multiple previous studies [10,13-15]. Finding effects among lower-educated participants is also in-line with previous studies on computer-tailored interventions [16,17]. This was the first computer-tailored intervention with a module on reducing high-energy snack intake. It is promising that both versions showed effects in reducing high-energy snack intake. This can be an important addition to interventions that aim to prevent overweight or obesity.

The plus version was most effective for fruit intake among participants who did not comply with guidelines for fruit intake and, among high-educated participants, for high-energy snack intake. For vegetable and saturated fat intake, however, no effects of the plus version were found. Compared to vegetable and fat intake, fruit and high-energy snack intake can be more easily changed without adapting complete dietary patterns. Therefore, it may be clearer which products can be purchased, making it easier to integrate and apply the information about availability and prices in supermarkets. The home food environment may also be easier to rearrange for high-energy snacks and fruit (eg, by having these products available at home less or more often or storing the products in invisible or visible places, respectively).

The environmental feedback component included feedback on availability of healthy food products and feedback and suggestions to rearrange the home food environment. As a result, it is not clear whether the (additional) effects of the plus version were caused by supermarket information or feedback on the home food environment or by a combination of both. Incorporating environmental-level information about availability and prices in supermarkets was very time-consuming because all supermarkets had to be observed to collect and update the data [43] making large-scale implementation of this version difficult. However, providing feedback on the arrangement of the home food environment is feasible. Future research on the mediating variables of the plus version of the intervention may provide insight into the potential of only targeting the home food environment.

We expected that targeting environmental-level factors would be more effective for lower-educated participants than for high-educated participants since environmental-level factors are suggested to be more important among lower-educated people [8,38]. However, no educational differences were found for fruit, vegetables, and fat. Moreover, for high-energy snacks, more and larger effects of the plus version were found for high-educated participants than for lower-educated participants. One explanation may be that high-educated people are better able to process information [69]; therefore, they may be better able to integrate and apply the environmental-level information, making the plus version more effective for this group. The plus version contained some more information than the basic version. The information on the availability and prices of food products in the supermarkets was provided in clear tables and the feedback on the home food environment contained only 8 to 10 lines of text. However, it may be that the plus version became too long to provide added effects among lower-educated participants.

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Because we additionally included self-regulation processes and environmental-level factors, we expected to achieve somewhat larger ES compared to previous studies [10,13]. Although self-regulation processes are suggested to be important to target in interventions [22,23], the results of this study showed that, compared to generic nutrition information, ES of targeting self-regulation processes in addition to individual cognitions were still mostly small. Important components of self-regulation that were included in the intervention are goal setting and action planning. Incorporating goal setting and action planning tools in Web-based computer-tailored interventions is challenging. Goals and plans are most effective when they are challenging and specific (ie, when they are of high quality) [70,71]. This requires guidance, which is difficult to provide in Web-based computer-tailored interventions. In our intervention, some guidance was provided by explicitly asking the components of goals (ie, how many products do you want to consume more or less?) and plans (ie, when and how) and by providing short instructions on how to formulate goals and plans. However, to fit with self-regulation, participants formulated their own goals and plans [72]. This may have resulted in goals and plans of low quality, as is found in another Web-based computer-tailored intervention [73]. Goals and plans of low quality may decrease the effects of self-regulation on behavior. Providing more insight into incorporating goal setting and action planning tools in Web-based computer-tailored interventions may increase efficacy.

Environmental-level factors are suggested to play an important role in dietary behavior [7,27,28,32-37]. The results of this study, however, indicate that additionally targeting these factors as was done in this intervention does not largely increase the efficacy compared to generic nutrition information or only targeting individual cognitions and self-regulation processes, except for fruit intake in the risk group and high-energy snack intake among high-educated participants. Although ES were slightly larger for the plus version than for the basic version for fruit and high-energy snack intake, these differences were not always significant. In addition, for saturated fat intake, the plus version was less effective than the basic version in the short term. One explanation may be that the provided environmental information was not extensive enough to have an additional effect. The home food environment, for example, was only a small part of the intervention, whereas adapting the home food environment is a complex behavior that includes multiple behavioral determinants, such as awareness and self-efficacy. Although we included all supermarkets in the selected cities, food products, especially snacks and high-fat products, may be bought in other stores, such as train or gas stations. In addition, for supermarkets that were not willing to participate, only very general information about the availability and prices in supermarkets was provided in the intervention. If we would have been able to provide more sophisticated environmental-level feedback, the added effects of the plus version may have been larger.

Another reason for finding small ES may be the nonoptimal exposure to the different modules and sessions, which often happens in Internet interventions [73,74]. In addition, participants could choose their own target behavior(s) and were consequently not necessarily exposed to all modules. Exposure was highest for the fruit module (it appeared first in the list of 4 modules) and lowest for the fat module (it appeared last in the list of 4 modules). Exposure also differed between study groups and was higher in the control group than in the intervention groups. One reason for this difference in exposure may be that the participant burden of the control version was lower than for both intervention versions because participants in the control group only had to read information and did not have to fill out assessment questionnaires and formulate goals and plans.

Limitations

When interpreting the results of this study, some limitations should be taken into account. We may have recruited a selective sample of the population due to selective response. Intake levels were more favorable compared to the general Dutch population [4], which may indicate that our study population was more motivated for or interested in healthy nutrition. However, because no intake differences were found between the study groups at baseline, the results are not expected to be biased by confounding variables. Despite our efforts to overrecruit low-educated participants (eg, by spreading extra flyers in low socioeconomic neighborhoods), response was selective according to educational level and only 19.3% (261/1349) of the study sample were low educated. Because intake differences between low and moderate educational groups are reported to be small [4], low- and moderate-educated participants were combined into 1 group. Consequently, intervention effects among very low-educated people are unknown. In addition to selective response, there was high dropout and dropout was selective for age and study group. A high dropout is not uncommon in Web-based computer-tailored interventions [24,74-76], but it may have influenced the intervention effects. By conducting linear mixed model analyses and by correcting the analyses for predictors for dropout, an attempt was made to minimize bias potentially caused by dropout. The selective sample and high and selective dropout may have decreased the external validity of the results. Therefore, the results are only generalizable to Dutch adults who are interested in healthy eating (but who can still improve dietary intake patterns). According to our power calculation, 1400 participants were needed to detect small intervention effects between the intervention groups and control group. Although fewer participants were included in the study than initially planned, we were still able to include 1349 available cases in the analyses. The effects for the differences between the 2 intervention groups, however, need to be interpreted with caution because the study was not powered to detect these differences. The differences in ES between both intervention versions were, however, quite small. Therefore, probably no other conclusions would be drawn when more people were included in the study and power was larger. Another component that may have influenced the intervention effects is the difference in length between both intervention versions. Although validated questionnaires were used to measure fruit, vegetable, and saturated fat intake, the study relied on self-reported data. This may be less valid than using more objective instruments, such as biomarkers. Effects based on self-reported intake levels may

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not be seen when using biomarker validation as was demonstrated in a study by Kroeze et al [77]. Using such objective instruments was not feasible in this trial because of the large number of participants, but future studies should verify the effects that were found in the present study using biomarkers of intake. The questionnaires are, however, suitable to rank people according to their intake levels and according to changes and differences in intake levels [61,63]. The items to measure high-energy snack intake were derived from validated questionnaires. These items are also used in previous studies to measure high-energy snack intake (eg, [24,78]). Although the method used to assess high-energy snack intake is also used in validated questionnaires to measure intake levels and products were derived from a validated questionnaire to measure (saturated) fat intake, validity and reliability of these items to measure the amount of snacks eaten per day are not known; therefore, these results should be interpreted with caution. In addition, the questionnaires were validated for hard-copy use only. However, because all 3 study groups filled out the same questionnaires, bias has probably been minimized.

Conclusions

The Web-based computer-tailored intervention targeting individual cognitions and self-regulation processes was effective in decreasing self-reported high-energy snack and saturated fat intake. Additionally targeting environmental-level factors was effective in increasing self-reported fruit intake in the risk group and high-energy snack intake. The intervention effects were more prominent among people who did not comply with dietary guidelines. Equal intervention effects were found for both higher- and lower-educated participants, except for high-energy snack intake for which additionally targeting environmental-level factors was most effective among high-educated participants.

No additional effects of also targeting environmental-level factors were found for self-reported saturated fat intake and, among lower-educated people, for self-reported high-energy snack intake. In addition, providing environmental-level information is time-consuming. Therefore, the basic intervention version may be more feasible for large-scale implementation for these dietary behaviors. For high-energy snack intake among high-educated people and fruit intake, however, additionally targeting the arrangement of the home food environment and the perception of the availability and prices should be considered.

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Conflicts of Interest

Hein de Vries is the scientific director of Vision2Health, a company that licenses evidence-based, innovative, computer-tailored health communication tools. The other authors declare that they have no competing interests.

Multimedia Appendix 1

CONSORT EHEALTH checklist V1.6.2 [79].

[PDF File (Adobe PDF File), 995KB - jmir_v17i1e23_app1.pdf]

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Abbreviations

CVD: cardiovascular diseases
ES: effect size(s)
RCT: randomized controlled trial

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Original Paper

Developing Internet-Based Health Interventions: A Guide for Public Health Researchers and Practitioners

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Abstract

Background: Researchers and practitioners interested in developing online health interventions most often rely on Web-based and print resources to guide them through the process of online intervention development. Although useful for understanding many aspects of best practices for website development, missing from these resources are concrete examples of experiences in online intervention development for health apps from the perspective of those conducting online health interventions.

Objective: This study aims to serve as a series of case studies in the development of online health interventions to provide insights for researchers and practitioners who are considering technology-based interventional or programmatic approaches.

Methods: A convenience sample of six study coordinators and five principal investigators at a large, US-based land grant university were interviewed about the process of developing online interventions in the areas of alcohol policy, adolescent health, medication adherence, and human immunodeficiency virus prevention in transgender persons and in men who have sex with men. Participants were asked questions that broadly addressed each of the four phases of the User-Centered Design Process Map from the US Department of Health and Human Services' Research-Based Web Design & Usability Guidelines. Interviews were audio recorded and transcribed. Qualitative codes were developed using line-by-line open coding for all transcripts, and all transcripts were coded independently by at least 2 authors. Differences among coders were resolved with discussion.

Results: We identified the following seven themes: (1) hire a strong (or at least the right) research team, (2) take time to plan before beginning the design process, (3) recognize that vendors and researchers have differing values, objectives, and language, (4) develop a detailed contract, (5) document all decisions and development activities, (6) use a content management system, and (7) allow extra time for testing and debugging your intervention. Each of these areas is discussed in detail, with supporting quotations from principal investigators and study coordinators.

Conclusions: The values held by members of each participating organization involved in the development of the online intervention or program, as well as the objectives that are trying to be met with the website, must be considered. These defined values and objectives should prompt an open and explicit discussion about the scope of work, budget, and other needs from the perspectives of each organization. Because of the complexity of developing online interventions, researchers and practitioners should become familiar with the process and how it may differ from the development and implementation of in-person interventions or programs. To assist with this, the intervention team should consider expanding the team to include experts in computer science or learning technologies, as well as taking advantage of institutional resources that will be needed for successful completion of the project. Finally, we describe the tradeoff between funds available for online intervention or program development and the complexity of the project.

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KEYWORDS

Internet; public health; intervention; development

Introduction

A goal of the US national initiative, Healthy People 2020, is to "Use health communication strategies and health information technology (IT) to improve population health outcomes and health care quality, and to achieve health equity [1]". Health research plays an important role in reaching that goal by developing and testing Internet-based health promotion interventions. Internet interventions have been defined as "systematic treatment/prevention programs, usually addressing one or more determinants of health…delivered largely via the Internet…and interfacing with an end user" (p. 274) [2]. Internet interventions range from relatively simple computer-tailored messaging and education [3,4] to more sophisticated website interventions [5,6]. More recently, mobile interventions that use text messaging and social media apps have emerged [7-9].

Internet interventions have been developed across a broad range of health areas. Researchers in the areas of human immunodeficiency virus (HIV) prevention [7,8,10], smoking cessation [4,6,11], diabetes self-management [5,12], and nutrition/physical activity promotion [3,13,14] are among those experimenting with the benefits offered by the Internet. Although reviews of technology-assisted intervention studies are mixed [3,7,10,13], their success in modifying some health behaviors suggests that using technology to support health interventions is a promising approach [2].

Despite support for the feasibility and efficacy of Internet-based health interventions, relatively little guidance is available to researchers or practitioners who are interested in online interventions from colleagues with more experience in developing interventions that are wholly or partly delivered online. The process of online intervention development is complex and usually involves multiple teams of persons with different skills sets, objectives, and perspectives. In a review of computer-assisted instruction for medical education, it was noted that the inexperience of investigators in the use of technology for interventions may hinder advancement in the eHealth field [15]. Advice regarding how to develop effective websites is available from the computer science, marketing, and business professions (eg, [16-18]); however, these guidelines often take the perspective of how best to develop interventions that increase purchases or user traffic. Such advice may not be directly related to the goals and purposes of online health intervention research and practice.

Researchers and practitioners interested in developing online health interventions most often rely on Web-based [19] and print (see [20] for a list of print resources) resources to guide them through the process of online intervention development. Although useful for understanding many aspects of best practices for website development, missing from these resources are concrete examples of experiences in online intervention development for health apps from the perspective of those conducting online health interventions. To fill this gap, Bull [21] recently discussed theoretical and procedural aspects of developing, implementing, and evaluating technology-based health promotion interventions.

To provide greater context and guidance for those interested in developing technology-based health interventions, we conducted interviews with principal investigators and project coordinators who successfully developed Internet-based health interventions. The primary purpose of the interviews was to understand the challenges of such work and gain firsthand accounts of lessons learned from their experiences. We were particularly interested in investigators' and coordinators' experiences in working with vendors, defined here as an outside company that assisted with the overall design of the intervention and whose employees actually programmed the online health intervention. This study is meant as a series of case studies in the process of developing online health interventions to provide insights for researchers and practitioners who are considering similar technology-based interventional or programmatic approaches.

Methods

Participants

Persons associated with five unique research studies were interviewed for the purposes of this study. A convenience sample of six study coordinators (two from one research study) and five principal investigators at the University of Minnesota were interviewed about the process of developing online interventions in the areas of alcohol policy, adolescent health, medication adherence, and HIV prevention with men who have sex with men (MSM) and transgender persons. No incentives were provided to coordinators or principal investigators.

Procedures

This study was not considered human subjects research since participants were not asked to provide information on themselves (rather they were asked to provide information about the research study); however, all research activities on the parent grant (under which this study was conducted) were approved by the University of Minnesota Institutional Review Board. One-on-one semistructured interviews with all but one respondent were conducted at their place of work, while one interview was conducted in a coffee house. Since the purpose of this study was to provide guidance to other researchers and practitioners in the process of online health intervention development, three of the authors (KJH, TT, and AE) who are involved in online health intervention research were interviewed by another study team member. Interviews were digitally recorded and lasted from 30-75 minutes. Audio recordings were transcribed in preparation for analysis.

Interview Guide Development

Development of the interview guide was based on the Research-Based Web Design & Usability Guidelines from the US Department of Health and Human Services [19]. The guidelines address multiple facets of user experience-based website development, including the fundamentals of user experience, developing content for websites, project

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management, and best practices for developing a visually appealing website. The process of developing a user-centered website is presented graphically, and referred to as the User-Centered Design Process Map [22], in four separate but interrelated phases: (1) the Plan phase includes how the original idea was conceived, what team members were involved in initial planning, and hiring the vendor, (2) the Analyze phase encompasses the adaptation of an existing website or curriculum, learning about the target audience, and formative research, (3) the Design phase entails defining the individual components of the websites, discussions about authoring and uploading content, and work processes with the vendor, and (4) the Test and Refine phase describes processes for internal testing, usability testing, and de-bugging. For the purpose of this study, we asked participants questions that broadly addressed each of these four phases (eg, study staff and their roles, planning the intervention, formative research on the target population, online data collection, website design and testing, and issues of cost and timeline). Similar, but separate, interview guides were developed for principal investigators and study coordinators.

In addition to the semistructured interview, quantitative information about each study was extracted from the interview and shown in Table 1.

Table 1. Study, research team, and vendor characteristics.

	Study 1	Study 2	Study 3	Study 4	Study 5
Study characteristics					
Topic	Alcohol Policy	Adolescent Health	MSM HIV Prevention	Transgender HIV Prevention	Medication Adherence
Grant time length (years)	5	3	5	5	3
Intervention development time (months)	18	12	24	30	13
Study type	Efficacy trial	Pilot trial	Efficacy trial	Efficacy trial	Pilot trial
Online only or hybrid (online & offline)	Hybrid	Online only	Online only	Online only	Online only
Prior offline version	Yes	No	Yes	Yes	No
Previous online version	No	No	Yes	Yes	No
Development cost (US$)	235,000	35,000	300,000	300,000	45,000
Research team					
PI: Experience with online research	No	No	Yes	Yes	Yes
Coordinator: Experience with online research	No	No	No	No	Yes
Vendor					
Prior vendor experience on research grant(s)	Yes	No	No	Yes	Yes
Method vendor chosen	Peer referral	Peer referral	Prior project	Prior project	Peer referral
Budget (at vs over vs under)	At budget	At budget	Over budget	Over budget	At budget
Vendor employee size (Small: 1-10; Medium: 11-49; Large: 50+)	Medium	Small	Large	Medium	Small
In close proximity of research team	Yes	Yes	Yes	Yes	No

Data Analysis

The coding scheme was developed by 3 study authors (KH, SH, and AE), who collectively are referred to as the “coding team”. Qualitative codes were developed using line-by-line open coding for all transcripts [23], with the unit of analysis being a complete thought reflecting one of the codes. As such, the unit of analysis could range from several words to multiple sentences. The initial coding categories were determined by each member of the coding team independently coding two transcripts and convening to discuss mutually agreed upon and overlapping codes. For each category, a definition was agreed upon (the coding book and definitions are available from the first author upon request). Next, a second round of coding was conducted in which two transcripts were coded by 2 members of the coding team, after which the coding team met to finalize the coding scheme and definitions. Finally, all transcripts were coded by 2 members of the coding team. Participants who were also involved in the design and interpretation of this study did not code their own transcript to avoid potential coding bias. Each pair of coders met to discuss all of the statements assigned under each code, with disagreements being resolved through discussion [24]. Once all transcripts were coded, the results were presented in a debriefing session with all of the authors for input and

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interpretation. The themes presented below represent the culmination of this coding and debriefing process.

Results

Summary

An overview of the characteristics of each study is shown in Table 1, including general information about the study, the research team, and characteristics of the vendor that developed the intervention. Intervention studies were drawn from a range of topics. Studies with longer grant periods typically allocated more time for intervention development, had larger research budgets, and had products that were substantially more expensive. Three studies were preceded by an earlier offline or online version of the intervention. Three of the five studies had a principal investigator (PI) with prior experience with online research; however, only two of the project coordinators had such experience. Vendors, which ranged from those with few to many employees, were chosen either by a referral from a peer who had prior experience with the vendor, or because the vendor was used on an earlier version of the intervention. In all but one case, the vendor was within relatively close proximity to the research team, allowing for face-to-face meetings. Three of the projects met their budget estimate, while two of the projects exceeded their budget estimate. The projects that exceeded their budget estimate were both large efficacy trials with relatively large estimated budgets at the onset.

The themes below are organized by the phases of the User-Centered Design Process Map (ie, Plan, Analyze, Design, and Test and Refine), and generally are arranged in chronological order in which tasks should be considered or completed.

Plan and Analyze

Overview

The themes identified under the Plan and the Analyze phases of the usability model include aspects of the study that prepare the team to develop the intervention, as well as conducting formative research to ensure that the intervention meets the needs of the target population.

Hire a Strong (or at Least the Right) Research Team

Assembling an intervention team that will ensure the success of the project is critical, as lacking expertise on the team or including team members who are not a good fit for technology-delivered projects may derail or postpone completion of the project. In addition to content experts who will be expected to develop and review content for the online intervention, hiring a study coordinator to act as a liaison between the intervention team and the vendor is essential to the success of the project. The coordinator will likely have the most day-to-day interaction with the vendor and must advocate on behalf of the intervention team. Coordinators devote much of their time to working closely with the vendor to ensure that the project remains on the timeline and within budget. Coordinators who had more experience with online research were aware of this responsibility and were able to more effectively communicate with the vendor regarding the budget and timeline:

> *I was pretty experienced in working in another intervention…It taught me a lot on how the academic process works with this. I've had a lot of experience with the vendors in technology projects, but I understand some of the academic process behind it and then being able to translate that to the vendor in a coherent manner…I think having someone who's really good at project management and that technical translation piece is really important.* [Coordinator, Medication Adherence]

However, coordinators with no prior online intervention experience developed an understanding of the importance of their liaison role as they became more experienced in the position:

> *It was really challenging and in a lot of ways because I think we didn't spell it out and there wasn't anyone [to guide me through the process]. If I went through it again now I would know. As the study coordinator I would think that was my role to at least work with the vendor to see what their plan was or to make sure that there was a timeline laid out, but I didn't know that at the time.* [Coordinator, Adolescent Sexual Health]

Interviewees reported that the coordinator must be available in order to respond to vendor requests during the development phase of the project, as well as be organized and detail oriented to track study progress (which is discussed in more detail under Design).

In addition to the coordinator, several persons noted that it is ideal to include team members who have experience in contract negotiations and someone who has expertise or experience in software programming. Contract negotiation is difficult without prior experience and may require team members to learn about contracts: "Certainly know what your contract is, know how to manage a contract, certainly understand what scope of work means and out of scope, and when is it legitimate to pay more money than what you agreed upon and when is it not legitimate to do so" (PI, Alcohol Policy). Including an expert in computer programming on the study team was critical since they could provide guidance to the study team about which programming language would be most sustainable for future iterations of the intervention and to advise the team about the appropriateness of the projected timeline and programming expense. The research team should assume that the online health intervention will go through multiple iterations in its life and that different persons and vendors may be working on the project over many years. Therefore, it is critical to develop the intervention using a common and widely used coding language since it may be necessary to hire different vendors to work on the code at different points in time.

Know Your Target Population and Anticipate How They Will Use Your Website

The importance of conducting formative research to understand their needs and preferences for intervention content and features has been well documented (eg, [25,26]). The same care should be taken to consider how target group members will react to and use different aspects of the technology. For example, it was

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noted by several persons that technology-based interventions are highly appropriate for some socially marginalized or isolated groups because members of these groups have been using technology to connect with one another:

> *The trans community are early adopters and are really interested in connecting online. Because they are such a marginalized community that has such a hard time connecting in person, that they were really quick and really eager to adopt online stuff…anything that's come along basically the trans community has jumped right on board.* [Coordinator, Transgender HIV Prevention]

However, other investigators faced challenges of trying to develop an intervention that would appeal to both high and low computer literacy users:

> *Our target audience, which is mostly owners and managers of bars and restaurants, has an incredibly varied level of comfort with using the Internet. We have some managers who are…on the Internet every day for many hours a day…and are very computer savvy. We also work with a lot of owners and managers who might be older, who might not even have an email address, who are not nearly as comfortable with using the Internet. So it can really vary.* [Coordinator, Alcohol Policy]

Once the digital literacy of the target audience is established, anticipating how users will react to different website features can assist with guiding the development of the intervention. Wrongly anticipating how participants will interact with the technology was common and demonstrates the need for formative research and usability testing. For example, in a study of teen sexuality, the investigators released exercises for teens to complete on a regular basis; however, they soon realized that these activities were premature and users did not take advantage of the exercises until much later:

> *We would introduce a few each week to try to encourage teens to log on weekly, or a couple of times a week. What ended up happening is that they would all log on just at the very end of the month and try to get through all of the required tasks, even though we let them know that that was difficult and it was really time-consuming to do it that way.* [PI, Adolescent Sexual Health]

At least one researcher noted that the research team underestimated the sophistication of their target population, which hampered engagement in the online intervention. The potential mismatch between researchers' expectations and actual use of the website by users should be anticipated to the degree possible prior to intervention launch and explored in usability or pilot testing to the extent possible.

Take Time to Plan Before Beginning the Design Process

Across researchers, it was apparent that much of the planning process could be accomplished before meeting with the vendor and writing the contract. Taking time to fully conceptualize the goals of the project and begin developing some of the content for the intervention will make the development process smoother once the vendor is engaged in the process. As persons with expertise in their field, researchers and practitioners will be required to develop content for the intervention. Some researchers noted that incorporating extra time in the grant timeline before hiring a vendor to conceptualize the project and begin some content development before the first meeting with the vendor would save time and money in the long run:

> *I think it would be very beneficial in the future to have a lot of your intervention created…before you get a Web vendor involved. Really think about who your target population is, what kind of Web experience they would want. Think about what you want your website to be able to do, particularly in the research environment where we want to collect all these outcome measures and process measures. Think about what kind of data you want to collect, what you want to get out of it.* [Coordinator, Alcohol Policy]

Developing content early will also help to avoid problems that could arise from simultaneously implementing the intervention while developing content for the intervention.

In sum, there are a number of critical steps and responsibilities that the intervention team needs to consider during the Plan and the Analyze phases of intervention development that may critically impact how smoothly the development process will go for the current intervention, as well as the long-term sustainability of the project.

Design

Overview

The themes identified under the Design aspect of the usability model are those that relate to the intervention itself or the process of developing the intervention.

Vendors and Researchers Have Differing Values, Objectives, and Language

Across all persons interviewed for this study, the most prominent theme observed was that vendors and researchers often have different and sometimes competing values that they bring to the intervention development process. As a result, project staff and vendors often have different objectives when embarking upon the development of the intervention. Examples of values for researchers, based on our own experience, are shown in Table 2. These competing values and objectives may be due to the for-profit versus non-profit nature of each party, which can often lead to miscommunication between parties. For example, when asked about the most difficult part of the working relationship between the research team and the vendors, one participant stated: "Communication between the two agencies, different values. I mean at the end of the day they are a private company that needs to make a profit. At the end of the day we're a public health agency that needs to have a deliverable that can go out" (PI, MSM HIV Prevention).

In addition, misunderstandings may arise because vendors are more familiar with working for for-profit organizations that need a website to interface with consumers of a product or service. The shift to working with academic institutions that

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value data privacy and proper data collection can create confusion:

> *They [the vendor] do a lot with [name of large international client] and not academic institutes and I think that was also the problem because they were more used to working on websites and doing stuff for companies…The user data is so valuable for us and they don't think like researchers, so sometimes it was really hard for them to understand what we wanted.* [Coordinator, MSM HIV Prevention]

Part of the problems that arose during the working relationship came from the use of different language by members of the research team and vendors. For example, it may be clear to researchers what the term "intervention" means and what requirements are needed to conduct an intervention study, vendors who are not familiar with research may conceptualize an intervention closer to a commercial website. These values and language discrepancies were most often worked out by explicitly acknowledging the problem and understanding them as a necessary part of the learning experience.

Challenges between the research team and vendors were often described as "miscommunication" that could be worked out during the intervention development process, and additional time and explicit attention to these issues should be included into the overall timeline. However, there were instances where such miscommunication led to a more lasting mistrust between the two parties. Even though these competing values, objectives, and language were universal among researchers we talked with for this study, there were also agreed upon methods to manage such conflicts. These are discussed in the following two themes.

Table 2. Example values and objectives from a research perspective.

Task	Value(s)	Objective(s)	Action steps/Website features & functions
Overall	Advance science and understanding of complex behaviors and events	Test the efficacy of an online intervention to improve a health outcome	Develop a functional and effective online health intervention
Contract & Budget	Be a good steward of public/grant funds	Stay within budget; an effective intervention for the least cost	Choose a vendor with skills and processes to finish the intervention
		Advocate for the research team	Assign advocate to hold explicit discussions with the vendor about website needs and budget limitations
	Making sure that the intervention is theoretically driven, and sufficiently potent to change behavior	Conduct intervention development in a thoughtful and methodological manner	Provide extra time in the contract to make important intervention design decisions
Website Look & Feel	Create an intervention that is engaging to the target population	Develop an intervention with graphics, features and functions that the target population will use	Conduct formative research; allow time before development begins to understand the technological capabilities and needs of the target population
Data Collection, Management, & Security	Protect participant confidentiality	Develop strong security protocols	Discuss security needs with the vendor and the importance of security protocols.
			Develop security protocols to limit access to the intervention from outside sources
	Collect data to inform research and practice	Build databases that can hold participant and online intervention usage data	Include extra funds in contracts to develop "back-end" databases that can be easily accessed by the research team

Develop a Detailed Contract

One way to manage miscommunication and conflict between vendors and the intervention team was to develop a detailed contract that established the scope of work, the working relationship between the two sides, and agreement on the budget. The contract is a critical document throughout the entire development process. It provides the starting point for what features of the intervention will be built, how the intervention and vendor team will divide the work during the development process, and (perhaps most importantly) how development costs will be charged. The only research team interviewed as part of this study that had little difficulty with the contract was the one in which the project coordinator had extensive experience from prior projects in writing up detailed contracts. Most often, the inexperience of researchers to understand or know what level of detail to include in the contract resulted in problems during the development process: "And in the setting up the contract…not using clear enough language…it [the contract] should have been exact. We thought we were being exact and we realized we should be even more precise" (PI, Adolescent Sexual Health). In addition to helping the development process run smoothly as a result of clearly defined scope and roles, the contract was a document that was continually referred to throughout the development process to resolve conflict between the research team and vendor. Persons interviewed for this study frequently provided examples in which the research team and vendors disagreed on the scope of work or aspects of the budget. However, a detailed contract often provided a basis on which to resolve conflicts:

> *We had a couple of the online components where they gave us drafts that we just thought were completely off base in terms of the discussions we had been having. So we would send back and ask for multiple drafts and I think we didn't get a lot of push back in*

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> *some of the early stages but we ended up getting pushed back and they came back and said the contract only covered one round of reviews. We had to point out that the contract actually didn't specify that.* [PI, Alcohol Policy]

All persons interviewed agreed that it is ideal that the contract explicitly state that the negotiated cost of the subcontract be for the complete, final working version of the intervention (ie, fixed bid contract) rather than expenses charged by hours of time worked. Contracts in which expenses are billed from the vendor to the research grant that are for the number of hours worked can quickly balloon and extend beyond the original budget estimate. This was especially a concern for grants that had a large initial budget, where costs may not be tracked closely:

> *We were under the assumption that we were getting a package deal for this dollar amount. What we came to find out that no, in fact all of the revisions, all of the work that we were having them do, that was adding on hours and our budget was simply no longer. I wish that would have been negotiated better at the get go…in the future I will put together a very specific expectations as to how many revisions will we get, how much money can we spend, how much time can we spend, what are deadlines for things.* [Coordinator, Transgender HIV Prevention]

In contrast, contracts that were clearly specified resulted in a far smoother development process. Several researchers also recommended including language in the contract for funds to support the intervention after it is launched and open for participants to enroll. Holding funds in reserve for technical support will ensure that technical problems that may arise after enrollment has begun will be able to be addressed by the original development team and in a timely manner. Otherwise, the project may be jeopardized by having to take time to renegotiate with the vendor to provide support and finding additional funds for that support.

Document All Decisions and Development Activities

A theme that emerged from our discussions was that all decisions and development activities should be carefully documented on an ongoing basis. There were two primary reasons for documenting decisions and activities. First, documentation provided the framework in which the intervention team and vendor could clarify the precise features and functions that were desired for the intervention. Intervention teams often found it difficult to clarify exactly what features and functions they would like to include in the intervention to the vendor, and creating a document to describe their wishes for features and functions was a starting point to make sure that the intervention features are built as wanted:

> *Where some of the difficulty came in was that neither the PI nor myself had experience really developing an online intervention in that way and so we didn't speak the same language as [the vendor] and so we would try to say, "this is what we want" and he would try to create that and it wouldn't be exactly what we wanted or we needed…As we started to learn the right language and as we started to learn to what to say we really needed, and then we also started making sure that we wrote it all down in a full document.* [Coordinator, Adolescent Sexual Health]

The second main reason of documenting all decisions and development activities was to assist with negotiating any potential conflict. Much like having a clear and detailed contract, documenting all decisions allowed for the resolution of conflicts that inevitably arise during the development process:

> *We discovered pretty early on in the development process that we had to write down every single thing that was agreed upon between the web vendor and ourselves…We would say yes, this is what we want. They would say actually that's going to cost more money. I ended up having to go through hundreds of emails over the course of this study and show documentation of where they had agreed to certain terms and have them follow through on what was promised. So I guess my advice would be to document as much of this process as possible as you're going through.* [Coordinator, Alcohol Policy]

In sum, creating a systematic way to document decisions and development activities throughout the entire process is a necessary aspect of the development process, albeit time consuming for research staff. However, this investment is time well spent for preserving and enhancing the functionality of the Web product and staying on budget.

Use a Content Management System

A content management system (CMS) is an interface that allows users to edit and publish content from a central portal. Users can be anyone designated to make changes to the content (eg, study coordinator or research assistants). While the CMS is primarily used to edit and modify written content on the website, CMSs may include visual content (eg, video or pictures) or audio clips. The primary advantage of the CMS was that it allowed the research team to easily make changes to the website without requesting changes through the vendor:

> *The good thing about a content management system is that you can change your content and keep uploading new stuff or work through it. But it took, because the website is so large, and because we have a couple versions of the website, it took at least a month to upload all the content.* [Coordinator, Alcohol Policy]

The alternative to allowing the research team to make changes to the website content through the CMS was to report changes to the vendor, who would make the edits to the code and subsequently wait for feedback from the intervention team. This process was both time consuming and costly since vendors charged for making such changes. Whichever process is used, allowing sufficient time and staff resources to effectively utilize the CMS was critical to the success of the study.

Test and Refine

Overview

The Test and Refine component of the usability model refers to the part of the process when the intervention is examined for

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technical issues and refined for final rollout. This process often includes internal testing (ie, testing by members of the intervention and/or vendor, often referred to as "alpha" and "beta" testing) and testing with members of the target population (also known as usability testing) [27-29]. As usability testing options have been described elsewhere [19] and the type of usability testing is unique to each study, we do not explore themes related to this part of the process. However, the following theme emerged with respect to the process of internally testing the intervention to prepare for usability and final launch of the intervention.

Allow Extra Time for Testing and Debugging Your Intervention

All researchers interviewed for the purposes of this study noted that the process of internal testing of the intervention to identify technical problems (ie, debugging) took much longer than anticipated. All the researchers noted that even though the contract with the vendor stated that the vendor team would conduct internal testing to identify and correct technical errors, errors and problems with the functionality of webpages and features were common. This was frustrating for many researchers interviewed here, as they did not anticipate having to use resources and time to conduct their own testing:

> *We should not have been doing beta testing, [the vendor] should have been doing that. But they acknowledged that in the end…we explained that this was really one of the most difficult things on our end to want to be starting the study and to find out that things weren't working. Even when we were going live, having things that weren't functioning properly.* [PI, Adolescent Sexual Health]

Furthermore, the timeline for the process of testing was often extended because it often took longer than anticipated to fix bugs, and occasionally a fix for one technical problem caused another unanticipated bug.

The process of communicating technical problems identified during usability testing varied from study to study. One study used an online interface (similar to a content management system) to communicate "bugs" to the vendor team, as discussed below:

> *Debugging was basically our research team, coordinator, research assistant and me going in and playing with the website and then just coming up with a list of things that worked and things that didn't work, and then we'd take it back to [the vendor] and…depending on how much work it was, he would fix it within anywhere from a day to up to a week.* [PI, Medication Adherence]

Other research teams communicated with the vendor by emailing a list of problems to the vendor and having the vendor indicate on that same list when the problem was fixed:

> *As I would find bugs, I would create a word document saying what I was finding. Usually you have to include a screenshot of what was wrong, and then I would submit a list every day to the developers. The developers would then add their own answers to each section of the word doc and so they would either say, "yes this has been fixed" or "we can't fix it because of this, but we made this change instead.* [Coordinator, Alcohol Policy]

Discussion

Principal Findings

The purpose of this study was to provide guidance and lessons learned to researchers and practitioners who are interested in developing online health interventions from the perspective of those who have been involved in such endeavors. Creating a knowledge base of lessons learned in the development of online health interventions is needed since the ultimate success of a particular technology-based intervention rests on attention paid to critical aspects of intervention development prior to launch. The User-Centered Design Process Map [22] was used to guide interviews with principal investigators and project coordinators who had prior experience with online health intervention development. A number of practical tips and suggestions were evident in the findings described here, from which research or other intervention teams would benefit from answering key questions to facilitate the development during various phases of an online intervention (see Table 3). It is also worth noting that the amount of time and effort required for each phase of online intervention development will vary depending on the complexity of the intervention and the extent of evaluation needs for the project. In the discussion below, we draw attention to several overarching points about the process of online health intervention development that appear to be most important from both the interviews that were conducted for this study and our own experience.

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Table 3. Key questions to consider in phases of the development process for online health interventions.

Phase	Questions
Plan & Analyze: Intervention conception; team member involvement in the initial planning; hiring the vendor; adaptation of an existing website or curriculum, learning about the target audience, and formative research	
	Does the study coordinator have experience with online health intervention development and with communicating with vendor?
	Does the study team include someone with experience in contract negotiations?
	Does the study team include someone with experience in software programming?
	Does the research team understand the target population, including their uptake of technologies, their computer literacy, and how they will react to various aspects of the intervention?
	Did the research team allow enough time to conceptualize goals of the project and develop some of the content prior to meeting with the vendor?
Design: Defining the individual components of the websites; discussions about authoring and uploading content; and work processes with the vendor	
	Has the research team conducted an inventory of their values and objectives for designing the online health intervention?
	Is there sufficient time to address communication problems that may arise during the development process?
	Is a detailed contract between the intervention team and the vendor in place prior to beginning development?
	Does the contract provide specific language about the scope of work?
	Are there sufficient funds remaining to pay the vendor to maintain the website after launch?
	Is there a system in place to document all decisions made between the research and vendor teams?
	Will the intervention have a content management system and is there sufficient time to upload content for the intervention?
Test & Refine: Internal testing; usability testing; and de-bugging	
	Is sufficient time set aside during internal testing and de-bugging?
	What are the processes for reporting bugs to the vendor and ensuring that bugs are fixed?

It is critical to consider the values held by members of each participating organization (eg, researchers, government agencies, or vendors) involved in the development of the online intervention or program, as well as the objectives that are trying to be met with the website. The values held by researchers interviewed here are reflected in the themes and quotes described earlier and are exemplified in Table 2. For example, values held by health researchers include advancing understanding of complex behaviors and events, and using the scientific inquiry to improve life expectancy and overall quality of life. The objective of assessing the efficacy of a specific intervention approach reflects these values, which often requires that researchers are entrusted as stewards of federal research grant money and must be responsible to the funding agency and the public. In contrast, for-profit businesses and organizations may value profits and have responsibilities toward employees, owners, or shareholders. For such organizations, their objectives of building a website may be to attract customers, increase visibility of the company and increase sales. The values and objectives of governmental agencies or community-based organizations also may differ in ways from researchers or for-profit companies, and these have implications for how the online health intervention is designed, as shown in the last column of Table 2. For example, since protecting participant identity is critical in research, the importance of blocking access to the online intervention to the public and developing strong security features must be clearly described to the vendor. In comparison, for-profit businesses may wish to widely market their website and encourage browsing of the website by consumers. For these reasons, we recommend that each organization take an inventory of their own values, objectives, and needs as a first step in developing an online health intervention.

With values and objectives of an organization clearly defined, accurately articulating them to the vendor is important so that an appropriate scope of work can be developed and the website can be developed within the allotted budget. All PIs and coordinators interviewed for the purpose of this study highlighted difficulties in communication with vendors as a barrier to developing the online intervention that was initially intended or conceived by the research team and/or staying within the initial timeline or budget. Common areas of miscommunication included whether a component of the intervention had been fully tested and who was responsible for testing, whether the vendor charged for their time by the hour or by the entire project, and how quickly (ie, the number of days) the intervention team should provide feedback to the vendor about a developed intervention component to ensure that the timeline is met. Thus, we recommend open and explicit discussion about these and other needs from the perspectives of the intervention team (or whichever organization is driving development of the website) and the vendor.

To the degree possible, details of these discussions should be included in the initial contract between the organization and the vendor to avoid confusion and frustration. Such agreements may also require that each team step outside of its comfort zone. Intervention teams, who may be familiar with taking extended

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amounts of time to consider different aspects of an in-person intervention, may be asked to make decisions more quickly when working with a commercial vendor to develop online interventions. Moreover, intervention teams may be comfortable altering different features of an in-person intervention well into the development of the intervention. In contrast, altering features or functions of online interventions after they have been programmed and completed is both costly (since additional programming will need to be paid for) and time consuming.

The points noted above highlight the importance of researchers and practitioners becoming familiar with online intervention development, and how it may differ from the development and implementation of in-person interventions or programs. To learn the nuances of Web-based intervention or program development, the intervention team should consider expanding the team to include experts in computer science or learning technologies, including outside consultants with skills and expertise who can manage specific aspects of the study (eg, a consultant with expertise in contract development and negotiations), and taking advantage of institutional resources that will be needed for successful completion of the project. Overall, careful consideration should be given to the composition of the team and should include members who have expertise outside of traditional health fields to successfully oversee the project. Once the appropriate team and resources are identified, this information may be overlaid with the timeline to introduce these team members and resources at the appropriate time.

Finally, we wish to draw attention to the tradeoff between funds available for online intervention or program development and the complexity of the project. We interviewed researchers and coordinators who participated in studies with a range of budget caps, from those with relatively small budgets (eg, US $40,000) to those with much larger budgets (eg, US $200,000 or more). It was evident that the greater availability of funds translates into websites that are more customizable and dynamic in appearance and functionality. All of the vendors hired by research teams with more than US $200,000 of funds available for development were able to hire a vendor with a large team of persons, each with unique skill sets. As such, interventions that had relatively large budgets available for development resulted in interventions that were complex and dynamic compared to those with relatively small budgets. However, because of their complexity, research studies with large development budgets were also at greater risk for going beyond their initial budget estimate and for miscalculating the timeline. These tradeoffs between affordability, complexity, and adherence to budget and timeline will need to be considered by all stakeholders, including funding agencies, researchers/practitioners, and vendors.

As Internet use becomes more ingrained in people's lives, users are becoming more technologically savvy and altering how they search for and use technology [30,31]. As such, end users of online health interventions may have increasing expectations that such programs be tailored, engaging, and sophisticated. Several persons we interviewed for this study noted that the final online intervention did not meet the needs and expectations of their target population, resulting in unexpectedly low engagement with the intervention. As such, we and others [2] recommend consistent consideration of features and functions that will maintain continual website utilization over time among its end users. This may be done by seeking input from the end user to assess their technology expectations and use prior to beginning development, as well as obtaining feedback about the look and feel of the intervention or program throughout the development period. Above all, planning for adequate budgets and development of products that incorporate expected features is important from the outset of a project.

Limitations

This study has several limitations that affect the generalizability of the findings. First, we interviewed a small number of researchers involved in the development of online health interventions, including authors of this study. We did not intend for the results to represent the experiences of all persons involved in online health intervention or program development. Rather, the purpose of this study was to share our own and others' experiences with developing Internet-based health interventions to provide possible guidance to other stakeholders interested in developing their own online health intervention or program. We believe that this study represents the collective experience of researchers across a variety of different health topics, and the themes and recommendations highlighted here will provide important cautionary considerations in the development of online health interventions and programs that are not typically found in current literature. Second, we interviewed only researchers involved with online health interventions at one institution. Greater or fewer resources may be available at other institutions, agencies, or organizations to develop online health interventions, and some themes and recommendations noted here may not be relevant for persons in other settings. We encourage readers to assess their own institutional capacity and resources to determine whether the recommendations made here are relevant. Third, we did not interview vendors to gain their perspective about the process of developing online health interventions. We encourage future researchers to interview vendors and compare their experiences to those described by research teams in this study to contribute to a fuller understanding of the development process.

Conclusions

The results of this study serve as important reminders of the complexity of developing online health interventions. Many of the procedures and practices commonly used to develop traditional, in-person interventions do not translate seamlessly to the development of Internet-based intervention development. We believe that the themes and recommendations put forth in this study will assist researchers and practitioners to more successfully navigate the complex process of online health intervention development.

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Conflicts of Interest

None declared.

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Abbreviations

CMS: content management system
HIV: human immunodeficiency virus
MSM: men who have sex with men
PI: principal investigator

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Review

“Friending” Teens: Systematic Review of Social Media in Adolescent and Young Adult Health Care

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Abstract

Background: Social media has emerged as a potentially powerful medium for communication with adolescents and young adults around their health choices.

Objective: The goal of this systematic review is to identify research on the use of social media for interacting with adolescents and young adults in order to achieve positive health outcomes.

Methods: A MEDLINE/PubMed electronic database search was performed between January 1, 2002 and October 1, 2013, using terms to identify peer-reviewed research in which social media and other Web 2.0 technologies were an important feature. We used a systematic approach to retrieve papers and extract relevant data.

Results: We identified 288 studies involving social media, of which 87 met criteria for inclusion; 75 studies were purely observational and 12 were interventional. The ways in which social media was leveraged by these studies included (1) observing adolescent and young adult behavior (n=77), (2) providing health information (n=13), (3) engaging the adolescent and young adult community (n=17), and (4) recruiting research participants (n=23). Common health topics addressed included high-risk sexual behaviors (n=23), alcohol, tobacco, and other drug use (n=19), Internet safety (n=8), mental health issues (n=18), medical conditions (n=11), or other specified issues (n=12). Several studies used more than one social media platform and addressed more than one health-related topic.

Conclusions: Social media technologies offer an exciting new means for engaging and communicating with adolescents and young adults; it has been successfully used to engage this age group, identify behaviors, and provide appropriate intervention and education. Nevertheless, the majority of studies to date have been preliminary and limited in their methodologies, and mostly center around evaluating how adolescents and young adults use social media and the resulting implications on their health. Although these explorations are essential, further exploration and development of these strategies into building effective interventions is necessary.

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KEYWORDS

social media; social networking sites; adolescents; young adults; health

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Introduction

Health care providers (HCPs) face several important challenges in caring for the adolescent and young adult population. Developmentally, adolescents and young adults are in the midst of a stage in life during which they are striving to establish a sense of independence and self-identity, while also aiming to "fit in" and gain acceptance from their peers [1]. It is a critical time when health-risk behaviors (eg, substance use and high-risk sexual behaviors) are often initiated [2,3]. It is also a time of life transitions, such as moving away from parental control and establishing independent relationships with HCPs. Adolescents and young adults have access to more health information than in the past and possess the capacity to take an active role in tasks such as self-monitoring their health and adhering to medications [4]. However, the interplay between developmental factors and the overall transience of this population can contribute to a lack of communication between these young individuals and their HCPs; young people may want to discuss issues around their health with HCPs, but often do not [5].

On the other hand, adolescents and young adults are the most well-represented population online, with over 95% accessing the Internet daily [6,7]. Young people are also the earliest adopters and heaviest users of the newest Internet communication technologies such as social media, which in recent years has become increasingly accessible as a result of the widespread adoption of mobile and wireless Internet access. In fact, 81% report that they use social media and 67% report using it at least once a day [8]. Furthermore, as active social media users, 88% report sending instant messages, 87% have commented on a friend's post, 86% have posted a status update, and 80% have posted a photo or video online [9]. Social media, by its nature of open sharing, collaboration, and exchange of user-generated content, has been shown to be useful in the creation and maintenance of social networks that are important in the spread of health behaviors [10-12]. Thus, to positively impact the care of young people, HCPs first need to recognize and understand the virtual landscape where they reside to ensure the validity and reliability of information available, and improve their knowledge and awareness of patients' health behaviors in order to engage this traditionally difficult-to-reach and often high-risk population.

A number of review articles have previously examined the use of social media or social networking sites (SNS) (these terms will be used interchangeably) for health-related research involving the adolescent and young adult population, but each is very focused on defined topic areas, such as specific medical conditions [13], mental health [14], other health-risk behaviors [15,16], and the effectiveness of SNS for health research [17]. To our knowledge, no review articles to date have focused on the use of social media as they relate to adolescent and young adult health care. Therefore, the purpose of this systematic review is to identify research on the use of social media for interacting with adolescents and young adults to achieve positive health outcomes.

Methods

This study was conducted using the Preferred Reporting Items for Systematic Reviews and Meta Analysis (PRISMA) guidelines [18]. To determine the ways in which social media has been used to interact with adolescents and young adults, we used a systematic approach to retrieve relevant papers from the literature. Articles were selected for this review using the following pre-defined selection criteria (Table 1): (1) involved original research, (2) published in peer-reviewed journals, (3) specified the use of SNS, (4) target population was exclusive to adolescents and/or young adults between the ages of 11-25 years, and (5) written in English. Within MEDLINE / the PubMed electronic database, we performed a search between January 1, 2002 and October 1, 2013. We included keywords (ie, social networking website, Web 2.0, Facebook, Twitter, MySpace), which were selected based on current definitions of social media at the time of this systematic review [15]. We then refined our search using the keyword "health", as well as keywords synonymous with the adolescent and young adult population (ie, teen, high school student, college student). In addition, we conducted a manual search of articles published within the Journal of Medical Internet Research (JMIR) to retrieve relevant papers. The resulting abstracts were critically reviewed for relevance. We chose to include individuals up to age 25 years in this review for a number of reasons, including the paucity of studies aimed at adolescents under age 18 years and the anticipated similarities in the use of social media, medical implications, and opportunities for intervention.

All full-text articles that met the inclusion criteria were downloaded from PubMed and critically reviewed by two separate researchers (LY, SZ). A checklist for data extraction from the studies was created (Table 2). The purpose of the study, type of social media used, participants and sample size, methodology, and significant findings were summarized. All studies were categorized by methodology (interventional vs observational). Studies were also categorized by the purpose for which social media was employed. These categories were adapted from previously published categorization of uses of social media for health communication [13] and included (1) studies that observed health behaviors by performing content analysis of SNS, assessing SNS use by interview or survey or eliciting reaction to a post on SNS, (2) studies that provided health information, (3) studies that engaged the community, either by facilitating communication with HCPs or creating an online community, and (4) studies that used social media as a means of recruiting participants for clinical research.

Data was extracted independently by the two reviewers and compared. Any discrepancies regarding data categorization were reviewed by a third author (CS) and discussed as a group, after which a consensus was reached and a final database was compiled. As our systematic review focused on the ways in which social media were used, rather than outcomes of its use, further meta-analysis was not performed.

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Table 1. Inclusion and exclusion criteria for systematic review.

Criteria	
Inclusion criteria	Original research
	Published in peer-reviewed journals
	Involves social media / SNS
	Study population: 11-25 years of age
	Written in English language
Exclusion criteria	Not original research: reviews, editorials, and commentaries
	Methodology or technical papers
	Target population not adolescents or young adults
	Not focused on, or involving, online SNS

Table 2. Checklist for data acquisition for papers included in the systematic review.

Data extraction category	Details
Authors	
Title	
Journal	
Year	
Purpose	
Type of social media	MySpace
	Facebook
	YouTube
	Mixed social networking sites
	Other
Target population	
Sample size	
Health issues assessed	Sexual behaviors, sexually transmitted infections
	Alcohol, drugs, or tobacco
	Cyberbullying or sexual predators
	Mental health issues
	Medical diseases
	Other
Outcomes assessed	
Limitations listed in study	
Study results	
Type of study	Observational
	Interventional
Use of social media	Assess or view social media sites
	Assess social media use via survey or interview
	Elicit reaction to postings on social media
	Provide health information or change behaviors via social media sites
	Recruitment through social media
	Improve communication with health care provider via social media
	Create community within social media

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Results

We initially identified 3136 studies involving social media; 1614 of these studies were categorized as applying to health medical subject heading (MeSH) terminology and, of these, 288 involved the adolescents and young adult population. Of these studies, 201 were excluded because they were not original research articles, were not specific to adolescents and young adults (ie, included ages outside of those established in our inclusion criteria of 11-25 years old), or did not involve social media (Table 3). The excluded studies are listed in Multimedia Appendix 1. The PRISMA flow diagram is shown in Figure 1.

Although our search began around the popularization of Web 2.0 in January 2002, only two studies were published before 2006 [14,17] and the largest number of original research studies were identified as being published in 2012 (n=29) (Figure 2).

Of the 87 studies that were included in our systematic review, 86% (75/87) were observational and 14% (12/87) were interventional. There were four primary ways in which social media were used within these studies: (1) observing adolescent and young adult health behaviors (n=77), (2) providing health information (n=13), (3) engaging the adolescents and young adult community (n=17), and (4) recruiting study participants (n=22). The study of adolescent and young adult health behavior was done in one of three ways: viewing social media sites/content analysis (n=25), assessing social media use by interview or survey (n=46), and eliciting reactions to public posting on social media (n=6). Second, researchers used social media platforms for providing health information (n=13). Third, social media platforms were used to engage the community either by improving communication with HCP (n=7) or leveraging social media to create an online community (n=10). Last, numerous studies used SNS as a means of research recruitment (n=23). Notably, several of the studies incorporated more than one method of using social media (Table 4).

The following types of social media were used: MySpace (n=6), Facebook (n=31), You Tube (n=2), and mixed social media platforms (n=37). A total of 11 studies exclusively involved other types of Web-based platforms, including Bebo, MyLOL.net, patient blogs, email listservs, Web 2.0 portals "Diabit", "Upopolis", "NevaEvaLand", and "Mindcheck.ca" (Table 5).

A range of health care issues are addressed by the studies included in this systematic review. Common themes that arose included high-risk sexual behaviors (n=23), alcohol, tobacco, and other drug use (n=19), cyberbullying or online sexual predators (n=8), and mental health issues (n=18). Several studies focused on specific medical conditions (n=11), such as diabetes, childhood cancers, or other chronic childhood diseases. Other topics (n=12) addressed included organ donation, compulsive Internet use, fitness, anxiety related to dental procedures, feasibility of using social media for research recruitment, social support systems, and general social media use. Several studies addressed overlapping topics. The summary of the findings from these studies is included in Multimedia Appendix 2.

Of the 87 studies, 29 were targeted toward adolescents 11-18 years of age, 53 of the studies included 19-25 year olds, and five of the studies did not define the use of the term adolescent. Of the 12 interventional studies, nine of the studies involved young adults between the ages of 19 and 25 years and only three involved those ≤18 years of age. The content of the studies had notable differences: studies focused on those ≤18 years of age were more likely to focus on cyberbullying/sexual predators and specific medical disease than studies including those of an older age group. Studies involving older adolescents were more apt to focus on sexual behaviors, alcohol, tobacco, and other drug use, and mental health. Studies geared toward younger adolescents were more apt to assess social media use, whereas studies aimed for older adolescents and young adults used social media to provide health information or for research recruitment (Table 6).

Limitations listed within the individual studies were reviewed (several studies reported more than one limitation); 53 of the observational studies reported sampling biases and uncertain generalizability (62%), 34 reported limited number of variables assessed (40%), 30 reported limitations related to self-report (35%), and 20 cited incomplete datasets available due to constraints of SNS (24%). Other limitations included small sample size (n=16, 19%) and inability to assess for causality (n=14, 17%).

Table 3. Summary of reasons for exclusion from systematic review (n=288).

Reason for exclusion	n
Not original research: reviews, editorials, and commentaries	59
Methods or technical papers	7
Guidelines	4
Papers not specific to adolescent or young adult ages	100
Papers not clearly involving online social media	30
Papers not relating to human health	1
Total number excluded	201

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Table 4. Use of social media within research studies.

Social media use	Study
Observing behaviors (n=77)	
Viewing social media sites/content analysis (n=25)	Moreno MA [16,19-25], Egan KG [26], Griffiths R [27], Ridout B [28], Whitehill JM [29], Jenssen BP [30], Pujazon-Zazik MA [31], Marcus MA [32], Lam CG [33], Clerici CA [34], Gao X [35], Egan KG [36], Stokes CE [37], Villiard H [38], Cash SJ [39], Lefkowitz ES [40], Robertson L [41], Brockman LN [42]
Assessing social media use via interview or survey (n=46)	Ybarra ML [14,43], Pantic I [44], O'Dea B [45,46], Egan KG [26,47], Moreno MA [48,49], Dunlop SM [50], Wang J [51], Lam CG [33], Clerici CA [34], Nordfeldt S [52,53], Divecha Z [54], Bauermeister JA [55], Stoddard SA [56], Lefkowitz ES [40], Yang CC [57], Jelenchick LA [58], van der Velden M [59], Vyas AN [60], Whiteley LB [61], Veinot TC [62], van Rooij AJ [63], Rice E [64,65], Madan G [66], Woolford SJ [67], Juvonen J [68], Perren S [69], Tucker JS [70], Machold C [71], Gowen K [72], Wolniczak I [73], Campisi J [74], Horgan A [75], Dowdell EB [76], Landry M [77], Li TM [2], Struik LL [78], Black SR [79], Selkie EM [80], Veinot TC [81], Pulman A [82]
Eliciting reaction to public comments ("posts") on social media (n=6)	Dunlop SM [50], Robertson L [41], Egan K [47], Litt DM [83], Young SD [84], Jones K [85]
Providing health information (n=13)	Lam CG [33], Clerici CA [34], Nordfeldt S [52,53], D'Alessandro AM [86], Moreno MA [24], Hedge KC [87], Rice E [64], Bull SS [88], Jones K [85], Livingston JD [89], Li TM [2], Lu AS [90]
Engaging a community (n=17)	
Improving communication with HCPs (n=7)	Whitehill JM [29], Nordfeldt S [52,53], Hedge KC [87], Jones K [85], Selkie EM [80], Lu AS [90]
Creating an online community (n=10)	Rice E [64], Nordfeldt S [52,53], Hedge KC [87], Tichon JG [17], Bull SS [88], Livingston JD [89], Jones K [85], van der Velden M [59], Li TM [2]
Research study recruitment (n=23)	Gunasekaran B [91], Jones L [92], Ramo DE [93], Fenner Y [94], Moreno MA [21-24], Whitehill JM [29], Rice E [64], Stoddard SA [56], Bauermeister JA [55], Gamage DG [95], Lord S [96], Ahmed N [97], Chu JL [98], Kraaij V [99], Ezell JM [100], Brockman LN [42], Jones K [85], Struik LL [78], Black SR [79], Veinot TC [81]

Table 5. Types of social media used in the studies included in the systematic review.

Social media	Study
MySpace (n=6)	Moreno MA [16,19,20,24,25], Cash SJ [39]
Facebook (n=31)	Egan KG [26,36,47], Ridout B [28], Whitehill JM [29], Ramo DE [93], Moreno MA [21,23] Bauermeister JA [55], Jones L [92], Fenner Y [94], Yang CC [57], Gunasekaran B [91], Madan G [66], Villiard H [38], Lefkowitz ES [40], Brockman LN [42], Wolniczak I [73], Gamage DG [95], Lord S [96], Campisi J [74], Ahmed N [97], Chu JL [98], Black SR [79], Ezell JM [100], Young SD [84], Bull SS [88], Jones K [85], Li TM [2], Litt DM [83], Woolford SJ [67]
YouTube (n=2)	Gao X [35], Clerici CA [34]
Mixed social media (n=37)	Ybarra ML [14,43], Pantic I [44], O'Dea B [45,46], Jenssen BP [30], Moreno MA [22,24,48,49], Dunlop SM [50], Wang J [51], Lam CG [33], D'Alessandro AM [86], Divecha Z [54], Hedge KC [87], Stoddard SA [56], Jelenchick LA [58], Vyas AN [60], Whiteley LB [61], Veinot TC [62], Rice E [64,65], van Rooij AJ [63], Juvonen J [68], Perren S [69], Tucker JS [70], Machold C [71], Nordfeldt S [52], Huang CG [101],Gowen K [72], Horgan A [75], Struik LL [78], Dowdell EB [76], Landry M [77], Selkie EM [80], Pulman A [82], Veinot TC [81]
Other social media (n=11)	Interactive website/portal: myLOL.net: Pujazon-Zazik MA [31], Diabit: Nordfeldt S [53], Upopolis: van der Velden M [59], NevaEvaLand: Stokes C [37], Dutch SNS: Kraaij V [99], mindcheck.ca: Livingston JD [89]
	Blog: Marcus MA [32], Lu AS [90]
	Bebo: Griffiths R [27], Robertson L [41]
	Listserv: sibkids: Tochon JG [17]

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Table 6. Comparison of studies included in systematic review, by age of target population (n=87).

Study type and content	Exclusively 11-18 years n (%)	Including 19-25 years	Unspecified adolescent age
Observational, n	26	44	5
Interventional, n	3	9	0
Content of studies			
Sex/sexually transmitted infection	5 (16%)	17 (31%)	1 (20%)
Alcohol, drugs, tobacco	7 (23%)	12 (23%)	0 (0%)
Cyberbullying/ sexual predators	7 (23%)	1 (2%)	0 (0%)
Mental health	3 (10%)	15 (29%)	0 (0%)
Medical disease	6 (19%)	2 (4%)	3 (60%)
Other	3 (10%)	8 (13%)	1 (20%)
Use of social media			
Observe behaviors			
View social media sites/ content analysis (n=25)	7 (24%)	15 (28%)	3 (60%)
Assess social media use by interview or survey (n=46)	19 (66%)	26 (49%)	1 (20%)
Elicit reaction to public posting on social media (n=6)	2 (3%)	4 (14%)	0 (0%)
Provide health information (n=13)	2 (3%)	9 (17%)	2 (40%)
Engage community			
Improve communication with HCP (n=7)	2 (7%)	5 (9%)	0 (0%)
Create online community (n=10)	3 (10%)	6 (11%)	1 (20%)
Research study recruitment: (n=22)	2 (3%)	21 (40%)	0 (0%)

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Figure 1. PRISMA flow diagram of selection procedure for systematic review.

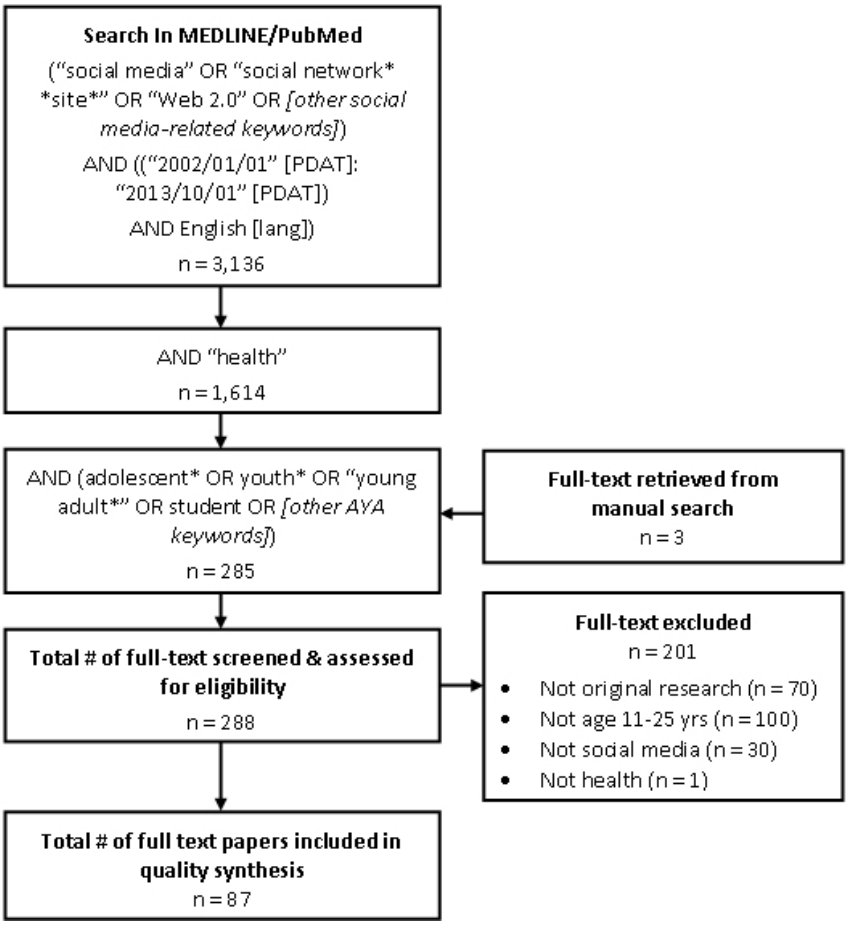
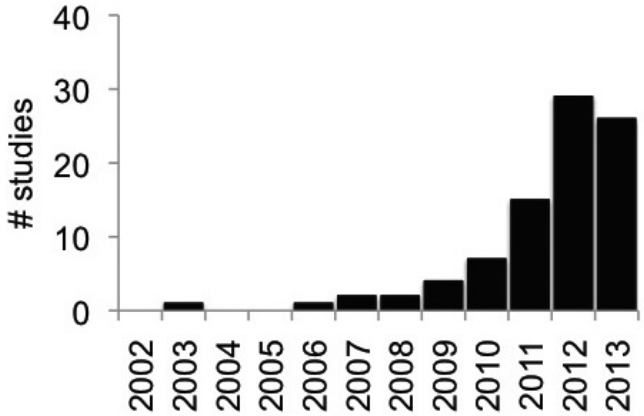


Figure 2. Number of studies meeting criteria for systematic review, by year (studies published through 10/1/2013).



Discussion

Overview

While the use of social media in health care remains in its infancy, a number of themes emerge on how this communication technology is being leveraged to better understand health habits of adolescents and young adults and improve health care delivery to this population. We have found that there are four primary ways in which social media have been used to interact with the adolescent and young adult population.

Observing Behaviors

Social media can offer powerful insights into the lives of young people. The majority of the studies in this systematic review were observational studies that either analyzed content of social networking profiles of adolescents and young adults, or assessed social media use though questionnaires or interviews of adolescents and young adults regarding their use of social media platforms. Common social behaviors that were observed related to sexual behaviors [26,33-35,44-46,55,57,60,73-75,77,78,90,93,95-97], alcohol, tobacco, and other drug use [26-30,32,45,47,50,52,57,63,65,68,83,92,94,101], mental health [24,25,31,36,39,48,59,62,64,67,71,85,91,98,99], and online

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safety [23,37,38,66,81,82,84,89]. By sharing life experiences with the larger public, social media users offer a window into their lives, often revealing the social pressures and expectations they experience. Their postings offer opportunities for HCPs to identify risky health behaviors and health problems that might have been missed during routine health screening, thereby offering opportunities for intervention.

The frequency with which mental health issues are discussed among young people using social media suggest that this offers a potentially fruitful area for the application of social media to help improve the lives of its users. A positive correlation has been found between depressive symptoms and time spent on online social networks [44], suggesting that depression may be common among individuals who spend a significant amount of time on social media. Another study found that over 50% of secondary school students experienced a need for mental health support and 47% believed that SNS could help with these mental problems [45]. Given that adolescents and young adults are already turning to social media for advice and shared experiences, it may behoove HCPs to listen and to seize this opportunity to reach out with accurate information and support.

By enabling individuals to share their thoughts, behaviors, and experiences with a larger audience, social media can also contribute to the establishment of social norms leading to the creation of pressures to "fit in" among adolescents and young adults. A well-known problem, confirmed by analysis of social media content, is the high prevalence of alcohol use among adolescents and young adults: 25% of teenagers ages 16-17 years old [16], 56% of 17-20 year olds [19], and 85% of college students [26] display references to alcohol on social media. The high prevalence of alcohol references on these "intoxigenic" digital spaces [27], a term used by one author to describe pro-alcohol sentiments on social media, leads to the normalization of alcohol use. Given that 60% of college students report potentially problematic alcohol use [28], such normalization of high-risk behavior online adds to the already daunting challenge that HCPs face in counseling against alcohol abuse. However, the use of social media by providers for this purpose may be limited by its perceived acceptability by adolescent and young adult users. One study investigating preferred means of communication regarding mental health issues found that adolescents did not feel comfortable having an unknown HCP screen their social media sites, and described having a stranger screening their Facebook pages for signs of depression as "creepy" [29].

The normalization of high-risk behaviors is not limited to alcohol alone. The use of tobacco and other drugs, violence, sexual behavior, and even suicidality are also commonly displayed on social media platforms. Tobacco imagery is frequently shared on social media [30] and 9% of teenagers aged 16-17 years describe or display cigarette use on their SNS profiles [16]; 15-24% of adolescents also displayed sexual references [20,31]. Such postings have particularly concerning implications, as they may increase sexual expectations when adolescents are using social media to evaluate potential partners [49]. Even suicidality has been found to be impacted by social media through the availability of suicide stories [50].

Online safety is a major concern among studies involving social media: 9% of children ages 10-17 years report having been harassed online over the course of a year [14] and 4% received unwanted sexual solicitation [43]. This has important implications, not just for safety, but also for mental health as cyber-bully victims have higher depression rates when compared to traditional "offline" bully-victims [51]. Adding to the potential risk is the fact that even potentially sensitive behaviors are typically not posted anonymously: one study found that 97% of SNS contained personal identifiers, such as including a profile photo, full name, and hometown [32]. However, privacy settings within different SNS varies and information that may be viewed publically may change over time.

Providing Health Information

A number of studies have used social media platforms as channels to provide health information to educate and invoke behavior change among young people. These platforms have tended to be disease-specific, providing information on childhood cancers [33,34], diabetes [53], and organ-donation [86]. Although it has been suggested that social media may not be a preferred method of contact regarding health information [54], most such studies nonetheless demonstrated a positive impact on their target audiences. For example, an intensive organ donation program utilizing multiple social media platforms to provide organ donation statistics and information was able to increase organ donor registration by 28% [86]. Another study, targeting adolescents at high risk for sexually transmitted diseases, found that brief preventive counseling in the form of a message sent by social media reduced the display of "risky" behaviors online [24].

Engaging Adolescents and Young Adults

Social media also provides an opportunity for the health care community to become involved in discussions with adolescents and young adults, thereby engaging them in ways not possible within the traditional office setting. This may indeed be the true "gold mine" of incorporating social media into health care for this population. As supported by our review of the literature, researchers have only recently begun exploring ways to reach out to adolescents and young adults through social media in the hopes of creating online communities to improve patient-provider communication. Studies performed to date have primarily assessed the acceptability of using social media through observational studies to interact with young people and have achieved mixed results, likely reflecting our collective lack of experience with the use of social media for this purpose. For example, a study that invited members to join an interactive Web 2.0 portal consisting of an extensive library of health education information, in the form of text, videos, and simulation software, social networking capability through message boards and blogs, services for renewing medications and scheduling appointments, and sending questions to the medical team, found that participants welcomed this type of health-related community as a source of information and support [53]. Nevertheless, engagement with the Web 2.0 portal was hindered by the lack of frequently updated information and complicated log-in procedures [53]. Clearly, a social media platform that fails to sustain user engagement is unlikely to be

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an effective means of improving health care outcomes in the long term [87].

Recruiting Adolescents and Young Adults for Research

Beyond engaging adolescents and young adults in discussions about health, social media can also be used in research recruitment efforts. A number of studies identified participants from their postings on social media and subsequently approached them about participating [21-23,29,55,56,93]. Another study was able to leverage social media to locate study participants who would have otherwise been lost to follow-up [92]. In addition to being a cost-effective and efficient means of research recruitment, social media enables researchers to reach a demographically representative sample of adolescents and young adults, including those traditionally underrepresented in research (eg, high-risk individuals and those living in rural communities), and also by providing real-time monitoring of recruitment efforts [94]. Such findings suggest that recruitment of adolescents and young adults for research studies may be achieved more effectively and efficiently through social media channels.

Barriers to Using Social Media

Despite the wealth of opportunities, there remains concern and potential barriers to using social media for health care applications in the adolescent and young adult population. Privacy and confidentiality issues are a concern, particularly when discussing sensitive or stigmatized health topics online through non-secured formats, and young people have expressed a preference for accessing credible health-related information anonymously [80]. Because adolescents generally prefer to seek help from their peers and people that they know rather than from HCPs and strangers, developing an acceptable way to leverage social media for health care purposes may be difficult [23,29]. In their efforts to interact with young people over social media in ways that will engage them, HCPs must be mindful of maintaining professional boundaries and patient privacy. Another concern is that HCPs would be expected to keep up with this ever-changing, fast-paced dialogue on social media that can evolve and spread quickly, with potentially dire consequences. For example, in the case of suicide contagion, it may not be possible for providers to recognize the problem and intervene quickly enough to prevent adolescents and young adults from harm. Furthermore, statements made on social media may not reflect the writer's actual state of health or behaviors, particularly if adolescents and young adults exaggerate or falsify information that they share over social media as a result of social desirability bias. It is important to also note that the majority of studies that we reviewed focused on publicly available content on social media, and what teens share openly may not fully reflect the true extent of their behaviors in their day-to-day lives. Last, because of the open nature of social media and the potential for posting of exaggerated, falsified, or untrue statements on these platforms, the credibility and trustworthiness of the posted content will remain an issue, unless there are systems in place to monitor the quality and content of information on social media platforms.

Limitations

The strengths of our paper lie in the comprehensive and systematic approach we took to review the literature, along with our deliberate and detailed approach to reviewing each full-text article. Nevertheless, there are limitations to this systematic review that warrant considering. First, it is possible that, despite our attempts to capture all pertinent articles through the use of numerous carefully selected search terms, some relevant studies may have unintentionally been excluded. Furthermore, because many social media platforms (including Twitter, Pinterest, and Flickr) do not include documentation of age, many of the observational studies on these platforms were excluded as the age of the study population could not be confirmed. Another potential limitation of the study is in our inclusion criteria for age. We chose to include research involving adolescents as young as 11 years old up to young, college-aged adults of ages up to 25 years due to similarities in the health risks and concerns, reported behaviors, and patterns of social media use. This broader age range provided a greater volume of studies, which we believe offered more comprehensive insight into the potential uses of social media to impact the health of young people. Furthermore, it is possible that studies pertinent to this review may have been missed as a result of keywords used in the article selection process. However, trends for use of SNS within adolescents and young adults were observed, as described above.

Future Directions

Social media and social networking platforms are relatively novel ways of communication, driven primarily by young people, which have been growing and changing ever since their emergence in the early 21st century. Currently, over 70% of adults obtain health information predominantly online [102], but given the growing popularity of social media, it has the potential of becoming a more significant source of online health information in the coming years. Users of social media and those in other fields, such as the advertising industry, understand how the medium can be leveraged for the sharing of information, but the medical and scientific community has been slow to embrace these technologies. Ironically, many health care providers overlook the fact that when they themselves search for health information online on search engines, they often find themselves on Wikipedia, which itself is a social media platform.

Understanding how individuals engage on SNS and consume information will enable HCPs and health care provider organizations to make their content and patient engagement strategies more online-friendly. The number of people using social networking platforms daily continues to grow steadily and this ubiquity can help HCPs engage with patients on a platform they may already be using. For example, communicating with patients about office appointments, lab tests, or even allowing them to ask questions and share content directly through SNS could greatly facilitate patient-provider communication and increase patients' participation in their own care. Additionally, with the emergence of mobile technology, SNS are becoming increasingly "real time", immediate, and local. The combination of SNS with mobile technology makes it possible to learn about patient behaviors and daily habits, and to intervene with relevant and timely messaging, coaching, and

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interventions. Furthermore, computer-generated predictive analytics could be established to screen SNS for keywords or images associated with health care-related issues, automating the process of SNS surveillance in a more patient-accepted format, which may feel less "creepy" to adolescents and young adults while still capturing important opportunities for positive intervention. In the future, the rich data available through SNS and mobile technology may enable HCPs to become more proactive about health care delivery.

Conclusions

Although many HCPs remain timid about the use of social media in the care of patients, this review demonstrates that social media is already being used for a variety of purposes and in a number of different ways to engage, educate, and improve the health of its users. Most studies done to date have been observational in nature, examining how adolescents and young adults communicate on social media and the resulting implications on their health. Although these explorations are essential, further exploration and development of these strategies into building effective interventions that can positively impact the health of young people is warranted. One of the greatest challenges in harnessing social media is the constant and rapid pace of evolution, including the continual development of new technologies and the ever-changing popularity and adoption of specific platforms among different user demographics. In order to stay on top of this rapidly evolving field, ongoing study of the use of SNS by adolescents and young adults will be critical. Further research is necessary to establish whether social media can be an effective tool to help achieve positive health outcomes in the adolescent and young adult population.

Conflicts of Interest

None declared.

Multimedia Appendix 1

List of excluded studies (n=201).

[PDF File (Adobe PDF File), 97KB - medinform_v17i1e297_app1.pdf]

Multimedia Appendix 2

Summary table of studies included in systematic review.

[PDF File (Adobe PDF File), 170KB - medinform_v17i1e297_app2.pdf]

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Abbreviations

HCP: health care providers
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta Analysis
SNS: social networking sites

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Original Paper

An Observational Study of Social and Emotional Support in Smoking Cessation Twitter Accounts: Content Analysis of Tweets

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Abstract

Background: Smoking continues to be the number one preventable cause of premature death in the United States. While evidence for the effectiveness of smoking cessation interventions has increased rapidly, questions remain on how to effectively disseminate these findings. Twitter, the second largest online social network, provides a natural way of disseminating information. Health communicators can use Twitter to inform smokers, provide social support, and attract them to other interventions. A key challenge for health researchers is how to frame their communications to maximize the engagement of smokers.

Objective: Our aim was to examine current Twitter activity for smoking cessation.

Methods: Active smoking cessation related Twitter accounts (N=18) were identified. Their 50 most recent tweets were content coded using a schema adapted from the Roter Interaction Analysis System (RIAS), a theory-based, validated coding method. Using negative binomial regression, the association of number of followers and frequency of individual tweet content at baseline was assessed. The difference in followership at 6 months (compared to baseline) to the frequency of tweet content was compared using linear regression. Both analyses were adjusted by account type (organizational or not organizational).

Results: The 18 accounts had 60,609 followers at baseline and 68,167 at 6 months. A total of 24% of tweets were socioemotional support (mean 11.8, SD 9.8), 14% (mean 7, SD 8.4) were encouraging/engagement, and 62% (mean 31.2, SD 15.2) were informational. At baseline, higher frequency of socioemotional support and encouraging/engaging tweets was significantly associated with higher number of followers (socioemotional: incident rate ratio [IRR] 1.09, 95% CI 1.02-1.20; encouraging/engaging: IRR 1.06, 95% CI 1.00-1.12). Conversely, higher frequency of informational tweets was significantly associated with lower number of followers (IRR 0.95, 95% CI 0.92-0.98). At 6 months, for every increase by 1 in socioemotional tweets, the change in followership significantly increased by 43.94 (P=.027); the association was slightly attenuated after adjusting by account type and was not significant (P=.064).

Conclusions: Smoking cessation activity does exist on Twitter. Preliminary findings suggest that certain content strategies can be used to encourage followership, and this needs to be further investigated.

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KEYWORDS

smoking cessation; Twitter; Internet; social network

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Introduction

While effectiveness evidence for smoking cessation interventions has increased rapidly [1-3], questions remain on how to effectively disseminate these findings [4]. The World Health Organization estimates that smoking causes the death of nearly 6 million people each year. Unless methods of reaching and engaging smokers are improved, the annual death toll could rise to more than 8 million by 2030 [5].

The potential of online social networks to disseminate health information has been recognized [6]. An estimated 73% of online adults in September 2013 used social networking sites. Of these, one in five adults went online to find others who might have health concerns similar to their own [7]. Twitter, in particular, provides a natural way of disseminating information. Created in 2006, Twitter is a live stream of news, opinions, and conversations [8]. Twitter allows users to communicate information through short messages called "tweets" consisting of a maximum of 140 characters. For many users, it has become their first source of information [8]. Health communicators can use Twitter to inform smokers, provide social support, and attract them to other interventions [9,10]. A key challenge for health researchers is how to frame their communications to maximize the engagement of smokers.

This study examined activities of Twitter accounts promoting smoking cessation. A content review was conducted of the tweets of these accounts and assessed the association between the tweet content and followership. We used a theoretically driven coding scheme—Roter Interaction Analysis System (RIAS)—which has been designed for biomedical and psychosocial content and is associated with important patient and provider outcomes [11]. Understanding this association may help in designing effective future interventions on Twitter.

Methods

Study Design

A retrospective examination of a cohort of active Twitter accounts promoting smoking cessation was conducted. This study was reviewed and determined to be non-human subjects research by the University of Massachusetts Medical School Institutional Review Board.

Setting and Sample

A search for smoking cessation-related accounts was conducted on Twitter using the terms "quit smoking" and "smoking cessation". Only accounts in English were considered for the sample. An inventory cohort of 130 smoking cessation Twitter accounts was identified. The date that the account was activated was determined by using the "how long have you been tweeting" Web service, which provides information about how long a Twitter account has been active [12]. From these data, the number of active days of the account was determined, along with the average number of tweets per day produced by each account. Accounts that averaged less than 1 tweet per day over the duration of the account's life were eliminated. Accounts that did not tweet in the 24 hours prior to the time at which the inventory was taken were also eliminated. Based on these criteria, 18 accounts were included in the study (see Table 1).

Content Coding of Tweets

There are several ways of coding communication, including using constructs from behavioral theory to guide the coding process. Behavior change theories frequently used in cancer prevention include Social Cognitive Theory, the Transtheoretical Model, and Theory of Reasoned Action [13]. Communication can also be coded based on clinical practice guidelines. Prochaska et al coded tweets based on clinical practice guidelines for treating tobacco dependence [14]. They can also be coded using a more inductive coding approach, by identifying and tagging content that may be pertinent to a specific user, including health and lifestyle status, health issues, and treatment options. In addition to coding for content, coding can be used to represent the structural aspects of the communication. Health messages are often evaluated on criteria studied in the field of health communication [15], including the types of appeals used in persuasive communication and their tone. Communication can also be coded in terms of complexity, including word count and literacy level.

We used a coding scale based on the RIAS motivational coding scheme. RIAS is a validated method of coding health communication and is associated with important patient and provider outcomes [11]. RIAS was designed to code communications and not to create effective messages. RIAS derives many concepts from social exchange theories related to interpersonal influence, problem solving, and reciprocity. RIAS provides mutually exclusive and exhaustive categories to code both the socioemotional, as well as the task-focused elements of communication. RIAS is proven to be practical, functional, flexible, and methodologically sound with high levels of reliability and predictive validity to a variety of outcome measures [11]. RIAS studies have demonstrated high levels of predictive and concurrent validity [16].

A subset of the RIAS codes was selected based on their applicability to the short message style of tweets. Seven mutually exclusive categories were used to code all tweets (see Table 2). Each tweet was independently coded by 2 coders. These coders were trained by authors (Pagoto and Houston) with prior experience in coding health communication. Initially, 84% agreement was achieved across both coders. All coding disagreements were resolved through a group review to achieve 100% agreement.

Tweets were categorized into three groups: (1) socioemotional support tweets, which included any tweet that involved personal remarks and reassuring statements, (2) encouraging/engaging tweets, which included the tweets categorized as gives orientation or suggestions, and ask open-ended questions, and (3) informational tweets, which promoted a product or event, as well as unrelated tweets that were not relevant to smoking.

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Table 1. Account tweets, followers, and classification.

Organization	Twitter handle	Description	Active days	# tweets	Baseline followers	Followers at 6 months	Change in followers
Yes	@NICORETTE	Tweets from Nicorette	961	6336	15645	15568	-77
Yes	@FDATOBACCO	News updates from FDA Center for Tobacco Products	759	1285	10455	12779	2324
Yes	@SMOKEFREEWOMEN	Tweets from National Cancer Institute	1050	2866	7807	9928	2121
Yes	@QUITTEA	Tweets from the Quit Tea company	959	2324	6891	8509	1618
No	@how2quitsmoking	Tweets from successful quitter of 2 years	1200	18596	3544	3912	368
Yes	@QUITSMOKING	Tweets from Everyday Health, an online health information company (http://www.everydayhealth.com)	406	3851	3156	3021	-135
No	@smokefreelife	Tweets from an individual with the explanation: exploring the possibilities at the intersection of digital media & public health. Motto: Don't give up! Tweets/thinking my own	953	8926	3014	3213	199
Yes	@TRUTHORANGE	Tweets from truth.com, an organization against the tobacco industry	1184	1602	1986	3348	1362
Yes	@SMOKEFREEINDY	Tweets from Smoke Free Indy, a coalition of state, local public health, and community organizations dedicated to reducing secondhand smoke, tobacco usage, and tobacco initiation through education, prevention, and advocacy	1259	2127	1792	1936	144
No	@altersmoking	Smokers of 10 years trying to quit smoking for a year	847	2738	1733	1844	111
Yes	@QUITFULLSTOP_UK	Tweets from quitfullstop.co.uk, a Web-based smoking cessation site	217	507	1209	934	-275
Yes	@QUITSMOKINGSOON	Tweets from http://quitsmokingonlineblog.blogspot.com/, a resource for quit smoking related articles	883	1156	753	859	106
No	@quitsmoking6	Tweets providing useful tips and advice to help users quit smoking	424	3724	589	612	23
No	@quit_smokin_now	Tweets about best ways to quit smoking	863	2392	586	586	0
Yes	@SMOKEFREEPCT	Tweets from the NHS West Kent SmokeFree Service, a specialist team helping local people to quit smoking for free http://www.smokefreewestkent.co.uk	706	729	453	0	-453
No	@quitsmokingform	Tweets providing information to help users to stop smoking	621	2161	342	354	12
Yes	@QUIT_SMOKING_OW	Organization sharing smoking cessation resources shared by health experts, advocates, and organizations into wisdom cards	1359	5174	340	403	63
Yes	@MNT_SMOKING	The latest smoking & quit smoking news published daily; articles from research centers, universities, and prestigious journals; http://www.medicalnewstoday.com/sections/smoking/	888	955	314	361	47

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Table 2. Coding scheme of tweet content.

Code grouping	Code and definition	Codes/Tweet (N=900), n (%)	Example
Socioemotional support	Personal remarks, social conversation: Success stories, thanking other users for following	125 (13.9)	@StopSmokingCIOS Thanks for the link! Yes, we've seen them. Very thought provoking. 10 Years - Full Circle: At 10 years smoke-free, Michelle has plenty to say about how she quit, and the benefits...http://bit.ly/z8gIkC
	Reassures, encourages, or shows optimism: Any tweet related to motivation, inspirational quotes	87 (9.7)	Finally, it's Saturday! Wishing you all a healthy and happy weekend. Make sure to pack it full of motivational activities.
Encouraging/ engaging	Gives orientation, instructions, suggestions: How to, any tips related to cravings, smoking cessation, and long-term success with quitting	91 (10.1)	#Tip Know your triggers. Create a plan for each. Exmpl: Smoke after meals-->Wash dishes, brush teeth, take a short walk to break routine.
	Asks open-ended questions: Any tweet that prompts a response or encourages interactions between users	35 (3.9)	How many days into quitting are you? Tweet at us, and we'll share for inspiration! #ThisIsYOURYear
Informational	Promotion of a product or event: Any tweet that mentions or endorses a product, or encourages attendance of an event on a specific date	122 (13.6)	It's a new day. A new week. A new you. Try to quit smoking today with @quittea http://ow.ly/cgqTt http://ow.ly/i/LZyy Retweeted by Quit Tea
	Unrelated comments: Does not explicitly mention smoking or smoking cessation methods	52 (5.8)	Heidi Klum and Seal separate: when's the downward spiral of celeb divorce going to end? http://trib.al/jUQ9Sz
	Gives information on a medical condition: Specific mention of a disease or condition related to smoking (lung cancer, respiratory problems)	48 (5.3)	NYT: Smoker presents w/ coughing fits & holes in bones: pulmonary Langerhans cell histiocytosis #PLCH. http://ow.ly/ciyFH
	Gives information on lifestyle: Day-to-day effects of quitting smoking including dietary changes, exercise suggestions, and smoking alternatives	83 (9.2)	Once you quit: Your bad breath is gone. The stains on your teeth, fingers, and fingernails fade. You have more overall energy to enjoy life.
	Gives information on psychosocial: Related to changing behavior as a result of social interactions, environment, and individual thoughts	38 (4.2)	Can Facebook Make You Quit Smoking The Daily Beast http://bit.ly/NpqaWQ
	Gives information on news: New developments related to quit smoking technology, recently published journal articles	174 (19.3)	ABC Nightline News: Is #BigTobacco profiting from kids? #Video. http://ow.ly/cj1lP
	Gives information on other: Contains content unrelated to a medical condition, lifestyle habit, psychosocial factor, or news	45 (5.0)	Indonesia Zoo Helping Orangutan Quit Smoking After 10 Years (Video) http://bit.ly/NIBp8V

Data Collection

We considered several methods for selecting tweets. We needed a sufficient number of tweets to achieve a stable within account estimates. RIAS has been found to be conservative resource making it possible to conduct research with smaller sample sizes [16]. In prior studies using RIAS, number of within cluster measures ranged from 6-20 [17-22].

Thus we chose 50 tweets. We considered a random sample, but because number of tweets varied by account and by time, we chose the 50 most recent tweets to reflect current account activity. An inventory of the 50 most recent tweets was manually collected for each of the selected 18 accounts on July 18, 2012. The median number of days for the 50 tweets was 27 (intraquartile range 10.75-48). From the account's homepage, we collected the number of followers that each account had at baseline and at 6 months. The type of account was also identified: Organization or Not Organization. Accounts that specifically stated that they represent or are associated with an organization, product, or initiative were classified as Organization accounts. Accounts owned by an individual tweeting about their experience with smoking cessation, or accounts that did not specifically relate to an organization, product or initiative, were classified as Not Organization accounts.

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Data Analysis

Cross-Sectional Association Between Number of Followers and Frequency of Tweet Content

A cross-sectional comparison of the association of number of followers (dependent variable) and frequency of individual tweet content (independent variable) at baseline was performed. We used a negative binomial regression model due to over-dispersion of the variance of the distribution of the dependent variable.

Longitudinal Analysis of Change in Followers and Frequency of Tweet Content

The change in followership was compared to the frequency of tweet content using linear regression. We calculated the change in followership as the difference in the number of followers of an account at follow-up (at 6 months) compared to baseline.

One challenge in using the absolute difference in followers is that this crude measure does not account for the size of followership at baseline. Thus, a new measure was developed—followership ratio. The followership ratio was calculated as the observed change in followership for a specific account divided by the mean change in followership for all accounts (ie, actual/expected).

Analyses were adjusted for by account type, and all analyses were performed using Stata version 11.

Results

Account Characteristics

The 18 accounts had 60,609 followers at baseline; 68167 at 6 months. More than half (12/18, 67%) of the accounts were organizations. Six could not be clearly identified as organizations and may represent individual accounts. Mean number of days the accounts had been active was 863 (SD 306, range 217-1359). Over the duration of their existence, these 18 accounts sent a mean number of 3747.17 tweets (SD 4281, range 507-18596). At baseline, the accounts had a mean followership of 3367 (SD 4224, range 314-15645); at 6 months the followership changed to 3787 (SD 4692, range 0-15568). One organization account had closed at 6 months (Table 1).

Content Coding of Tweets

As noted, the total number of tweets was 900. We found that 13.9% (125/900, mean 6.9, SD 8.5) of tweets were personal remarks or social conversation, 9.7% (87/900, mean 4.8, SD 5.0) reassured, encouraged, or showed optimism, 10.1% (91/900, mean 5.1, SD 5.6) gave orientation, instructions, or suggestion, and 13.6% (122/900, mean 6.8, SD 10.0) promoted a product or event. Very few of the tweets (5.8%, 52/900, mean 2.9, SD 4.2) were unrelated to smoking cessation (Table 2). In fact, 23.6% of tweets were socioemotional support (212/900, mean 11.8, SD 9.8), 14.0% (126/900, mean 7, SD 8.4) were encouraging/engagement, and 62.4% (562/900, mean 31.2, SD 15.2) were informational.

Cross-Sectional Association Between Number of Followers and Frequency of Tweet Content

At baseline, after adjustment for account type, tweets with higher frequency of reassuring messages were significantly associated with higher number of followers (incident rate ratio [IRR] 1.14, 95% CI 1.03-1.26) (Table 3). Higher frequency of socioemotional support and encouraging/engaging tweets was also associated with higher number of followers (socioemotional: IRR 1.09, 95% CI 1.02-1.16; encouraging/engaging: IRR 1.06, 95% CI 1.00, 1.11). Higher frequency of informational tweets was significantly associated with lower number of followers (IRR 0.95, 95% CI 0.92-0.98).

Table 3. Association of number of followers and frequency of tweets.

	IRR (95% CI)	IRR (95% CI) after adjustment by account type
Personal	1.03 (0.97-1.09)	1.02 (0.96-1.08)
Reassure	1.15 (1.04-1.26)[b]	1.14 (1.03-1.26)[a]
Suggest	1.06 (0.96-1.18)	1.06 (0.97-1.17)
Question	1.08 (0.99-1.18)	1.08 (0.99-1.17)
Info	0.94 (0.92-0.97)[b]	0.95 (0.92-0.97)[b]
Product	0.98 (0.93-1.04)	0.99 (0.94-1.05)
Unrelated	0.97 (0.87-1.08)	1.01 (0.88-1.16)
Socioemotional	1.08 (1.03-1.14)[b]	1.09 (1.02-1.16)[b]
Encourage/Engage	1.06 (1.01-1.11)[a]	1.06 (1.00-1.11)[b]
Informational	0.95 (0.92-0.97)[b]	0.95 (0.92-0.98)[a]

[a]$P<.05$.

[b]$P<.01$.

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Longitudinal Analysis of Change in Followers and Frequency of Tweet Content

The longitudinal analysis was conducted first using change in followers—the difference in the number of followers at follow-up (compared to baseline). The median change in followers was 84.50 (interquartile range 19.25-616.50). For every increase by 1 in socioemotional tweets, the change in followers increased by (beta coefficient 43.94, *P*=.027); the association was slightly attenuated after adjusting by account type and was not significant (*P*=.064). For every increase by 1 in socioemotional tweets, the change in followers increased by (beta coefficient 43.94, *P*=.027); the association was slightly attenuated after adjusting by account type and was not significant (*P*=.064). For every increase by 1 encouraging/engaging and informational tweets, the change in followers decreased (encouraging/engaging tweets: beta coefficient -0.33, *P*=.99; informational tweets: beta coefficient -18.30, *P*=.175).

Additionally, we conducted a longitudinal analysis using the followership ratio calculated as the observed or the actual change in followership over the expected or the mean change in followership. The median followership ratio was 0.20 (interquartile range -0.04-1.50). For every increase by 1 in socioemotional tweets, the followership ratio increased by (beta coefficient 0.10, *P*=.027). The association was slightly attenuated after adjusting by account type and was not significant (*P*=.064). For every increase by 1 encouraging/engaging and informational tweets, the change in followers decreased (encouraging/engaging tweets: beta coefficient -0.0008, *P*=.99; informational tweets: beta coefficient -0.043, *P*=.175). After adjustment, this did not change.

Discussion

Principal Findings

Numerous accounts exist that promote smoking cessation on Twitter. The accounts identified in this study had 60,609 followers in total. The content of the accounts was informational and also included socioemotional and encouraging/engaging tweets. Interestingly, socioemotional content was associated with increased number of followers at baseline and over 6 months, while accounts that tweeted mostly informational tweets about the harmful effects of smoking had fewer followers. Identifying strategies that increase engagement is an important social networking and public health question [4]. Future intervention research on Twitter should compare different content strategies on engagement and smoking cessation outcomes.

Twitter has been used to recruit subjects for health behavioral studies [23,24] and deliver health-related social support [25,26]. Other studies have reviewed Twitter account activity [10,27-30]. Prochaska et al coded the tweets based on clinical practice guidelines for tobacco treatment dependence. They classified the tweets into three major categories (personal communications to support cessation, postings via an automatic newsfeed, or links to commercial sites for purchase of cessation products) [10]. A significant correlation between total tweets and followers (Spearman rho=.57, *P*<.001), number of active days and followers (Spearman rho=.48, *P*<.001), and number of active days and total tweets per account (Spearman rho=.23, *P*=.005) was found. In addition to adapting a standard health communication coding schema for coding tweets, our analysis is unique in that we also longitudinally assessed the association between content and followership.

Furthermore, this study also has a methodological contribution. A new estimate (followership ratio) was developed to account for the size of population at baseline. Similar ratios such as the Standardized Mortality Rates are used outside the social networking research to account for a change in a factor of a subgroup with respect to the general population [31]. Although the results of this study using the new estimate were not different from the crude absolute measure that was also used (change in followership), other studies might have different results. Additional research is needed to further study and develop this new followership ratio estimate, which is an important area in social networking research [4].

Limitations

One limitation of this study was the sample size. Only 18 relevant accounts were identified. Additionally, only 50 tweets were viewed in a snapshot of time per account, and these might not be representative of the account. The goal was to assess tweets at a particular instance in time and then to prospectively look at followership at 6 months. Thus, it may not represent everything that happened within the account. Additionally, to achieve a sufficient number of tweets to achieve a stable within-account estimate, we chose 50 of the most recent tweets, not a random sample of tweets. Furthermore, this study did not assess whether these accounts had any impact on cessation efforts. It is also unknown if followers of these accounts are primarily smokers.

Conclusions

Twitter has the potential to be a new channel for smoking cessation interventions. Although easily accessible, evidenced-based tools exist in smoking cessation, they are underused [32-35]. Current recruitment methods such as search engine advertisements are limited in that they require the user to initiate the contact and come to the intervention [32-35]. Delivering the intervention where smokers are already engaged could be a more effective engagement approach. This study further highlights the potential of Twitter as a smoking cessation resource and indicates certain content strategies that can be used to encourage followership. Further research is needed to assess whether smokers engaged on Twitter can also be encouraged to use additional cessation resources such as a Web-assisted tobacco intervention.

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Acknowledgments

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Conflicts of Interest

Dr Pagoto is on the advisory board for Empower Fitness, has consulted for Apple, and receives funds to produce social media content for Sears FitStudio.

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Abbreviations

IRR: incident rate ratio
RIAS: Roter Interaction Analysis System

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Original Paper

Earned Media and Public Engagement With CDC's "Tips From Former Smokers" Campaign: An Analysis of Online News and Blog Coverage

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Abstract

Background: In March 2012, the US Centers for Disease Control and Prevention (CDC) launched the first-ever paid national tobacco education campaign. At a cost of US $54 million, "Tips from Former Smokers" (Tips) ran for 3 months across multiple media, depicting the suffering experienced by smokers and their families in graphic detail. The potential impact and reach of the Tips campaign was not limited to that achieved through paid media placements. It was also potentially extended through "earned media", including news and blog coverage of the campaign. Such coverage can shape public understanding of and facilitate public engagement with key health issues.

Objective: To better understand the contribution of earned media to the public's engagement with health issues in the current news media environment, we examined the online "earned media" and public engagement generated by one national public health campaign.

Methods: We constructed a purposive sample of online media coverage of the CDC's 2012 Tips from Former Smokers television campaign, focusing on 14 influential and politically diverse US news outlets and policy-focused blogs. We identified relevant content by combining campaign and website-specific keywords for 4 months around the campaign release. Each story was coded for content, inclusion of multimedia, and measures of audience engagement.

Results: The search yielded 36 stories mentioning Tips, of which 27 were focused on the campaign. Story content between pieces was strikingly similar, with most stories highlighting the same points about the campaign's content, cost, and potential impact. We saw notable evidence of audience engagement; stories focused on Tips generated 9547 comments, 8891 Facebook "likes", 1027 tweets, and 505 story URL shares on Facebook. Audience engagement varied by story and site, as did the valence and relevance of associated audience comments. Comments were most oppositional on CNN and most supportive on Yahoo. Comment coding revealed approximately equal levels of opposition and support overall. We identified four common arguments among oppositional comments: government intrusion on personal behaviors, problematic allocation of governmental spending, questionable science, and challenges regarding campaign efficacy. Supportive comments tended to convey personal stories and emotions.

Conclusions: The Tips campaign received limited coverage on either online news or blog sources, but the limited number of stories generated engagement among online audiences. In addition to the content and volume of blog and news coverage, audience comments and websites' mechanisms for sharing stories via social media are likely to determine the influence of online earned

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media. In order to facilitate meaningful evaluation of public health campaigns within the rapidly advancing media environment, there is a need for the public health community to build consensus regarding collection and assessment of engagement data.

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KEYWORDS

mass media; tobacco; health communication

Introduction

In March 2012, the US Centers for Disease Control and Prevention (CDC) launched "Tips From Former Smokers" (Tips) [1], the first-ever paid national tobacco education campaign. Tips ran for 3 months across multiple media—television, radio, movie theaters, online, billboards, newspapers, and magazines—at a cost of US $54 million. Featuring graphic portrayals of real people suffering from smoking-related illnesses, the campaign aimed to build awareness of the immediate damaging effects of smoking on smokers as well as those exposed to secondhand smoke and to encourage smokers both to quit and to not smoke around others. Tips' primary target audience was smokers aged 18-54.

Health communication campaigns can be powerful when well-crafted messages are placed where members of target audiences are likely to see or hear them. Exposure to a campaign such as Tips can be separated into "paid" and "earned" media. Paid media is similar to conventional advertising: a market-based fee is paid for the placement of campaign ads in front of a target audience. Earned media includes donated media that appears very similar to paid media, for example, public service announcements (PSAs), and also includes discussion or coverage of an issue or campaign in the news. To the extent that some aspect of a campaign sparks journalistic interest (among both "formal" journalists and "citizen" journalists or bloggers), earned media may increase exposure to a campaign message without incurring additional cost. Earned media also may spread a message beyond the targeted audience, convey pertinent background information about an issue, and heighten issue salience among stakeholders as well as the general public [2-5]. Both paid and earned media can play a role in a campaign's reach and potential capacity to bring about desired change.

Recent changes to the journalistic landscape, particularly the emergence and growth of online news [6], provide a platform for earned media to spread with unprecedented speed and potentially well beyond the audience exposed through the paid campaign [7]. The online communication landscape now enables a multidirectional flow of information where consumers increasingly encounter content that is tailored to their interests in a format that facilitates immediate engagement, response, and sharing with one's social network [8]. For example, a description of a campaign may feature multimedia elements, such as campaign spot videos or interviews with viewers, and such information is likely to appear alongside entertainment and analysis [9]. Further, many news and blog platforms provide opportunities for the public to interact with content by posting public comments, rating or "liking" stories, or sharing content through other social media platforms [10]. The avenues for active audience participation and sharing provided by online outlets may potentially expand the reach and influence of online earned media beyond that possible with traditional earned media.

Simultaneously, the online media environment holds the potential to undermine support for public health campaigns. For example, some have suggested that the proliferation of online sources might in fact have narrowed the type of coverage to which some readers are exposed. Thus, while it is easier than ever to find content to match one's interests, it is also now quite possible for people to avoid exposure to content that challenges their current opinions and beliefs [11]. It is also potentially more difficult to differentiate between credible and non-credible sources [7,12,13]. Furthermore, several recent experimental studies indicate ways that audience interaction presented alongside online content might undermine campaign messages. For example, in one study, the civility of audience-generated comments significantly influenced readers' perceptions of a science news story [14]. Similar effects were found in relation to an anti-smoking video PSA: the presence of comments was associated with viewers evaluating the PSA as less effective, particularly when the commentary was negative [15]. The authors proposed that user-submitted commentary, even when supportive, may disrupt the transportive property of a PSA.

The online media environment is also subject to both journalist and audience-generated attempts at message agenda-setting and framing, both of which influence the impact of a health campaign. Agenda-setting refers to placing emphasis on specific issues in a media message in order to influence the importance the audience attributes to that message [16]. Framing may be understood as efforts, either by the communicator of a message or its recipient, to build a context within which a problem is defined, its causes diagnosed, and moral reactions and remedies suggested [17]. Agenda-setting relies on story selection as an indicator of issue importance, while framing focuses on the way those issues are presented and processed [16]. Given the polarized nature of many health policy debates [18], including those around tobacco control [19-23], it becomes important to understand these complex and dynamic interactions. From an agenda-setting and framing perspective, it is important to consider that, in the online setting, not only do journalists set the stage for determining which issues attract audience attention and how that attention is characterized, but audience reaction (such as user-generated comments, likes, and shares) also influences the stories and angles on which journalists choose to focus [24]. Earned media around a campaign such as Tips can affect both the importance the public places on tobacco control and the framework of opinion within which the public views the issue.

In a traditional print news environment, public debates around tobacco control feature a range of narrative, informational, and

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economic appeals [19,21] as well as arguments regarding the role of the state and individual liberties. While similar appeals likely emerge in online public debates, many online news and opinion (blog) sites also feature distinct norms and standards of public engagement. Notably, online public engagement often features incivility and "trolling", perhaps due in part to the anonymity that online comment forums afford to those who engage [25-30]. Further, there is substantial variability in levels at which different online platforms implement codes of conduct and curate or monitor comment fields [10]. While some sites discourage or even edit out off-topic or uncivil threads, other platforms allow users to introduce entirely new subjects, with or without explicit reference to the original story. In the context of health policy and media campaigns, online earned media coverage can provide a forum for public engagement with important issues. In contrast, public engagement on online forums can also serve as an avenue for spreading oppositional arguments, or even misinformation, which might serve to undermine these same campaigns' messages [31]. To date, little is known about how online earned media and the related public debate it generates might affect campaign success.

New methods are required to fully understand the extent, character, and influence of earned media in an online context [7]. Given its unprecedented scale and graphic content, the CDC Tips campaign had the potential to generate considerable earned media, providing new opportunities for the public to encounter and engage with the campaign. We seek to contribute to understanding the role of online earned media by analyzing news coverage about Tips and the level and type of public engagement that it generated. In this paper, we examine news and blogs from prominent online sources during and immediately following the first wave of the campaign in 2012, quantifying the total number of news stories and blog postings and characterizing their content and focus. We also describe total public engagement reported alongside each story, including numbers of shares, likes, and comments garnered. Finally, we characterize the content of a sample of audience-generated comments, including the extent to which these specifically reference the campaign and their valence with regard to tobacco control. We also describe major themes in oppositional and supportive comments.

The digital media landscape and the data it yields offer opportunities to conduct qualitative research on a quantitative scale. Examining the amount of earned coverage about Tips and analyzing the themes and valence of both news stories and responsive comments contributes to the development of effective methods for measuring and analyzing earned media and subsequent public engagement. Such methods will be crucial to building support for future public health campaigns within the rapidly advancing media environment.

Methods

In October 2012, we constructed a purposive, diverse sample of online news and blog coverage of the CDC's Tips From Former Smokers television campaign, which aired between March and June 2012. We constructed a politically diverse sample of blog and news sites including five leading US policy-focused blogs (Huffington Post, Politico, Daily Beast, RedState, and the National Review) and nine news media sites (MSNBC, Yahoo News, CNN, Fox News, New York Times, USA Today, Wall Street Journal, Los Angeles Times, Washington Times). News and blog sources were selected based on their readership/audience as well as balance between liberal and conservative perspectives. Traditional news sites were selected from among major regional and national sources to represent the breadth of mainstream political perspectives, and Tips-related keywords were used to search each selected site for relevant articles. Traditional sites also were chosen on the basis of their estimated readership numbers. Audience estimates were collected from Nielsen Insights [32] and from comScore [33]. Readership numbers are presented in Table 1.

Table 1. Readership figures for traditional news sources.

News website	Nielsen (May 2012)	comScore (August 2012)
CNN	39,559,000	38,979,000
Daily Beast[a]	16,000,000	16,000,000
Fox News	21,555,000	29,866,000
Huffington Post	29,016,000	43,700,000
LA Times[a]	23,000,000	23,000,000
NY Times	29,248,000	73,099,000
USA Today	15,104,000	26,300,000[a]
MSNBC	30,175,000	123,337,000[a]
Wall Street Journal[a]	13,971,000	13,971,000
Yahoo	142,959,000	163,723,000
Washington Times	9,750,000	9,750,000

[a]Numbers retrieved from the website's media kit.

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Constructing a purposive sample of relevant, influential blogs was somewhat more challenging as we are unaware of any publicly available definitive source of data on blog reach. We therefore referenced various blog ranking sites (eg, technocrati, bynd, ebizmba) to construct our sample by identifying examples of searchable blogs representing diverse perspectives on policy initiatives. We used Google and Google Advanced search engines to conduct our searches, combining website-specific keywords (eg, "CNN") with a series of keyword combinations related to Tips. We collected all media pieces that contained the exact phrase "tips from former smokers" or all the words "government", "campaign", and "smoker", or that included "CDC" in combination with "Tips", "smoker", "smoking", or "tobacco." To ensure that all relevant pieces were gathered, we repeated the searches on media outlet websites where searchable archives were available. This repeated search did not reveal any additional stories, suggesting that our search strategy was comprehensive for relevant content on the selected sites.

Our initial search strategy yielded 46 online media pieces; we reviewed each piece to confirm its relevance to the CDC Tips campaign. We excluded articles that included our keywords but did not mention Tips, for example, several that discussed state anti-smoking campaigns or CDC budget issues. We coded 36 pieces as relevant to the Tips campaign, defined by inclusion of at least a mention of the campaign, and 27 pieces as primarily focusing on Tips, which is reflected in story headlines that refer to the campaign. These 27 pieces were the focus of our final analysis, and each story was coded for publication date, presence of multimedia content (videos, pictures), and social media engagement data (shares, likes, tweets) (see Multimedia Appendix 1). We also coded whether pieces were posted to blogs or news sections of websites. The text of each piece was then subject to a basic thematic analysis of key content and messages. This basic thematic story coding was conducted by a single researcher (KS) using an open coding process that allowed for ongoing identification of emerging themes.

For media pieces where reader commenting was enabled (n=21), we manually compiled all comments in a Microsoft Access database. We coded comments that began new threads as "primary comments" (N=4040) and comments that responded to existing threads as "replies" (N=5507). We linked "reply" comments to the associated primary comment in the database. For each story, we calculated the reply rate, defined as the average number of replies generated by each primary comment.

In our initial review of the data, we noted that reply comments were often ambiguous without context from the threads from which they were generated (eg, "That's hot", "I agree!!", "Dana get a clue..."). We therefore focused our analysis on primary comments, which typically responded in some way to the media story. The volume of comments was such that we needed to create a sampling strategy to facilitate further coding of comments. We coded a simple random sample of primary comments across all media pieces (1370/4040, 33.91%) for two characteristics: (1) whether the comment mentioned the CDC Tips campaign, either by name or by reference to its cost, medium, or content, and (2) the comment's valence with regard to Tips, or to governmental tobacco control efforts (where there was no specific mention of the campaign). Valence was coded as supportive (of tobacco control), oppositional, or unclear/irrelevant. A team of 5 trained coders analyzed the comments. Each comment was coded by 2 coders, and discrepancies were adjudicated by a third coder. To assess interrater reliability, Cohen's kappa was calculated for all codes (Tips mention, .80; No Tips mention, .78; Support, .74; Opposition, .70; Unclear/Irrelevant, .45). For each article with comments, we took the first 20 primary comments (or all primary comments if <20) and performed open content coding to characterize the major justifications provided for support or opposition of the campaign. The first 20 comments were selected on the basis that the earliest comments are often displayed alongside articles and are most likely to be viewed and engaged with by readers.

The coding team then independently reviewed the comments to identify major themes. The themes then were discussed among all coders to aggregate overlapping codes and reach consensus on final categories. We conducted analyses of overall reader engagement (ie, Facebook likes, comments, tweets, shares), comment valence, and frequency of Tips campaign mentions in comments. We also made comparisons across media pieces as well as across websites.

Results

Online Blog and News Coverage of the Campaign

Our search of 5 online news sites and 9 policy blogs revealed 36 media pieces that mentioned the CDC's "Tips from Former Smokers" campaign in the months following the campaign's release. All the blog and news outlets we searched included at least one piece mentioning Tips with the exception of the National Review and RedState. Collected pieces had posting dates between March 14 and June 16, 2012, with the majority of stories accompanying campaign launch in March. Of these pieces, 23 were news articles, 11 were blog postings, and 2 were video or image reels (see Multimedia Appendix 1). Nine pieces mentioned but were not primarily focused on the Tips campaign, for example, two stories from the Wall Street Journal that summarized a number of news items ("AM Vitals") and one from Huffington Post that mentioned Tips in the context of racial disparities in smoking rates ("Smoking Rates Increase With Perceived Racial Discrimination, Study Says"). The nine "non-Tips focused" pieces are included in Multimedia Appendix 2, but we did not analyze the public/audience engagement they generated.

Most articles (both those posted on news as well as blog sites) shared considerable content, suggesting that they were closely based on content from a press release or from a single wire (eg, Associated Press) story. Stories routinely reported on the fact that the Tips campaign is the largest ever federal program of its kind, as well as the cost of the campaign (US $54 million), the need for the campaign due to the stall in reduction of adult smoking rate (at around 20%), and the number of smokers (50,000) who might be expected to quit smoking after seeing the ads. Calling upon a wide variety of terminology, the news and blog pieces universally included a reference to the graphic nature of the ads (gruesome, difficult to watch, powerful, hard hitting, grisly, emotional, brutally honest, harsh). The actual

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ads were often either embedded in the story or described in detail in the text.

Assessment of the presentation of the campaign goals revealed some differences in coverage. Several stories focused on the ads' potential to prompt quit attempts, whereas others identified their potential to prevent youth initiation. Stories typically related the ads to a desire to "shock", "jolt", or "scare" the audience, and act as a "wake-up call". In contrast, few stories highlighted the potential for the ads to "educate". The campaign was often presented in the context of other tobacco control policies whose impact has been limited or now seems to have stalled; tobacco taxes and smoking bans were specifically mentioned in this regard. The framing of campaign cost also differed somewhat between stories; some highlighted the extreme expense of the campaign while others contrasted the US $54 million spent by the federal government with the tobacco companies' US $10 billion marketing budget.

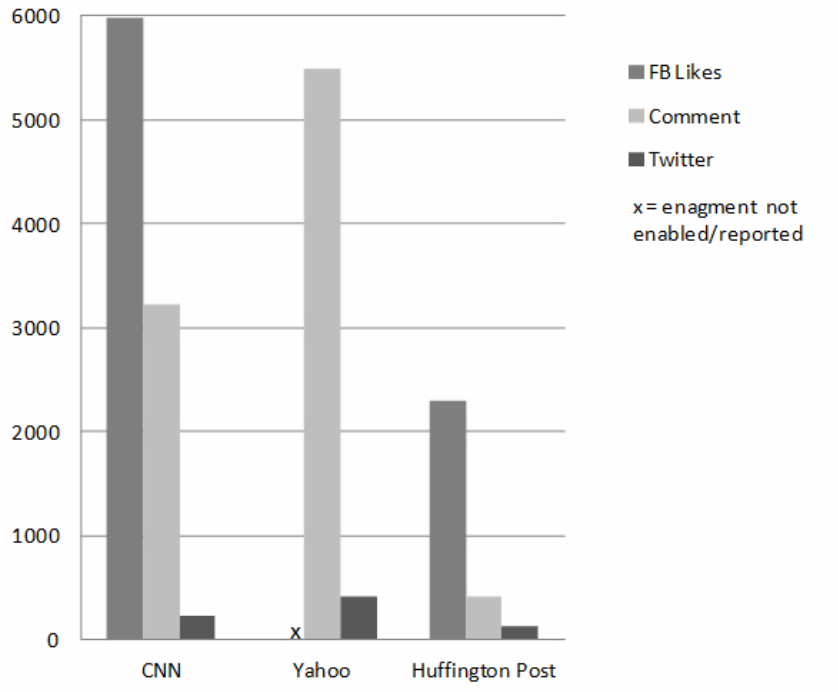
Context for campaign coverage was provided by inclusion of quotes from government officials (namely, Kathleen Sebelius from US Health and Human Services and Thomas Frieden from the Centers for Disease Control and Prevention), as well as representatives of public health agencies and tobacco control organizations (John Seffrin from the American Cancer Society and Matthew Myers from Campaign for Tobacco Free Kids). A few stories mentioned that Philip Morris declined to officially comment, and one story provided a quote from an RJ Reynolds spokesperson comparing the ad campaign to the issue of graphic warnings on cigarette packs.

Public Engagement

Engagement with online coverage of the CDC Tips campaign was tabulated from audience interaction data provided alongside the stories, although not all forms of engagement were reported by all outlets (see Multimedia Appendix 1). Across the 27 stories primarily focused on Tips, the most common form of engagement was commenting on the host site, with 9547 comments collected from the 21 pieces where commenting was enabled. Of these comments, 4040 began new threads, with the remainder responding to existing threads (average reply rate = 1.3). "Liking" stories on Facebook was the second most common form of engagement, with a total of 8891 likes reported for 18 stories where data were available. In total, 22 stories reported data related to Twitter for a total of 1027 tweets of story URLs; 10 stories reported a total of 505 shares of story URLs on Facebook.

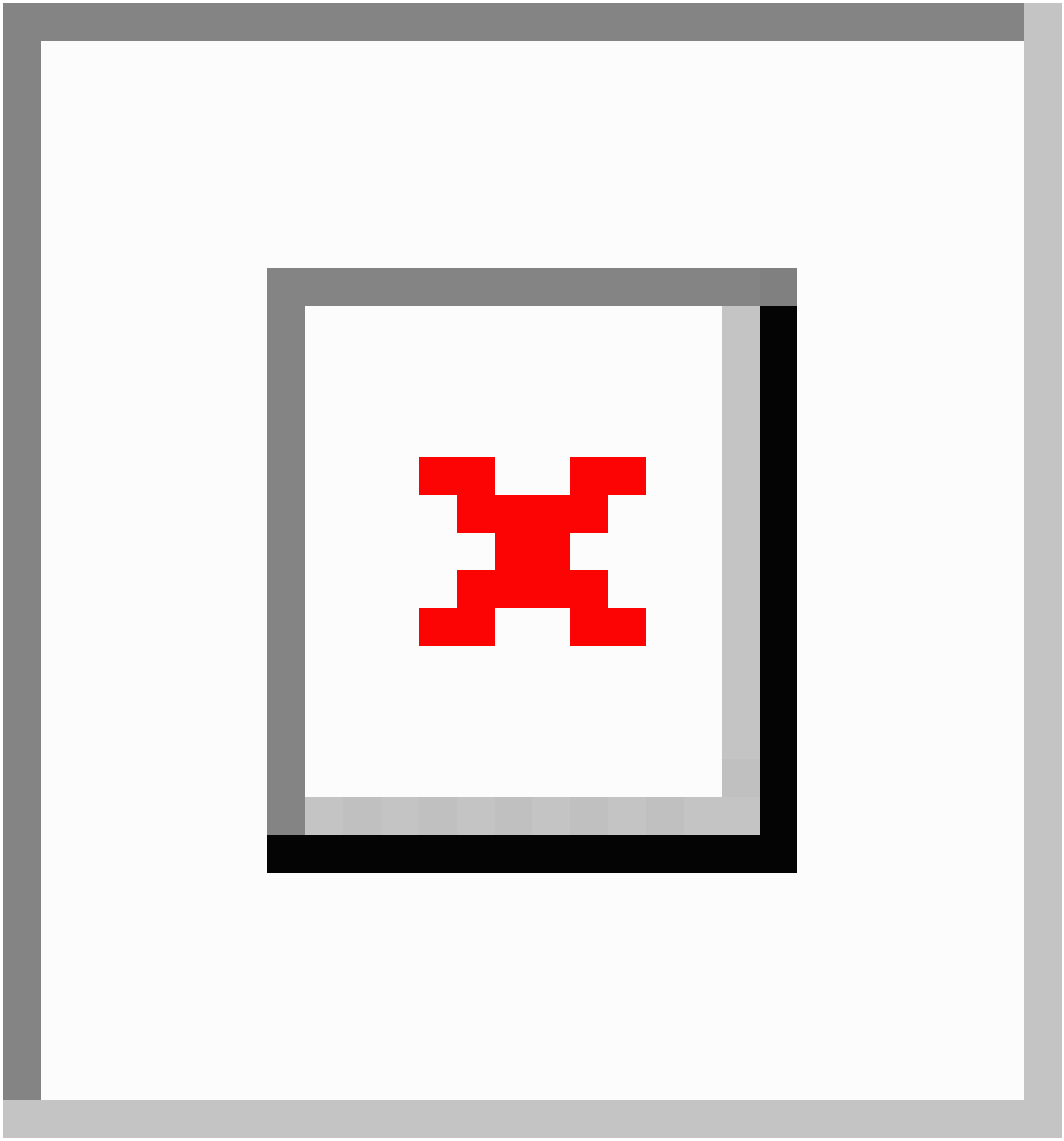
Mode and level of engagement varied considerably by story (see Multimedia Appendix 1) and by website (see Figures 1 and 2); CNN, Yahoo, and the Huffington Post were associated with considerably more engagement than other outlets. On CNN, Facebook likes were the most common form of engagement (n=5974), followed by commenting (n=3221) and tweets (n=237). On Yahoo, where Facebook likes were not enabled, there were a total of 5493 comments and 418 tweets. The Daily Beast and the Huffington Post both enabled Facebook shares, but only the Huffington Post was associated with a sizeable number of shares (n=484). The six Huffington Post stories were also associated with 2290 Facebook likes, 406 comments, and 133 tweets. Although the New York Times stories allowed sharing links through Facebook and Twitter, the number of shares was not reported. Politico, RedState, and the National Review did not include Tips-focused stories, and the LA Times coverage garnered a negligible level of engagement; these outlets are not represented in Figure 2.

Figure 1. Level and mode of reader engagement with Tips news coverage on high engagement websites.



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Figure 2. Level and mode of reader engagement with Tips news coverage on low engagement websites.



Comment Characteristics

Figures 3 and 4 depict comment valence and frequency of campaign mentions in the sample of primary comments from four outlets, selected on the basis that each had a high number of public comments posted across multiple stories. The valence of comments varied by outlet/site, with the greatest proportion of supportive comments found on Yahoo (43.2%, 380/880) and the lowest on CNN (19.6%, 64/327) and MSNBC (24%, 9/38). The proportion of "on topic" comments mentioning the Tips campaign was highest on Huffington Post (71%, 29/41) and MSNBC (53%, 20/38) and lowest on CNN (39.8%, 130/327). Only one New York Times story allowed comments to be posted, and this piece was unusual in that it was a learning blog where school children responded to a prompt about the potential efficacy of the Tips campaign. The school children's comments were largely formulaic and supportive, making this distinct from other comments sections.

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Figure 3. Valence of primary comments with regard to tobacco control, by website.

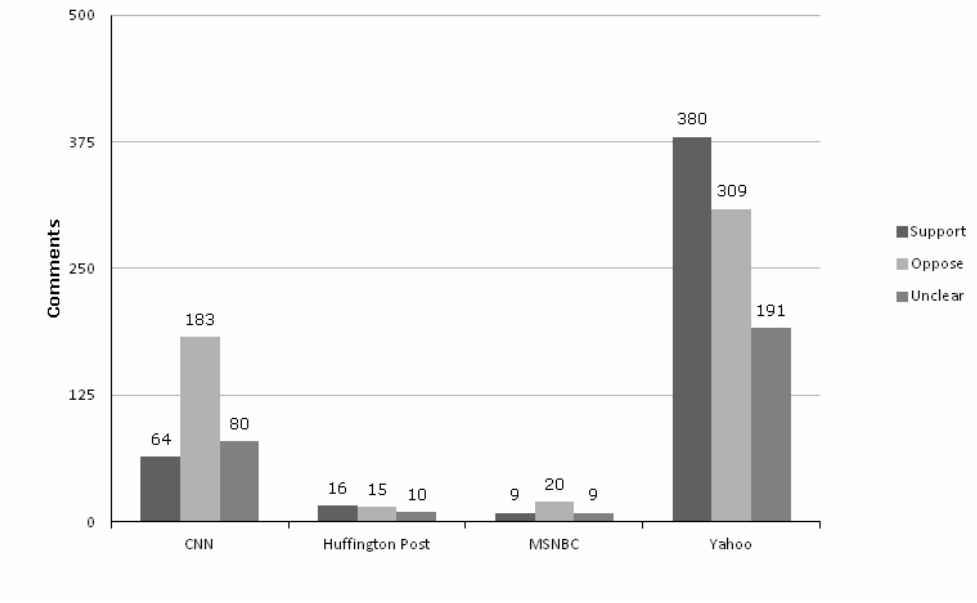
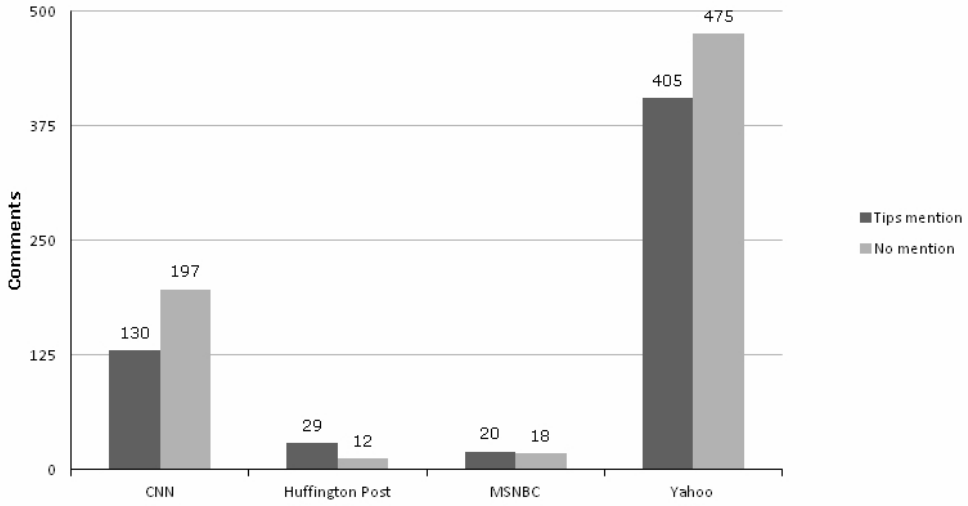


Figure 4. Comments with and without mentions of the CDC campaign, by website.



We generated a thematic coding frame for comments by a process of open coding the first 20 primary comments for each story (n=270) (see Table 2). Below, we outline four predominant criticisms of the campaign within the comments that were coded as oppositional to the campaign as well as primary themes we identified within supportive comments. Among oppositional comments, we extracted themes of questioning: (1) the appropriateness of federal government's involvement in influencing individuals' health behaviors, (2) the allocation of funds and efforts to tobacco issues specifically, (3) the evidence upon which anti-smoking arguments are based, or (4) the effectiveness of campaigns. Comments supporting the campaign less frequently made an explicit case for the campaign, likely reflecting that most news/blog stories had already provided the campaign's rationale. These comments instead tended to (1) disclose personal stories related to smoking, (2) express support for quitting or disapproval of smoking, and (3) convey reactions to the campaign.

Among oppositional comments, arguments regarding message appropriateness typically depicted governmental health promotion campaigns as a threat to individual liberties, often tying programs to the expanding role of government (eg, "...It used to be that, when a person was an adult, then he/she was in charge of his/her own actions. Now the Nanny State wants to control our actions..."). Arguments regarding allocation questioned why anti-smoking efforts were deemed more worthy of governmental attention than other health or policy issues such as other drugs or obesity (eg, "And just WHEN will we be seeing the same type anti-alcohol use billboards???"). Others questioned the evidence linking smoking to serious health outcomes (eg, "...everyone I have known to get cancer never smoked a cigarette in their lives...") or questioned the efficacy of the ads (eg, "Everyone in the USA has known that smoking is hazardous to your health since the 1960s at least"). In contrast to oppositional comments, which typically developed explicit arguments against the campaign, supportive comments tended to endorse the campaign indirectly, often through personal

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anecdotes and reactions. Many commenters shared detailed narratives about their own or others' experiences with smoking, smoking-related diseases, and with quitting. Others expressed the importance of not smoking, but varied greatly in their tone and civility; some offered support and encouragement to those attempting to quit while others expressed disdain for smoking. Finally, many responded to the content of the campaign, noting its personal impact or potential effectiveness.

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Table 2. Major themes within oppositional and supportive comments.

Themes	Comments
Oppositional comment themes	
Appropriateness (role of government)	
	The bottom line is that smoking is legal. If it is legal, then leave people alone. If people choose to ignore the health risks, then that is their business. Non-smokers should stop trying to control the behavior of others- smokers are no longer allowed to smoke indoors, near doorways, in bars, in public parks, etc. It used to be that, when a person was an adult, then he/she was in charge of his/her own actions. Now the Nanny State wants to control our actions.
	Liberty, do we even remember what the word means?
	What is really scary is the government interfering with peoples lives I read a book on this It was called The Communist Manifesto by Karl Marx
	People smoking is not the govt's business. if people smoke and get sick that is their problem and they can pay for the consequences.
	More big government. Why do we have to pay for this. Get the government out of our every day life,
Allocation	
	I think diabetes and obesity are a much bigger and more fatal problem right now. Smoking can cause weight loss :-)
	And just WHEN will we be seeing the same type anti-alcohol use billboards??? Alcohol kills more innocent people than tobacco and drugs COMBINED!!!
	this is all fine and dandy, when are they going to show cancer stricken patients dying in their last days from skin cancer from to much time in tanning booths
	What marketing effort is the CDC doing to reduce the damage alcohol is doing to our society?
Evidence	
	I know people who have smoked 50+ years and none of this stuff has ever happened to them. And they are still very healthy people! These commercials are a tad dramatic.
	How odd that the number of smokers has decreased (big-time), but people still get cancer (big-time). Matter of fact, everyone I have known to get cancer never smoked a cigarette in their lives. When are people going to figure out that we are going to die, no matter what we do?
	And how many smokers die of just old age?
	Buerger's Disease is very rare in the US and is more common in the middle and far east. I wish they would stop trying to buffalo people!
Effectiveness	
	Everyone in the USA has known that smoking is hazardous to your health since the 1960s at least.
	People are not going to stop smoking just because of commercials, pictures, or warning labels. Even watching a family member die due to lung disease or cancer doesn't seem to convince people smoking is bad.
	If all this is aimed at keeping young people from smoking it isn't going to work. Young people just don't have the ability to care about what might happen to them when they are old (30 is old to them). At least have the good sense to show what it does to their teeth and skin. Something that they care about now. Now is all young people care about.
	Only the person that smokes, can make the decision to quit..NONE ELSE, can convince them to quit, NOT ADS,,NOT Family or friends or strangers..ONLY the FEAR in their own souls can make them quit!!!
Supportive comment themes	

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Themes	Comments
Personal stories	
	I had my last cigarette during my first heart attack in 1991. Gained a bunch of weight but I'm still kickin' in 2012.
	My mother died recently of congestive heart failure brought on by over 60 years of smoking. When My wife and I started cleaning her house for sale. It took over 4 weeks to just clean the tar and nicotine from the walls, ceilings, appliances, etc. Still didn't get it all. Once white curtains were dark yellow/brown. Her lungs had to look the same way. Bless you all.
	My dad has stopped smoking after smoking for 30+ years and I could not be any happier that he has.
Support for quitting/anti-tobacco	
	Good luck to anyone who is trying to stop wish you nothing but the best!
	People stop Smoking !
	I can't believe in this day and age people still smoke....
Reactions to ad content	
	I just saw the commercial with Terrie yesterday....I am still haunted. The scary and sad thing is quitting is so very hard and you never think things like that will happen to YOU! This PSA was probably one of the "best" I have ever seen.....I hope it helps a lot of people.
	These commercials are very effective. I quit over ten years ago, but if I had not, these new anti-smoking commercial would definitely make me want to.
	Very powerful! Thumbs up!

Table 3 depicts the overall levels of supportive and oppositional comments across the 27 media pieces that focused on the campaign. We excluded 297 comments from analysis on the basis that their valence was coded as unclear or irrelevant, leaving 1073 comments. Overall, 555 comments (51.72%) were coded as oppositional while 518 (48.28%) were coded as supportive of tobacco control. The fraction of oppositional comments was higher among those that mentioned Tips specifically (57.6%, 316/548), for stories posted to news sections of websites (73.6%, 290/394), and for stories that did not include videos from the Tips campaign (65.6%, 242/369). Reply rates were higher for comments with oppositional valence (1.6 vs 1.3 replies per comment). Reply rates were also higher for comments that did not mention the campaign specifically (1.7 vs 1.3 replies per comment).

Table 3. Characteristics of supportive and oppositional primary comments across Tips-focused stories (N=1073).

Characteristics	Opposition, n/N (%)	Support, n/N (%)
Total	555/1073 (51.72)	518/1073 (48.28)
Reply rate	1.6	1.3
Tips mention	316/548 (57.6)	232/548 (42.3)
No mention	239/525 (45.5)	286/525 (54.5)
Blog	265/679 (39.0)	414/679 (61.0)
News	290/394 (73.6)	104/394 (26.4)
Includes Tips video	313/704 (44.5)	391/704 (55.5)
No Tips video	242/369 (65.6)	127/369 (34.4)

Discussion

Principal Findings

We examined online earned media generated by the 2012 CDC Tips From Former Smokers campaign by compiling a diverse sample of leading online news outlets and blogs. We sought to summarize coverage of the campaign as well as indicators of public engagement. The volume of earned media coverage generated about Tips was fairly limited; we identified 36 pieces that mentioned the campaign, of which 27 were focused on Tips. Across our sample of 14 leading online news sources and blogs, most coverage clustered closely within a day of campaign launch. Our content analysis indicated that the news and blog pieces did not deviate greatly from the campaign press release. Media coverage of the campaign (including blog postings) generally included a set of core content with many pieces using visuals (photos or video) seemingly to provide exposure to or understanding of the ads' graphic nature. The nature of the coverage did not suggest deep engagement with the issue on the part of journalists or bloggers. Earned media is sometimes seen as a way to develop understanding of an issue beyond what can be achieved in a 30-second or 60-second ad, but the news and blog pieces themselves provided little evidence of such development.

While the extent of earned media coverage about Tips may have been limited, even this small set of articles and postings generated notable audience engagement in the form of social media shares and comments posted on news/blog sites. The

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stories yielded over 9000 comments and almost 9000 Facebook likes, in addition to diffusion and dissemination of content via a variety of other social media channels. Such levels of audience engagement may indicate that the campaign and the issues it raises are salient to a sizable number of people [34]. The social media and comment data available adjacent to a story may also serve to indicate story importance (agenda-setting) to other audience members, with a potential cyclical effect. No directly comparable studies are available with which to compare the engagement levels found in this research. However, although drawn from different sources and related to different topics, two prior studies did suggest a much lower level of commenting on average than was found in this study [25,35]. Our research may provide a baseline that future studies can build upon to analyze audience engagement.

Levels of engagement varied considerably between sources, ranging from fewer than 100 shares/likes/comments to several thousand for a single piece (on the CNN site). Notably, not all sites facilitated user engagement in the same way; FoxNews and USA Today, for example, enabled comments only on a subset of the stories they posted. If audience engagement is to become part of how we conceptualize earned media, it is important to better understand why some sites generate far more active engagement than others, and the rationale behind decisions by some sites not to facilitate certain sharing or commenting mechanisms. Such insight could lead to targeted efforts to generate interest on the part of key journalists/writers who serve as gatekeepers to extensive social networks for information diffusion.

The review of user-submitted public comments revealed that they did not universally reference the campaign directly and many had unclear valence. Only about half of comments explicitly referenced the Tips campaign, although most others did include more general discussion of the role of government, the value of government-funded health campaigns, tobacco control policy, and health effects of tobacco use (see Multimedia Appendix 1). In some cases, no clear link to tobacco control (very broadly defined) could be discerned. Furthermore, we could not discern the valence of 297 of 1370 coded comments (21.68%) either because they were ambiguous or off-topic. Some of these off-topic comments might be seen as “trolling” or “spam” but, in any case, it was difficult to assess any relevance to the campaign other than the presence of negative noise [14].

There was an almost even split between the valence of comments across all Tips-focused pieces between those that were oppositional to a public health position (51.72%, 555/1073) and those that presented a supportive stance (48.28%, 518/1073). Thus, these data suggest that raw counts of audience engagement would be of limited utility to assess the likely effectiveness of earned media in supporting a campaign; by no means did all comments indicate support for the campaign or the issues it touched upon (including acknowledgement of the harmful effects of tobacco). The fact that comments explicitly referencing the Tips campaign were more likely to espouse an oppositional perspective suggests that the campaign itself may be more challenging than tobacco control more broadly conceptualized, or perhaps that oppositional comments reflected a more considered effort at argumentation. It is possible that the Tips campaign may be effectively pushing against oppositional commenters’ opinions and knowledge in such a way as to move public opinion over time. Alternatively, recent research suggests that some common public health messaging approaches not only fail to influence target populations as intended but may in fact strengthen opponents’ resolve [36]. The variety of online public forums may provide an efficient avenue for such parties to quickly register their opposition and to advance counter-arguments. Accordingly, when crafting press releases, it is important to consider the arguments that will inevitably surface in relation to tobacco and tobacco control (smoking as an issue of individual liberty, for example) and address these in relation to any specific story. This point also speaks to the importance of agenda-setting and framing of messages about the campaign; for example, a story may or may not compare levels of campaign advertising spending to the amount spent on tobacco advertising and may or may not address the issue of individual liberties, and so forth.

Our analysis of the relationship between website and story features and levels of supportive and oppositional engagement revealed both surprising and unsurprising findings. Consistent with our expectations, we found that stories that included video from the Tips campaign were associated with more supportive commentary, suggesting that exposure to the ads themselves may have achieved positive influence. In contrast, we were surprised to find that oppositional comments were more prevalent in response to news stories as compared with blog posts. Further comparison of the nature of commentary in response to blogs (which are explicitly opinionated) versus news pieces is warranted to fully understand the value of each to shaping public discourse. There were also differences in comment valence by website, with comments on Yahoo more likely to be supportive than those on MSNBC or CNN. Such differences are difficult to explain from this analysis, and the findings do not align easily with the political perspective espoused by these various news sources. Perhaps these findings point to more spam/troll activity on some sites than on others.

Developing effective methods for tracking news media and consumer responses to public health campaigns is critical for public health efforts. An analysis of the interactive online environment provides an opportunity for the public health community to monitor sentiment in real time, identify the most productive platforms and pathways for information sharing, and anticipate and address points of resistance. This paper is focused on earned media as it manifests in online outlets.

Limitations

We faced several limitations in conducting this research. First, because we limited our analysis to a subset of news and blog websites, we are unable to provide a comprehensive view of online earned media related to the Tips campaign. In measuring public engagement, we were constrained by the fact that the sample websites did not have uniform ways of reporting engagement metrics, and some metrics were not reported at all by some sites. Although the New York Times stories we collected were likely associated with sharing via social media such as Twitter, the number of shares was not reported alongside

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these stories at the time of data collection. We also did not characterize login procedures or standards of anonymity among the websites we examined, although these features may affect decisions of whether and how readers respond [26,37,38]. Further, although we characterized the major themes appearing in campaign coverage, we did not examine whether different ways of framing the campaign affected the level and type of audience engagement. Given the websites' varying standards of reporting commenters' names and the possibility that a commenter might post under multiple names or accounts, we also could not characterize the distribution of total comments across unique commenters. Our content analysis of commentary was limited by our difficulty in interpreting some comments, especially given their variety and informality of language and potential for sarcasm, perhaps contributing to our marginal kappa score for the unclear/irrelevant valence category [39]. Replies to existing comment threads were particularly ambiguous, and thus we excluded them entirely. Furthermore, there is some difficulty in interpreting the levels of support and opposition we identified since it is not known to what extent commenters represent the general population or even each outlet's readership. We also do not know whether commentary reflected any organized efforts to promote an agenda with regard to tobacco control or the Tips campaign, although we did not detect evidence for this such as repeated blocks of text across comments. Finally, the content and valence of comments are likely to influence how stories are interpreted, but it is further unknown what fraction of readers consults comments, and this is likely to vary by outlet.

Conclusions

The large scale and graphic nature of the Tips campaign gave it potential to obtain important levels of earned media on both traditional and online platforms. While the campaign may have received limited coverage on either online news or blog sources, earned media that did cover Tips generated significant engagement among online audiences. To extend their reach and impact, future tobacco control campaigns should include advocacy efforts to capture the attention of a wider set of journalists and opinion leaders in order to build earned media and facilitate productive public engagement.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplemental table showing online news and policy blog coverage of CDC's "Tips From Former Smokers" Campaign. Stories primarily focused on CDC's Tips From Former Smokers Campaign.

[PDF File (Adobe PDF File), 116KB - jmir_v17i1e12_app1.pdf]

Multimedia Appendix 2

Supplemental table showing stories not primarily focused on CDC's Tips From Former Smokers Campaign.

[PDF File (Adobe PDF File), 79KB - jmir_v17i1e12_app2.pdf]

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Abbreviations

CDC: Centers for Disease Control and Prevention
PSA: public service announcement
Tips: Tips From Former Smokers campaign

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Original Paper

Exploring How the Tobacco Industry Presents and Promotes Itself in Social Media

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Abstract

Background: The commercial potential of social media is utilized by tobacco manufacturers and vendors for tobacco promotion online. However, the prevalence and promotional strategies of pro-tobacco content in social media are still not widely understood.

Objective: The goal of this study was to reveal what is presented by the tobacco industry, and how it promotes itself, on social media sites.

Methods: The top 70 popular cigarette brands are divided into two groups according to their retail prices: group H (brands with high retail prices) and group L (brands with low retail prices). Three comprehensive searches were conducted on Facebook, Wikipedia, and YouTube respectively using the top 70 popular cigarette brands as keywords. We identified tobacco-related content including history and culture, product features, health warnings, home page of cigarette brands, and Web-based tobacco shops. Furthermore, we examined the promotional strategies utilized in social media.

Results: According to the data collected from March 3, 2014 to March 10, 2014, 43 of the 70 representative cigarette brands had created 238 Facebook fan pages, 46 cigarette brands were identified in Wikipedia, and there were over 120,000 pro-tobacco videos on YouTube, associated with 61 cigarette brands. The main content presented on the three social media websites differs significantly. Wikipedia focuses on history and culture (67%, 32/48; $P<.001$). Facebook mainly covers history and culture (37%, 16/43; $P<.001$) and major products (35%, 15/43), while YouTube focuses on the features of major tobacco products (79%, 48/61; $P=.04$) and information about Web-based shops (49%, 30/61; $P=.004$). Concerning the content presented by groups H and L, there is no significant difference between the two groups. With regard to the promotional strategies used, sales promotions exist extensively in social media. Sales promotion is more prevalent on YouTube than on the other two sites (64%, 39/61 vs 35%, 15/43; $P=.004$). Generally, the sale promotions of higher-cost brands in social media are more prevalent than those of lower-cost brands (55%, 16/29 vs 7%, 1/14; $P<.001$ for Facebook; 78%, 28/36 vs 44%, 11/25; $P=.005$ for YouTube).

Conclusions: The prevalence of cigarette brands in social media allows more pro-tobacco information to be accessed by online users. This dilemma indicates that corresponding regulations should be established to prevent tobacco promotion in social media.

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KEYWORDS

cigarette brands; promotional strategy; social media; tobacco control; tobacco promotion

Introduction

To fight against diseases associated with the use of tobacco products—one of the biggest public health threats the world has ever faced—the World Health Organization's Framework Convention on Tobacco Control introduced a series of measures to implement effective strategies for tobacco control. For example, the packaging and labeling of tobacco products need to carry health warnings describing the harmful effects of tobacco use [1] and terms (such as "low tar", "light", or "mild") that are misleading, deceptive, or likely to create an erroneous impression about tobacco products are prohibited [1].

However, the partial bans prohibiting the advertising and promotion of tobacco products in traditional marketing made the tobacco industry divert to social media with indirect marketing tactics [2]. With more and more people embracing social media sites, such as Facebook and YouTube, the commercial potential of social media with tens of millions of potential consumers connected is emerging. The popularity of social media such as Facebook and YouTube presents the opportunity to raise the visibility of tobacco products and promote tobacco use. A recent study found that British American Tobacco employees were taking advantage of social networking sites to promote the company's products [3]. On YouTube, many users are exposed to pro-tobacco videos ranging from product reviews to smoking fetish imagery to tobacco-related scenes [4-7]. Obviously, tobacco companies stand to benefit greatly from the marketing potential of social media, without putting themselves at significant risk of being implicated in violating any laws [4].

Many social media sites have policies that outlaw the promotion of tobacco products on their advertising networks. Facebook's advertising policies claim that ads may not promote or facilitate the sale or consumption of illegal or recreational drugs, tobacco products, or drug or tobacco paraphernalia [8]. Advertisements and commercial content (including Page post content) on Facebook fan pages are subject to these advertising guidelines as well [9]; for YouTube, users are allowed to flag "inappropriate" videos [10]. However, it is still hard to regulate indirect tobacco promotion online.

To regulate tobacco promotion activities in social media, it is necessary to uncover the kinds of information being delivered and how they are presented in social media. This paper examines the top 70 popular cigarette brands and investigates the prevalence of promotion of these cigarette brands in social media. The present study has two specific aims. First, it provides a comprehensive understanding of the kinds of information being delivered in social media for tobacco promotion. Second, it investigates the promotional strategies used. Given the unregulated marketplace for the tobacco industry in social media, useful insights might be gained to inform future regulatory policies by investigating how the tobacco industry presents and promotes itself in social media.

Methods

Data Collection

First, a set of cigarette brands was identified. To maximize the coverage of cigarette brands in our dataset, we collected cigarette brands from three perspectives: tobacco manufacturers, tobacco vendors, and cigarette smokers. According to the US Tobacco Control Act, manufacturers and vendors must be registered and provide a list of tobacco products being manufactured or distributed [11]. Therefore, we choose several official cigarette brand lists [12] and Web-based tobacco shops [13] to cover cigarette brands from the perspective of manufacturers and vendors. On the other hand, for smokers, favorite cigarette brands can be delivered in social media. We integrated the cigarette brands from user-generated data such as tobacco-related wiki webpages [14] and tobacco review websites [15]. This method not only provided many cigarette brands ranging from the multinational tobacco industry such as British American Tobacco to the domestic/local tobacco industry, but also constructed a representative dataset of cigarette brands including the top 10 best-selling cigarette brands in the world [16] and the best-selling cigarette brand in each country [17]. In total, we obtained 186 cigarette brands and counted the number of times that each brand occurs in those data sources respectively. Finally, we chose the representative brands according to the average of occurrence frequency, and got 70 representative brands from the collection of cigarette brands.

In addition, the retail prices of the top 70 cigarette brands were obtained from the price labels found in Web-based tobacco shops. Since there are many variants for each cigarette brand with different retail prices, for this paper we calculated the average retail price of each cigarette. According to the median of average retail prices, these 70 cigarette brands were divided into two groups: brands with high retail prices (group H) and brands with low retail prices (group L). The size of group H is 39, and 31 for group L.

Based on the 70 cigarette brands, three comprehensive searches of cigarette brands were conducted on Facebook, Wikipedia, and YouTube respectively, which are among the top 15 most visited websites in 2014 [18]. For Facebook, we focused on the fan pages named after these cigarette brands. A fan page is a public profile that enables users to share their business and products with Facebook users, where page likes, comments, and sharing are the most common interaction activities [9]. For Wikipedia, we conducted searches using the cigarette brands as keywords and removed websites unrelated to cigarette brands. Due to a huge number of video clips on YouTube, we reviewed the first 20 pages of search results for each brand to capture pro-tobacco video clips.

For Facebook and YouTube, we evaluated whether retrieved results were related to tobacco promotion by examining the page profiles personally. Manual checking of tobacco-related topics was also used in the previous work [4,19-21]. Specifically, the "About" section of profiles is used to determine

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whether the given fan pages are related to tobacco. The "About" section provides basic information about the fan page, such as the goals of the page, location, operating hours, email address, mobile phone number, and product information. In addition, the website links such as the home pages of the given brands may be provided as well. According to the retrieved results, the majority of them were written in English. However, some non-English content written in Italian, German, French, and even Arabic was obtained as well. For the non-English content, we determined whether or not it was pro-tobacco based on the pictures or videos clips embedded in the posts. For a given fan page on Facebook, if the majority of multimedia content including pictures and video clips was pro-tobacco, the fan page was regarded as a pro-tobacco fan page. For YouTube, if content such as images of young men and women smoking, smoking sexual fetish scenarios, smoking animals or cartoon characters, logos of cigarette brands, and cigarette reviews were presented, the video clip was grouped as pro-tobacco. Content that didn't show pro-tobacco pictures or videos was excluded directly. For non-English content, sites that didn't show pro-tobacco pictures or videos directly were excluded. Cigarette brands were coded if we identified at least one cigarette product through a distinct name or logo.

Measures

The data collection was conducted from March 3, 2014 to March 10, 2014. For the three social media sites, we manually reviewed and classified the user-generated data into five types: history and culture, major products, health warnings, company websites, and Web-based tobacco shops. The content of each type are presented in Table 1.

For Facebook, we reviewed the user-generated data (textual posts, photos, and video clips) and the "About" section of fan pages. In the "About" section of fan pages, the account owner can add different types of basic information about the page, which enables potential followers to quickly learn about the page. For YouTube, we reviewed the "About" section related to video clips as well. To classify the content of video clips, we reviewed video clips manually. The early commercial ads and non-pro-tobacco videos were excluded. For the URLs embedded in video clips, we accessed those websites and classified them as company websites or Web-based tobacco shops.

For tobacco promotional strategies, many researchers have examined how tobacco companies promote themselves. We summarized the most widely utilized strategies from existing literature [3,4,20-23] and analyzed what kinds of methods play important roles in tobacco promotion in social media. Specifically, we investigated the following five promotional strategies: brand promotion, sales promotion, fetish imagery, sponsorship, and misleading information. The descriptions of these five promotional strategies are presented in Table 2. To differentiate brand promotion and sales promotion, we checked the content presented in the profile. Brand promotion covered the following content: product launch time, origin of brand name, ownership, market share, slogan and ads, brand stories, achievements, and even the home pages from the tobacco manufacturing industry presented in social media. For sales promotion, tobacco is promoted with price discounts, coupons, free shipping, no tax, embedded URLs of tobacco shops, etc.

All classifications of content and promotional strategies were conducted according to Tables 1 and 2 by three coders cooperatively. The three coders voted for the categories of the retrieved data. When the three coders disagreed with each other, they discussed the categories and tried to reach consensus. If it was still difficult to achieve an agreement after discussion, the retrieved data was excluded from our dataset.

Table 1. Classification of user-generated data in social media.

Content	Description
History and culture	Product launch time; origin of brand name; ownership; market share; slogan and ads; brand stories; manufacturer and distribution location; achievements
Major products	Varieties of products; flavor; packaging; length; tar content, nicotine content, and carbon monoxide content; price
Health warning	Warnings about the side effects of smoking
Company websites	Home pages of tobacco companies
Web-based tobacco shops	URLs of Web-based tobacco shops

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Table 2. Description of promotional strategies in social media.

Promotional strategies	Description
Brand promotion	Company websites are embedded in the textual data or video clips; content about the history and culture of cigarette brands.
Sales promotion	Promote tobacco sales with price discounts, tobacco coupons, free shipping, no tax, and embedded URLs for tobacco shops, etc.
Fetish imagery	Images of young men and women smoking, smoking sexual fetish scenarios, smoking animals or cartoon characters, etc.
Sponsorship	Provide funds for sports matches, festivals, racing, etc. Eg, Formula One, tennis matches, music bands, and festivals are common places to see logos or brand names from the tobacco industry. In social media, lots of pictures and videos related to social events funded by cigarette brands are presented.
Misleading information	Slogans to smooth or blur the side effects of smoking. Eg, low tar content is emphasized to demonstrate the products are healthier.

Results

Classification of Content

As shown in Table 3, in total, 43 cigarette brands had created 238 fan pages on Facebook; 48 cigarette brands created articles on Wikipedia; while for YouTube, more than 120,000 video clips were associated with 61 of the given 70 cigarette brands (87%). The prevalence of cigarette brands in social media demonstrates that the tobacco industry is aware of the commercial potential of social media and embarks on tobacco promotion in social media.

The main content presented on the three social media websites is different. Wikipedia has a different purpose than the other two sites. Wikipedia mainly focuses on brand promotion with history and culture (67%, 32/48; P<.001) and major product features (56%, 27/48) instead of sales promotion (4%, 2/48); Facebook mainly focuses on history and culture (37%, 16/43; P<.001) and major products (35%, 15/43); while YouTube focuses on major products (79%, 48/61; P=.04) and Web-based shops (49%, 30/61; P=.004). Obviously, the content concerning major products plays an important role in social media to promote tobacco products. Many details about tobacco products including tobacco flavor, package, tar content, and varieties are presented, which may help potential buyers to quickly learn about product features.

Regulations about the health warnings on cigarette packaging are enforced by many countries. The health warning labels on cigarette packaging illustrate the health dangers of tobacco products. However, as shown in Table 3, the side effects of smoking are rarely presented in social media. By contrast, the home pages of tobacco corporations or Web-based tobacco shops are presented frequently. Tobacco sales promotions exist extensively on YouTube with embedded URLs of Web-based tobacco shops (49%, 30/61); 26% (11/43) for Facebook. The embedded URLs make it more convenient for potential buyers to access those websites and result in brand loyalty and tobacco consumption. Concerning the content presented in groups with high and low retail prices, there is no significant difference between the two groups (see Table 4).

Table 3. Classification of pro-tobacco content on Facebook, Wikipedia, and YouTube.

	Facebook	Wikipedia	YouTube	*P* value		
				Facebook vs Wikipedia	Wikipedia vs YouTube	Facebook vs YouTube
Number of brands	43	48	61			
History and culture, n (%)	16 (37)	32 (67)	5 (8)	<.001	<.001	.001
Major products, n (%)	15 (35)	27 (56)	48 (79)	.04	.03	<.001
Health warnings, n (%)	1 (2)	3 (6)	2 (3)	.04	.95	.47
Web-based tobacco shops, n (%)	11 (26)	2 (4)	30 (49)	.004	<.001	.004
Company websites, n (%)	11 (26)	11 (23)	4 (7)	.77	.02	.009

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Table 4. Differences in content presented in two tobacco groups[a].

	Facebook (n=43)			Wikipedia (n=48)			YouTube (n=61)		
	H	L	*P* value	H	L	*P* value	H	L	*P* value
Number of brands	29	14		31	17		36	25	
History and culture, n (%)	13 (46)	3 (21)	.10	22 (71)	9 (53)	.40	3 (8)	3 (12)	.97
Major products, n (%)	14 (49)	2 (14)	.01	20 (65)	8 (47)	.24	31 (86)	18 (72)	.30
Health warnings, n (%)	1 (3)	1 (7)	.31	2 (6)	1 (6)	.94	2 (6)	1 (4)	.78
Online tobacco shops, n (%)	10 (34)	2 (14)	.12	2 (6)	0 (0)	.14	19 (53)	11 (44)	.32
Company websites, n (%)	10 (34)	2 (14)	.12	8 (26)	3 (18)	.50	5 (14)	0 (0)	.02

[a]Group H (brands with high retail prices) and Group L (brands with low retail prices).

Promotional Strategies

Table 5 shows the tobacco promotional strategies utilized by these 70 cigarette brands in social media. Company website, fetish imagery, and sponsorship are more widely utilized for brand promotion; while sales promotion plays an important role in tobacco sales campaigns. In particular, URLs of Web-based tobacco shops are frequently embedded in the posts and profiles for sales promotions. For example, Winston, Black Devil, and Camel cigarettes provided the links of Web-based cigarette shops. Even though it is difficult to determine how many users accessed those given links, it is obvious that those links make it convenient for smokers to purchase cigarettes.

According to Table 5, sales promotion is more prevalent on YouTube with a share of 64% (39/61). The sales strategies include embedded URLs of online tobacco shops (49%, 30/61) and other sales methods including price discounts, tobacco coupons, and free shipping. Similarly, sales promotion is often adopted by Facebook as well (35%, 15/43). Furthermore, the tobacco industry misleads potential users with statements that their products are less harmful to one's health. Many brands use terms (such as "low tar", "light", "mild") to blur the numerous side effects and to create an erroneous impression about tobacco products by emphasizing the low tar content, nicotine content, and carbon monoxide content. For example, American Spirit marketed its products as being "100% Additive-Free Tobacco" and as being less radioactive cigarettes with organic tobacco. Many manufacturers provide product variants with reduced tar. In addition, the tobacco industry tends to promote cigarette brands with sponsorships of social events such as Formula One racing, music festivals, marathons, etc.

For sales promotion, tobacco industries also try to persuade users on Facebook to buy cigarettes, with many different approaches: (1) the administrators of fan pages use postings to lure followers to buy cigarettes online, and (2) some Web-based tobacco shops such as "cheap cigarette 4 you", "foreign cigarettes", and "buy cigarettes online Canada and USA" were linked with cigarette brands. Even the links directing to Web-based cigarette shops are posted on fan pages, which makes it easier for potential buyers to purchase cigarettes online by clicking on those links directly.

Compared with less expensive cigarette brands, expensive brands are more successful in brand promotion and sales promotion (see Table 6). They are more likely to embed home pages in Facebook pages (34%, 10/29 vs 14%, 2/14). More importantly, the sales promotions of expensive brands in social media are more prevalent than those of less expensive brands (55%, 16/29 vs 7%, 1/14; *P*<.001 for Facebook; 78%, 28/36 vs 44%, 11/25; *P*=.005 for YouTube). This implies that the marketing channels for expensive brands are more flexible and their distribution networks are more powerful.

Table 5. Comparison of promotional strategies on Facebook, Wikipedia, and YouTube.

	Facebook	Wikipedia	YouTube	*P* value		
				Facebook vs Wikipedia	Wikipedia vs YouTube	Facebook vs YouTube
Number of brands	43	48	61			
Brand promotion, n (%)	11 (26)	11 (23)	4 (7)	.77	.02	.009
Sales promotion, n (%)	15 (35)	2 (4)	39 (64)	<.001	<.001	.004
Fetish imagery, n (%)	11 (26)	2 (4)	22 (36)	.003	<.001	.25
Sponsorship, n (%)	4 (9)	9 (19)	6 (10)	.19	.12	.93
Misleading, n (%)	6 (14)	7 (15)	4 (7)	.94	.18	.23

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Table 6. Differences of promotional strategies in two tobacco groups[a].

	Facebook			Wikipedia			YouTube		
	H	L	*P*	H	L	*P*	H	L	*P*
Number of brands	29	14		31	17		36	25	
Brand promotion (%)	10 (34)	2 (14)	.12	8 (26)	3 (18)	.50	5 (14)	0 (0)	.02
Sales promotion (%)	16 (55)	1 (7)	<.001	2 (6)	0 (0)	.14	28 (78)	11 (44)	.005
Fetish imagery (%)	10 (34)	2 (14)	.12	2 (6)	0 (0)	.14	16 (44)	7 (28)	.09
Sponsorship (%)	3 (10)	1 (7)	.72	7 (23)	3 (18)	.87	5 (14)	2 (8)	.46
Misleading (%)	5 (17)	1 (7)	.31	6 (19)	2 (12)	.47	5 (14)	0 (0)	.02

[a]Group H (brands with high retail prices) and Group L (brands with low retail prices).

Discussion

Principal Findings

The intent of this study was to reveal what the tobacco industry presents and how it promotes itself on social media sites including Facebook, YouTube, and Wikipedia. Our findings show that the main content presented on the three social media websites is different. Wikipedia focuses on history and culture (67%, 32/48; *P*<.001). Facebook mainly focuses on history and culture (37%, 16/43; *P*<.001) and major products (35%, 15/43); while YouTube focuses on the features of major tobacco products (79%, 48/61; *P*=.04) and information about Web-based tobacco shops (49%, 30/61; *P*=.004). With regard to promotional strategies, sales promotions occur extensively in social media. Sales promotion is more prevalent on YouTube (64%, 39/61 vs 35%, 15/43; *P*=.004). Generally, the sale promotions of higher cost brands in social media are more prevalent than those of inexpensive brands (55%, 16/29 vs 7%, 1/14; *P*<.001 for Facebook; 78%, 28/36 vs 44%, 11/25; *P*=.005 for YouTube). This implies that the marketing channels for expensive brands are more flexible and their distribution networks are more powerful.

Prevalence of Cigarette Brands

The popularity of social media such as Facebook, YouTube, and Wikipedia has provided the opportunity for the tobacco industry to raise the visibility of tobacco products and promote tobacco use. On Facebook, 43 of the 70 cigarette brands have created 238 fan pages with 1,189,976 page likes and 19,022 posts. As shown in Figure 1, the post volume on fan pages is increasing steadily. The accumulating pro-tobacco content on Facebook poses a challenge for tobacco control. Although it is difficult to evaluate the impact of pro-tobacco content for starting or developing smoking habits, the potential is there due to the large number of Facebook users exposed to pro-tobacco content.

The statistical features of cigarette brands presented on Facebook are presented in Figure 2. The exterior labels illustrate all 43 cigarette brands on Facebook. The numbered ring indicates how many fan pages are named after the given cigarette brand. For example, 43 fan pages are named after Gold Flake; while Camel, Dunhill, Gauloises, and Pall Mall closely follow with over 10 fan pages. Pertaining to page likes, Lucky Strike overwhelms other brands with, in total, 172,862 page likes on 9 fan pages. Dunhill, Black Devil, and Camel are also popular cigarette brands with 120,696, 63,758, and 44,355 Facebook page likes respectively. In terms of post volume, Gold Flake, Lucky Strike, and Dunhill are the top 3 brands with 2981, 2651, and 2592 posts respectively.

Furthermore, we measured whether or not user interaction is active on the given fan pages by information entropy [24], which was originally introduced from information theory, where entropy is defined as the average amount of information contained in each message and is understood as a measure of uncertainty. In this paper, we use entropy to measure the uncertainty of user interaction in online tobacco-related communities. The users with higher entropy are regarded as active users and may have more powerful influence on the followers. In this paper, the term “interaction entropy” is equal to “entropy”. We use different colors to present the interaction entropy for a given cigarette brand. According to the interior sectors in Figure 2, Marlboro, Dunhill, Gold Flake, and Lucky Strike are the top 4 brands with higher interaction entropy. This demonstrates that Marlboro is the most active cigarette brand on Facebook to interact with Facebook users. Obviously, cigarette brands on Facebook succeeded in attracting Facebook users to interact on fan pages with latent brand promotion and sales promotion.

Furthermore, many fan pages try to enhance user engagement with multiple strategies, for example, attracting users with positive impressions. A page named “animal smoking durrys” posts a huge number of pictures that present smoking animals. This attracts many users to interact with this page via likes, comments, and reposting. Also, images of young men and women smoking are utilized to promote the idea that smoking is cool and fashionable. In addition, online user surveys were conducted on those fan pages. Questions such as “What made you start smoking and at what age?” and “Would you rather die young and smoke durries or have a long life without durries?” were posted and attracted hundreds of followers participating in the online interaction, thus increasing user engagement.

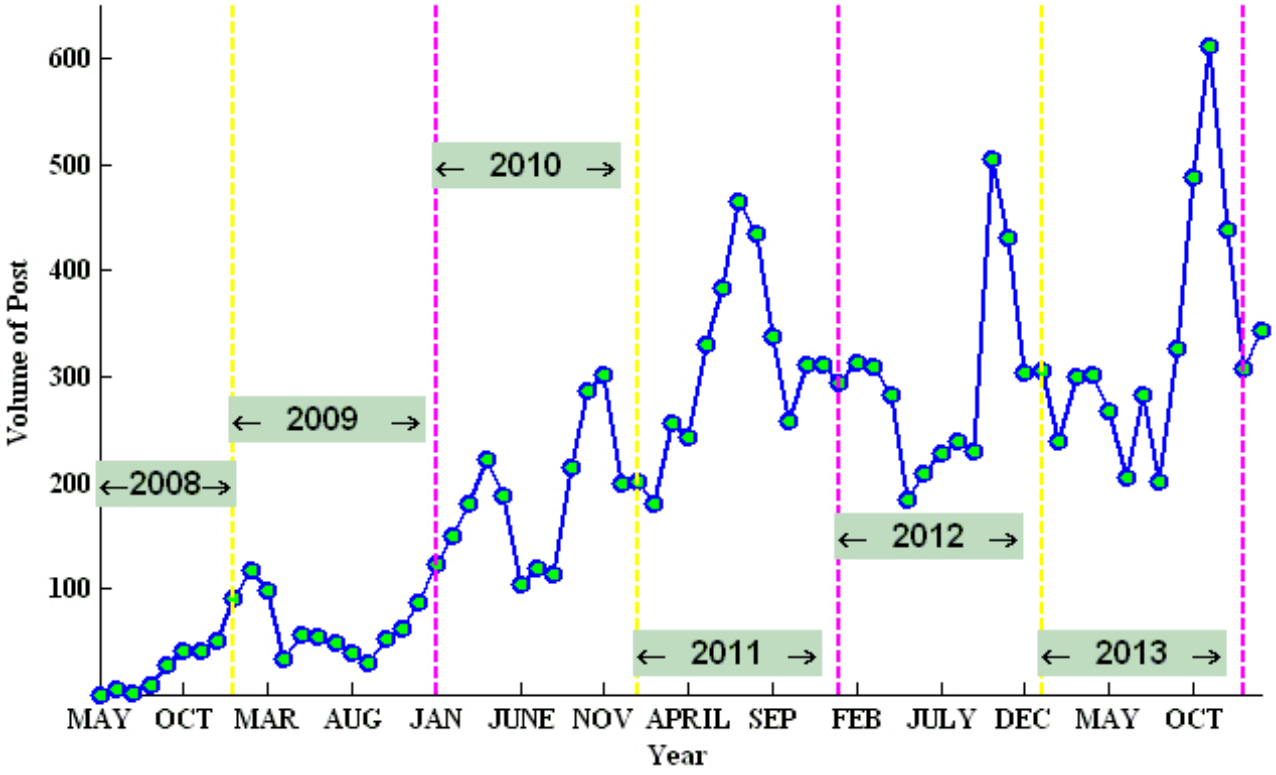
Additionally, many cigarette brand-related articles in Wikipedia could be accessed by Facebook users by Facebook likes. These articles cover lots of tobacco-related information such as history, brand culture, major products, etc. We analyzed the volume of page likes on these articles. In total, 876,183 Facebook users liked these 43 cigarette brands sourced from Wikipedia. As

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shown in Figure 3, Marlboro, followed by Lucky Strike with 119,185 and NewPort with 95,777, is ranked first with 428,646 Facebook fans. Davidoff and Benson & Hedges are ranked in the top 5 popular brands in terms of volume of fans as well. First, the wiki open platform provides an opportunity for the tobacco industry to promote corporation history and culture. Therefore, many articles are created by anonymous volunteers as a reliable source of crowd knowledge [25]. Second, a huge number of Internet users are exposed to cigarette brand-related articles. Even though the impact of articles on potential smokers is difficult to quantify, the aggregation effects are obvious with a large number of users in favor of these cigarette brands.

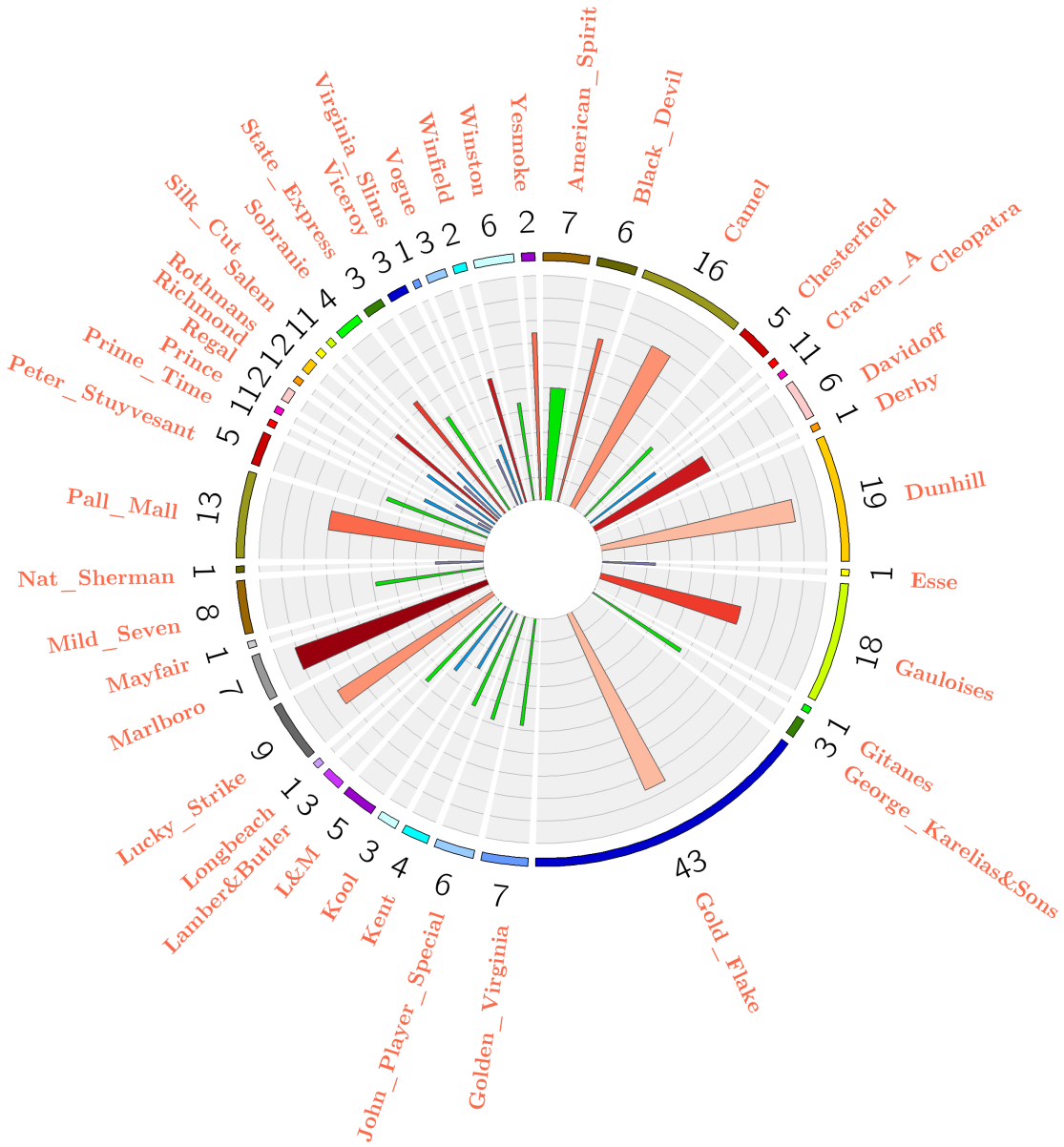
Through the analysis of user interaction on Facebook and the distribution of page likes for cigarette brand-related articles on Wikipedia, we aim to provide evidence to show the prevalence of cigarette brands in social media. With the popularity of social media such as Facebook, YouTube, and Wikipedia, a huge number of users are exposed to pro-tobacco content and even interact with such information. Obviously, the tobacco industry utilizes social media to raise the visibility of tobacco products and promote tobacco use. As exposure to tobacco promotion is positively associated with a higher smoking prevalence and may encourage smoking initiation [26], regulations about tobacco control in social media should be enforced as soon as possible by decision makers.

Figure 1. Temporal patterns of post volume on tobacco brand-related fan pages.



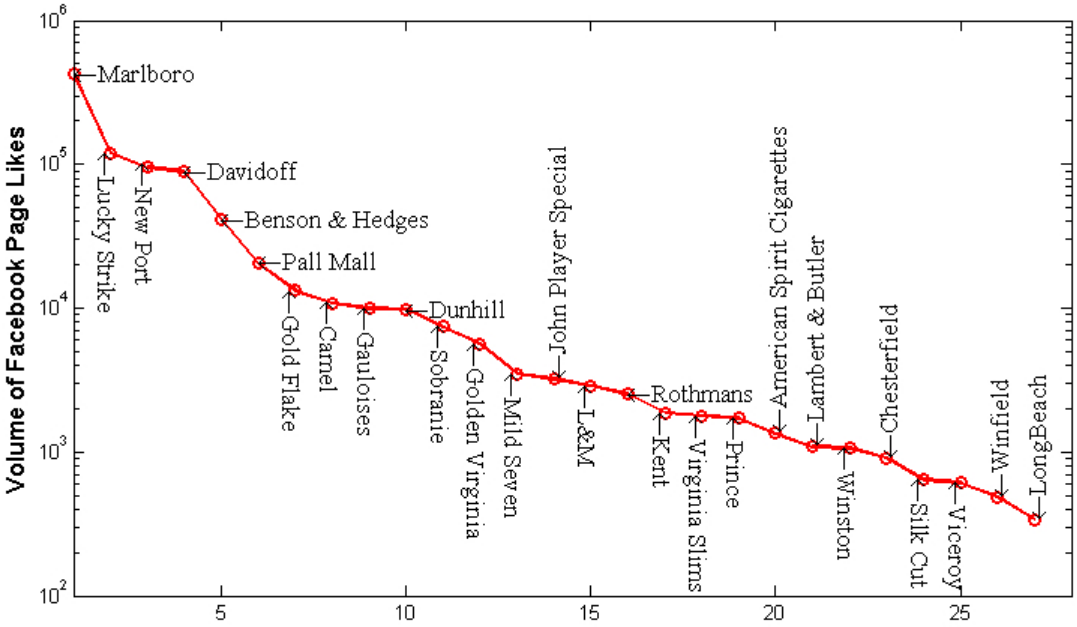
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Figure 2. Statistical features of tobacco brands on Facebook.



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Figure 3. Distribution of user likes for Wikipedia webpages.



Potential Methods

Through the analysis of Facebook fan pages, we found 61% of brands (43/70) are dedicated to tobacco promotion, especially for international cigarette brands such as Pall Mall and Mild Seven. Furthermore, a surging number of Facebook users have accessed and interacted with these fan pages. Although it is difficult to quantify how those pro-tobacco pages impact users' attitudes toward tobacco products, we are aware that the presence of cigarette brands in social media is recognized by the tobacco industry or pro-tobacco agencies. Freeman et al [3] investigated two cigarette brands, Dunhill and Lucky Strike, on Facebook. In their literature, there were 44 Facebook fan pages related to Lucky Strike with 28,309 fans in total. For Dunhill, it was 6 pages with 1903 fans. In our study, we found that there were 172,862 fans on 22 pages for Lucky Strike and 120,696 fans on 9 pages for Dunhill respectively. Although some Facebook fan pages have been deleted by their creators or administrators, the volume of fans who like those two cigarette brands has rapidly grown. The explosive growth of page fans demonstrates that social media has played an important role in disseminating cigarette brands.

Our findings also exhibit the loopholes in the mission of tobacco control. Many social media services have policies that outlaw the promotion of tobacco products on their advertising networks. However, those policies do not work well as they require seamless monitoring of content on those websites. The lack of consistent regulation of tobacco promotion, whether directly or indirectly, in social media means that pro-tobacco information is likely to be accessed and shared by anyone, anywhere, no matter what age.

From a legal perspective, we are still at a preliminary stage for tobacco control in social media. Although there is a tobacco advertising ban for social media, it mainly focuses on the advertising that appears as click-through advertisements that display on the sidebar of website pages. With the explosive growth of user-generated pro-tobacco content, we should pay more attention to the content with potential effects for tobacco promotion, as pro-smoking content online, regardless of whether it is commercial or personal in origin, could equally influence users [21].

From a technical standpoint, an online pro-tobacco content surveillance system is needed for the automatic collection and analysis of content relevant to tobacco [27]. With the progress of tobacco wars in social media, seamless online tobacco surveillance is vitally important to properly assess the current situation, the potential risks, and the kind of countermeasures to be taken. In addition, identification of pro-tobacco information in social media is crucial. Technically, the progress of text mining will assist in the discovery of potential pro-tobacco content. Text mining could be utilized to find tobacco-related postings from large-scale user-generated content and sentiment analysis could be employed to uncover the emotions toward tobacco. In addition, to distinguish user postings from industry postings, social media analysis could be introduced to find topological patterns such as clustering coefficients and popularity. Furthermore, social media should be utilized for tobacco control campaigns and tobacco cessation services. The cascade model of information dissemination in social media will help tobacco control campaigns to access hard-to-reach populations [28,29]. Social media can also be adopted for health promotion interventions [30].

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Acknowledgments

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Conflicts of Interest

None declared.

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Original Paper

Patient-Reported Outcomes and Therapeutic Affordances of Social Media: Findings From a Global Online Survey of People With Chronic Pain

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Abstract

Background: Patient-reported outcomes (PROs) from social media use in chronic disease management continue to emerge. While many published articles suggest the potential for social media is positive, there is a lack of robust examination into mediating mechanisms that might help explain social media's therapeutic value. This study presents findings from a global online survey of people with chronic pain (PWCP) to better understand how they use social media as part of self-management.

Objective: Our aim is to improve understanding of the various health outcomes reported by PWCP by paying close attention to therapeutic affordances of social media. We wish to examine if demographics of participants underpin health outcomes and whether the concept of therapeutic affordances explains links between social media use and PROs. The goal is for this to help tailor future recommendations for use of social media to meet individuals' health needs and improve clinical practice of social media use.

Methods: A total of 231 PWCP took part in a global online survey investigating PROs from social media use. Recruited through various chronic disease entities and social networks, participants provided information on demographics, health/pain status, social media use, therapeutic affordances, and PROs from use. Quantitative analysis was performed on the data using descriptive statistics, cross-tabulation, and cluster analysis.

Results: The total dataset represented 218 completed surveys. The majority of participants were university educated (67.0%, 146/218) and female (83.9%, 183/218). More than half (58.7%, 128/218) were married/partnered and not working for pay (75.9%, 88/116 of these due to ill health). Fibromyalgia (46.6%, 55/118) and arthritis (27.1%, 32/118) were the most commonly reported conditions causing pain. Participants showed a clear affinity for social network site use (90.0%, 189/210), followed by discussion forums and blogs. PROs were consistent, suggesting that social media positively impact psychological, social, and cognitive health. Analysis also highlighted two strong correlations linking platform used and health outcomes (particularly psychological, social, and cognitive) to (1) the narrative affordance of social media and (2) frequency of use of the platforms.

Conclusions: Results did not uncover definitive demographics or characteristics of PWCP for which health outcomes are impacted. However, findings corroborate literature within this domain suggesting that there is a typical profile of people who use social media for health and that social media are more suited to particular health outcomes. Exploration of the relationship between social media's therapeutic affordances and health outcomes, in particular the narration affordance, warrants further attention by patients and clinicians.

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KEYWORDS

social media; chronic disease; chronic pain; therapeutic affordances; patient-reported outcomes

Introduction

Reports of health outcomes from social media use in chronic disease management continue to emerge in academic literature. This paper presents findings from a global online survey that examined patient-reported outcomes (PROs) by people with chronic pain (PWCP) who use social media as part of their self-management. Previous articles report a positive outlook for the therapeutic potential of social media [1-4], yet many do so without examining what it is about social media use that produces such effects. Few examine PROs within a general framework that could account systematically for underlying mechanisms impacting health effects and health outcomes from social media use.

Our study draws from the behavioral psychology theory of "affordances" to explain this. Affordances refer to individual behaviors based on the relationship that exists between the individual and their environment [5]. The idea of affordances has previously been applied to new media technologies in the field of design [6-8]. Our research adapts the term as a way to describe the therapeutic mechanisms through which social media use may impact health outcomes. We therefore use the term "therapeutic affordances" throughout this paper to describe the factors that may underlie social media's impact on PROs. This phrase has previously been used in mental health and neurological rehabilitation research. However, its connotation was different [9,10]. For the purposes of our study, "therapeutic affordances" becomes useful to conceptualize the properties of different social media affording therapeutic effects.

Earlier work provided scope for this study through an extensive literature review and development of a research framework, within which our concept of therapeutic affordances is elaborated [11,12]. The findings reported here are intended to validate this earlier work and lay the groundwork for future testing of more targeted social media use in clinical settings. This study updates and expands research into the use of social media by people living with chronic disease, using PWCP as a case study. Chronic pain was chosen as a suitable subset of chronic disease due to the global burden it poses for health and society and because pain is often a major symptom of various chronic diseases and/or can co-exist as a chronic disease in its own right [13].

The aim of the survey was to better understand use of social media for self-management and what underlying therapeutic uses participants perceive to be most relevant to health outcomes. This therapeutic affordances perspective aims to advance research in the field of social media in health. It may prove useful to guide a more sophisticated approach to social media, tailored to the characteristics and preferences of different groups of patients, leading to better overall health outcomes in the management of chronic disease. We hypothesize that (1) health outcomes from social media use will vary according to demographic and health profiles of individuals, and (2) health outcomes from social media use will vary according to therapeutic affordances underlying use and platforms used.

Methods

Overview

This paper presents findings from analysis of quantitative data collected from a global online survey of PWCP, investigating PROs from social media use to manage chronic pain. It follows approaches to developing and evaluating conceptual models in health [14] and is compliant with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [15,16]. The Human Research Ethics Committee at the University of Melbourne approved this study (ID No. 1339414).

Survey Design

The survey was conducted using SurveyMonkey. It was a self-administered questionnaire of 240 questions, asking participants to provide quantitative and qualitative data about a variety of areas: demographics, health/pain status, social media use, therapeutic affordances, and PROs from use (Multimedia Appendix 1). The major sections of the survey were influenced by previous studies in this domain and validated survey models in chronic disease and chronic pain [17-20]. A full description of the survey design (and reference to other surveys conducted in this area) was the focus of another published paper [21]. The focus of this paper is on the quantitative data from the survey. Supplementary to this data were free-text responses, which are the subject of a separate paper [22].

A survey design expert from the Statistical Consulting Centre at the University of Melbourne was consulted regarding sample size, survey length, questions, potential bias, and recruitment [21]. One of the major issues discussed was survey fatigue, and 15-20 minutes was agreed on as an appropriate length. This was achieved using skip logic or adaptive questioning, as well as piloting the survey before opening the survey. Piloting was done through technology experts from the Department of Computing and Information Systems at the University of Melbourne and social media-using patients. This is described elsewhere in full [21].

Recruitment and Data Collection

Adults (18 or older), with chronic pain (3 months or greater) who used social media as part of self-management were invited to participate via social media channels. Google search was performed periodically from March 1 to May 20, 2013, to identify potential recruitment channels. Terms such as "online health networks", "online pain support communities", "chronic disease organizations", "chronic pain organizations", and "international pain organizations" were used. Searching was limited to English language. We also included common social networks and targeted active chronic pain groups such as those on Facebook, Twitter, Daily Strength, and PatientsLikeMe. Other influencers were contacted (at the support group/organizational level and individual level based on word of mouth).

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Each identified organization or group moderator was emailed for assistance. We made it clear that the survey was focusing on "pain interference" as a result of living with the condition in question. Each email contained a link to the survey, where the plain language statement and informed consent information could also be viewed. This allowed moderators to review the suitability of the study to their members. A recruitment video was also created by the study's primary investigator to complement the email, and the link was pasted into the email text [23]. If the moderator was willing to share the survey with their members, a link to the survey was placed on the websites of the groups, shared on social media, and included in newsletters where appropriate. Using social media for participant recruitment has been reported in academic literature [24-26], and a paper discussing our study recruitment was published elsewhere [21]. Participants were not incentivized to participate, and it was made clear that participation was voluntary. Relying on viral dissemination of the survey link via social media and not inviting participants directly via individual emails meant it was not possible to calculate response rate traditionally based on number of invitations and responses. However, based on the ratio of number of participants initiating the survey and those submitting the final page (218/231), a completion rate of 94.4% was obtained. The survey also prevented duplicate entries by preventing users with the same IP address to enter responses twice. It was open from May 21 to June 30, 2013.

Measures

Participant Demographics

The first domain asked participants about general demographic information (eg, gender, age, education, employment). These questions were taken from the World Health Organization's World Health Survey [17] for construct validity.

Health-Specific Information

Participants were asked questions about their health and chronic pain. Examples were "Do you suffer from chronic pain (pain over 3 month's duration)?" (with 3 months selected in line with definitions of chronic pain provided in [27,28]), "Have you been undergoing treatment for your chronic pain during the last year?", and "Have you been formally diagnosed with a chronic disease that has caused your pain?".

Health Status

Given the focus on chronic pain, the outcome measure we chose to examine health-related quality of life (HRQL) was the Patient Reported Outcomes Measurement Information System (PROMIS) "Pain Interference" item bank (PROMIS-PI). Unlike commonly used legacy measures, it demonstrates good reliability and validity across a range of chronic diseases, including chronic pain conditions, and shows moderate to strong correlations with other common outcome measures [18,29]. All statements employed a 5-point Likert scale; 16 "pain interference" statements were included and 1 "pain behavior" item to measure pain severity.

Social Media Use by People With Chronic Pain and Perceptions of Therapeutic Affordances

This was the most comprehensive section of the survey. Participants were asked specifically about their use of social media in chronic pain self-management. For example, "In the last year, have you used social network sites when you go online for information, communication, or interaction about your chronic pain?". The statements that followed asked participants to provide details of the types of social media they used to manage their chronic pain, the activities they performed, perception of various therapeutic affordances, and whether they felt use of the platform had positively impacted various PROs. For example, "Do you feel that your use of social network sites has in any way helped your…?". Questions about therapeutic affordances were phrased to elicit perceptions about different underlying uses. They were designed to better understand the degree to which the therapeutic affordances are present and relate to PROs. Five therapeutic affordances of social media, qualitatively extracted from published literature review [11], were examined through 15 statements using a 5-point Likert scale, each consisting of three exploratory components (Multimedia Appendix 1). These measured (1) identity: preferences regarding identity disclosure, (2) flexibility: synchronous and asynchronous communication (as well as geographic freedom), (3) structure: guidance towards useful information and moderated interaction, (4) narration: sharing experiences of chronic pain, and (5) adaptation: frequency and type of use.

The same line of questioning was used for each platform, with participants requested to answer questions only for the platforms they used as part of self-management.

Data Analysis

The data were analyzed using statistical software package SPSS. Data analysis methods included descriptive statistical analysis, frequency counts, as well as cross-tabulation to examine any statistical associations between variables (either using Pearson's chi-square or the gamma statistic for ordinal-by-ordinal or ordinal-by-binary computations).

Data from social media platforms with less than 20 responses were excluded from any further analysis, due to low cell counts leading to poor statistics. Hence, no detailed statistical analyses are presented for photo sharing sites, tagging/aggregation sites, chat rooms, and virtual worlds.

To compare the interactions between all three variables (platform, outcome, and therapeutic affordance components), we ran a cluster analysis using Cluster 3.0 [30] with data coming from the statistical analyses of combined platform-outcome variables and the therapeutic affordance components. To facilitate visualization using heat maps, we used TreeView [31]. To emphasize the statistical relevance of the association between these elements during the visualization process, we applied the following data transformation: $X=2*Gamma*(-Log_2(P \text{ value}))$.

To represent the relationships between demographic characteristics and platform-outcomes, we applied a hierarchical clustering method on the transformed data from the combination of the three most used platforms and the two most reported

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positive health outcome domains with demographic characteristics. We used a similar approach to visualize associations among the individual components of each therapeutic affordance and platform-outcome data.

Results

Demographics and Health Characteristics

Data for this study were obtained from 231 individuals, providing a diverse and global dataset. More than half of participants were from Australia (55.4%, 128/231), followed by the United States of America (17.7%, 41/231) and United Kingdom (10.0%, 23/231). Other countries were represented in smaller numbers: Canada, Spain, New Zealand, Ireland, South Africa, China, Kenya, Pakistan, Burma, and Taiwan. Only 24.7% (57/231) of participants reported where and how they were made aware of the survey, with 6.5% (15/231) indicating through Chronic Pain Australia.

Participant demographics are presented in Table 1. Four of the 231 participants supplied no further information, and a further 9 answered "no" to the question "Do you have chronic pain?". The final dataset thus represented 218 completed surveys. The majority of participants were female (83.9%, 183/218). Age range varied, but the greatest representation was of 40-49 years olds (31.2%, 68/218). Over half (58.7%, 128/218) reported being married/partnered, and the cohort represented a largely well-educated population, with 67.0% (146/218) with a university degree and 24.8% (54/218) with a post-graduate degree also. Work status varied considerably, with 54.1% (118/218) "not working for pay". Of the 218, 116 answered the next question, with 75.9% (88/116) of those not working for pay indicating this was due to ill health. "Not working due to ill health" was greatest among 30-39 year olds (P=.05).

In regards to health status, 88.8% (190/214) reported a formal diagnosis of chronic pain by a health professional. We sought to examine what condition caused pain in each case; 77.1% (165/214) reporting being formally diagnosed with a chronic disease as the root of their pain. Of these, 55.1% (118/214) provided further details. Most reported was fibromyalgia (46.6%, 55/118), then rheumatoid arthritis (16.9%, 20/118), osteoarthritis (10.2%, 12/118), complex-regional pain syndrome (10.2%, 12/118), back pain (7.6%, 9/118), and diabetes (4.2%, 5/118). The remainder included various chronic diseases (ie, chronic fatigue syndrome, multiple sclerosis, and endometriosis). Participants reported various offline methods (in the last 12 months) for pain management. Most took medication (85.9%, 177/206) and saw a doctor (81.1%, 167/206) as primary management, with physical therapy/physiotherapy as the third most common method (59.5%, 102/206). Other responses supplied as free text included, but were not limited to, acupuncture and eastern medicines, other physical therapies (eg, remedial massage, chiropractic), exercise, surgery, injections/nerve blocks, and other self-management strategies (eg, cognitive behavioral therapy).

Table 1. Participant demographics (N=218).

Characteristics	n (%)
Gender	
Male	35 (16.1)
Female	183 (83.9)
Age range	
18-29	37 (17.0)
30-39	48 (22.0)
40-49	68 (31.2)
50-59	46 (21.1)
60+	19 (8.7)
Marital status	
Never married	48 (22.0)
Currently married/Partnered	128 (58.7)
Separated/Divorced/Widowed	42 (19.3)
Level of education	
High school or less	72 (33.0)
College/University completed	92 (42.2)
Post-graduate degree completed	54 (24.8)

Chronic Pain Status and Pain Interference

Pain interference (PI) was the primary pain outcome examined. Also included was one pain-behavior item, measuring pain intensity via a visual analogue scale. Most participants (90.6%, 184/203) rated their average day-to-day pain between 3 and 8 out of 10, with 62.6% (127/203) indicating pain of 6 or higher (mean 6.9, SD 1.9). Table 2 provides the cumulative percentage

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of participants reporting PI from "somewhat to very much" in the last 7 days. Reports suggested that activities of daily living (ADLs) and social health were most affected by pain. However, the three other PI domains were similarly reported. "Ability to stand (>30mins)" was the most reported physical limitation by participants.

Table 2. Impact of pain interference reported as "somewhat to very much".

Domain of pain interference (n responses)	Pain interference variable	Cumulative % of participants, n (%)
Cognitive (204)	Ability to take in information	140 (68.6)
	Sleep	155 (76.0)
	Concentration	155 (76.0)
Social (203)	Enjoyment of life	178 (87.7)
	Social activities	174 (85.7)
	Relationships with others	163 (80.3)
	Family life	149 (73.4)
ADL (204)	Day-to-day activities	174 (85.3
	Household chores	179 (87.7)
	Ability to work (including work at home)	167 (81.9)
Psychological (203)	Emotional burden	175 (86.2)
	Anxiety	152 (74.9)
	Depression	159 (78.3)
Physical (204)	Sit (>30mins)	147 (72.1)
	Stand (>30mins)	182 (89.7)
	Walk (>30mins)	174 (85.7)

Social Media Use

Overview

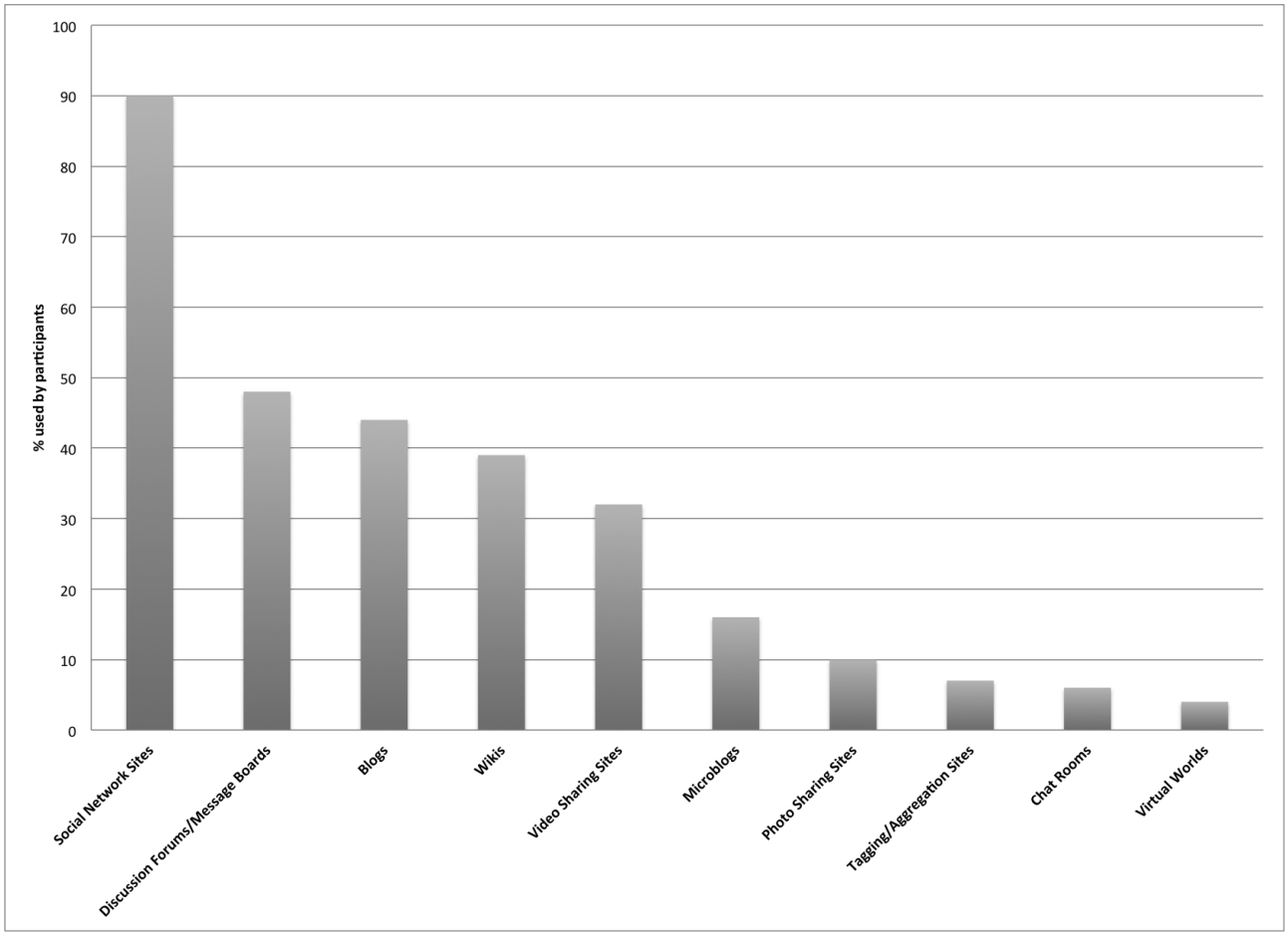
Participants were asked to respond to questions about only those platforms related to their own pain self-management. For this reason, response numbers varied for each platform. Results are ranked from most used to least in the last 12 months (Table 3; Figure 1). Social network sites (SNS) accounted for more than twice as many users as any other platform. Chi-square tests were conducted to examine whether chronic disease diagnosed correlated to platform used, but no significant associations were observed.

Table 3. Number of people with chronic pain using each social media platform.

Platform	Responses, n	"Yes" to use, n (%)
Social network sites	210	189 (90.0)
Discussion forums	180	86 (47.8)
Blogs	199	88 (44.2)
Wikis	191	74 (38.7)
Video sharing sites	183	60 (32.8)
Microblogs	185	29 (15.7)
Photo sharing sites	180	18 (10.0)
Tag/Aggregators	184	12 (6.5)
Chat rooms	177	11 (6.2)
Virtual worlds	183	7 (3.8)

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Figure 1. Social media platforms used by people with chronic pain (PWCP).



Perceived Value of Social Media as Part of Self-Management

We asked participants how much they valued different platforms for self-management of chronic pain (Table 4). Again, response numbers varied for each platform. The cumulative percentage of responses (somewhat to very much) showed that the platforms were valued by 85.7% (144/168) of SNS users, 88% (69/78) of discussion forum (DF) users, 83% (67/81) of blog users, 81% (50/62) of wiki users, 76% (41/54) of video sharing site (VSS) users, and 85% (22/26) of microblog users.

Table 4. Perceived value of social media platforms for chronic pain self-management.

Platform/Responses (n)	Not valuable, n (%)	A little bit, n (%)	Somewhat, n (%)	Quite a bit, n (%)	Very much, n (%)
Social network sites (168)	4 (2.4)	20 (12.0)	33 (19.6)	52 (31.0)	59 (35.1)
Discussion forums (78)	2 (2.6)	7 (9.0)	15 (19.2)	24 (30.8)	30 (38.5)
Blogs (81)	1 (1.2)	13 (16.0)	23 (28.4)	29 (35.8)	15 (18.5)
Wikis (62)	3 (4.8)	9 (14.5)	22 (35.5)	16 (25.8)	12 (19.4)
Video sharing sites (54)	1 (1.9)	12 (22.2)	14 (25.9)	17 (31.5)	10 (18.5)
Microblogs (26)	0 (0.0)	4 (15.4)	9 (34.6)	6 (23.1)	7 (26.9)

Frequency of Social Media Use

Frequency of use is presented in Table 5. Frequency was measured on a scale ranging from “at least daily to less than monthly”. SNS and microblog use appear more “daily” to “weekly”, whereas, blogs, VSS, and wikis appear to be used more “monthly” to “less than monthly”. DF use was more varied.

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Table 5. Frequency of use of social media platforms for chronic pain self-management.

Platform/Responses (n)	At least daily, n (%)	At least weekly, n (%)	At least monthly, n (%)	Less than once a month, n (%)
Social network sites (169)	60 (35.5)	70 (41.4)	24 (14.2)	15 (8.9)
Discussion forums (80)	11 (13.8)	29 (36.2)	18 (22.5)	22 (27.5)
Blogs (79)	7 (8.9)	21 (26.6)	28 (35.4)	23 (29.1)
Wikis (64)	1 (1.5)	6 (9.4)	19 (29.7)	38 (59.4)
Video sharing sites (54)	1 (1.9)	13 (24.1)	18 (33.3)	22 (40.7)
Microblogs (26)	11 (42.3)	9 (34.6)	3 (11.5)	3 (11.5)

Activities Performed When Using Social Media

Multimedia Appendix 2 provides a detailed account of the activities participants perform when using social media as part of chronic pain self-management. Most notable are the results favoring "passive" behaviors over "active" ones, that is, participants report engaging with activities and content produced by others more than creating and disseminating their own content.

Patient-Reported Outcomes and Social Media Use

Overview

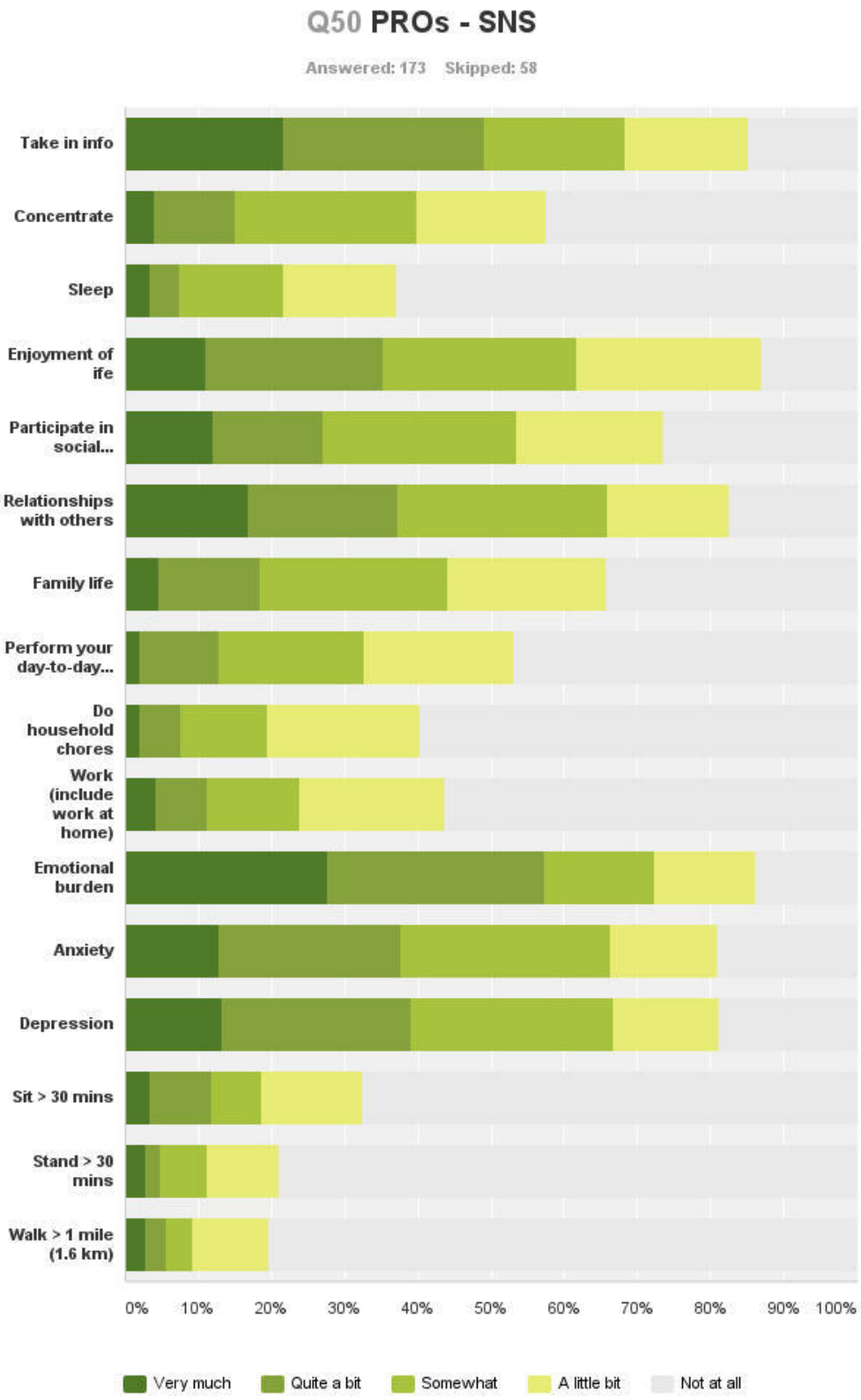
Graphical representations of PROs for each social media platform can be found in Multimedia Appendix 3. Figure 2 provides the PROs relative to SNS use as an example. The same PROMIS-PI scale was used to ask participants whether they felt social media had in any way "helped" various health outcomes. Number of responses varied considerably for each platform but also for each individual health variable assessed. The cumulative percentage of participants reporting "somewhat to very much" is used for each health variable to indicate a "positive" impact. The greatest number of reports indicating a positive impact from social media use was seen for psychological, social, and elements of cognitive health.

Psychological Health

Psychological health consistently demonstrated the greatest number of positive reports from social media use, with "emotional burden" most reported, followed by "depression" and "anxiety". Table 6 provides the cumulative percentage of reports (somewhat to very much) for all three domains of psychological health for each platform used. The smallest number of positive reports for psychological health benefits was for wiki use.

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Figure 2. Patient-reported outcomes from social network site use.



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Table 6. Positive patient-reported psychological health reports from social media platform use (somewhat to very much).

Psychological variable	Platform/Responses (n)	Cumulative % of participants, n (%)
Emotional burden	Social network sites (166)	120 (72.3)
	Discussion forums (64)	39 (60.9)
	Blogs (66)	41 (62.1)
	Wikis (40)	12 (30.0)
	Video sharing sites (42)	24 (57.1)
	Microblogs (20)	11 (55.0)
Depression	Social network sites (159)	106 (66.7)
	Discussion forums (57)	30 (52.6)
	Blogs (63)	40 (63.5)
	Wikis (38)	9 (23.7)
	Video sharing sites (39)	24 (61.5)
	Microblogs (19)	9 (47.4)
Anxiety	Social network sites (157)	104 (66.2)
	Discussion forums (59)	31 (52.5)
	Blogs (65)	37 (56.9)
	Wikis (42)	13 (31.0)
	Video sharing sites (41)	21 (51.2)
	Microblogs (20)	12 (60.0)

Social Health

Social health showed consistently positive PROs. Most reports were for “enjoyment of life”: using microblogs (72%, 13/18), SNS (62%, 100/162), VSS (59%, 23/39), blogs (55%, 35/62), DF (52%, 31/60), and wikis (18%, 7/39). Both “participation in social activities” and “family life” were also well reported. However, there were a greater number of cumulated responses for “relationships with other people” across all platforms: SNS users (65.8%, 106/161), followed by microblogs (55%, 11/20), blogs (51%, 31/61), DF (50%, 32/64), VSS (32%, 12/37), and wikis (8%, 3/36).

Cognitive Health

“Ability to take in new information” was consistently reported positively for all platforms. The greatest number of positive PROs was by VSS users (74%, 32/43). This was also the stand-out health outcome reported by wiki users (70%, 31/44). Reports from use of all other platforms were equally positive: microblogs (70%, 14/20), SNS (68%, 110/161), blogs (67%, 45/67), and DF (65%, 43/66). “Ability to concentrate” had fewer positive responses and those for “ability to sleep” were minimal.

Activities of Daily Living

Number of reports of a positive impact of social media use on the three components of ADLs was small. “Ability to perform day-to-day activities” was most reported. This can be seen in Multimedia Appendix 3.

Physical Health

Impact on physical health was also generally consistent across all platforms, showing only a relatively small number of positive reports. Positive impact on physical health was predominantly reported as “not at all”.

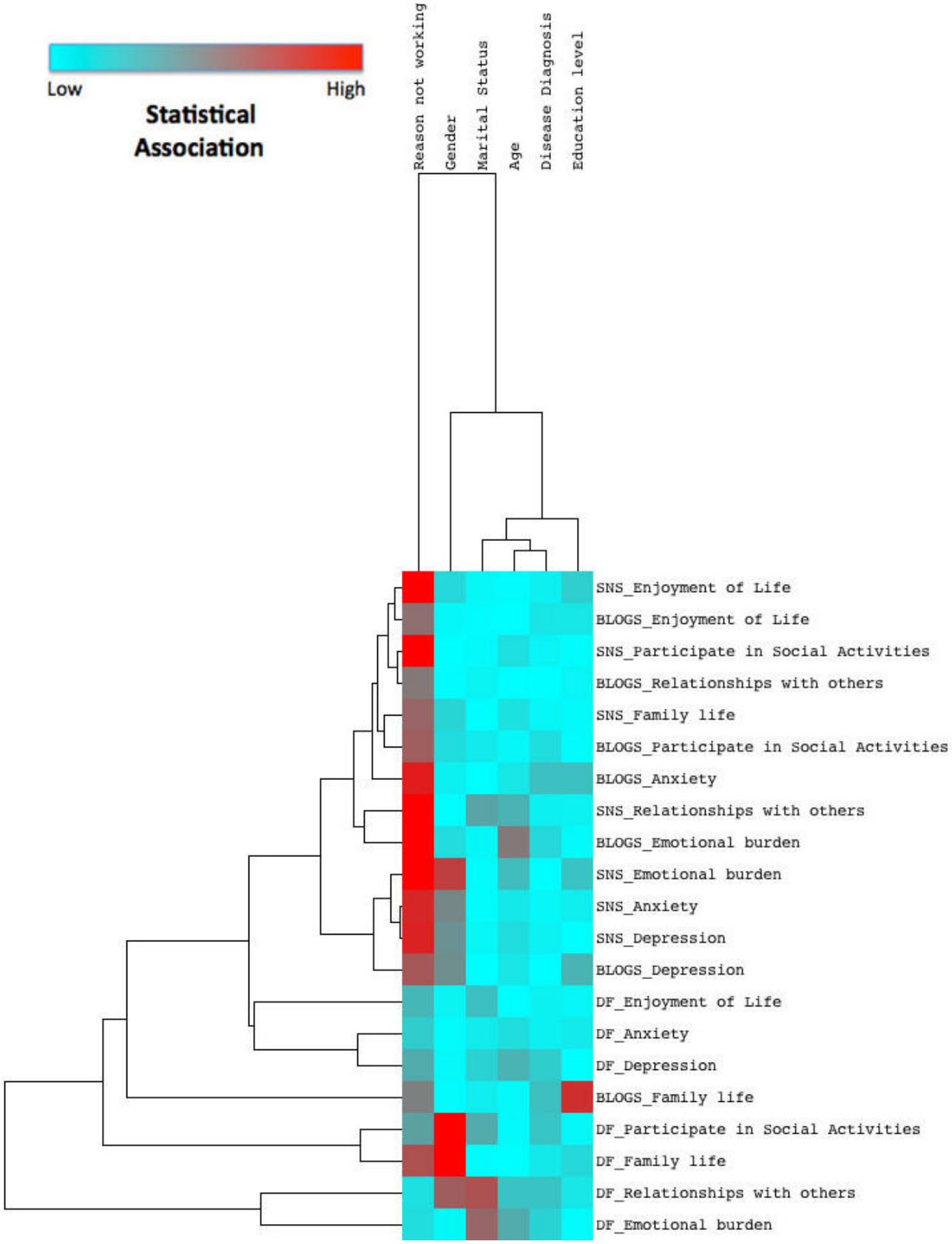
Association Between Demographic Characteristics and Patient-Reported Outcomes

Figure 3 shows the relationship within the explanatory variables (demographic characteristics) and within the combined platform-health outcomes reported for the three most reported platforms (SNS, blogs, and DF) and two most reported health outcomes (psychological and social). The color scheme is described in the legend. It ranges from blue to red, showing the strength of the statistical association between demographic characteristic and health outcome (red=strong association). Full statistical analysis can be found in Multimedia Appendix 4.

“Reason not working” (due to ill health in 76% of cases) was most strongly correlated to the PROs. It showed the highest statistical significance in regards to psychological and social health reports for all three most reported platforms, but with less significance in DF use than in SNS and blog use. Gender also showed statistical association with PROs. However, its influence appeared to be limited to psychological well-being reported from SNS use, and social life from DF use.

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Figure 3. Relationship between demographic characteristics and patient-reported outcomes.



Therapeutic Affordances of Social Media

Overview

The scale used to assess perceived value/preferences regarding the therapeutic affordances underlying social media use was different to that measuring PROMIS-PI, ranging from “strongly disagree” to “strongly agree”. Components of the “adaptation” affordance (frequency of use when flared or stable) were the exception, measured as “not at all” to “very often”. Results are again reported as cumulative percentages of participant reports.

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Largely positive reports within a narrow band included "control the amounts and sorts of things others know about them" and "ability to interact when it suits" (asynchronous communication). The "narration" affordance was most notable for its statistical association to PROs, with "learning from others' experiences" most significant.

Identity

The three individual components of "identity" asked participants to rate the following preferences: (1) preference to control the amounts and sorts of things others knew about them, (2) preference to remain anonymous, and (3) preference to know details about the people they were interacting with. The first was supported by the greatest number, with a cumulative percentage of responses (agree to strongly agree) ranging from 83% (20/24 microblog users) to 93% (39/42 VSS users) across all platforms. The second preference showed considerably more variability ranging from 29% (50/170 SNS users) to 83% (34/41 wiki users). Finally, the third preference was supported by a lesser number, 15% (6/41 wiki users) to 37% (63/172 SNS users).

Flexibility

Perceived value for the "flexibility" social media offer examined (1) asynchronous interaction, (2) synchronous interaction, and (3) geographic freedom, that is, using social media away from home. Cumulated positive responses were numerous for asynchronous interaction, ranging from 80% (57/71 blog users) to 92% (158/172 SNS users and 47/51 wiki users). Conversely, synchronous interaction was supported by markedly fewer participants, ranging from 0% (VSS, blog, and wikis users) to 8% (14/169 SNS users). Finally geographic freedom was supported by moderate numbers of users across platforms, ranging from 63% (46/73 DF users) to 71% (119/168 SNS users).

Structure

"Structure" examined social media's ability to guide participants to useful information and support. It also examined preferences for moderated and facilitated online interaction. Support for each component was highly varied: (1) filtering/guiding to useful information ranged from 61% (25/41 VSS users) to 81% (59/73 DF users), (2) preferred presence of health professional ranged from 68% (51/75 DF users) to 89% (51/57 wiki users), and (3) preferred presence of a moderator/facilitator ranged from 43% (17/40 VSS users) to 75% (56/75 DF users).

Narration

The "narrative" effect examined social media's ability to foster shared experiences of illness. Between 44% (19/43 wiki users) and 92% (71/77 blog users) perceived that social media are "effective platforms for recording stories of chronic pain". More specifically, participants were asked to indicate level of agreement regarding "sharing one's own experiences", which ranged from 18% (7/40 wiki users) to 82% (139/170 SNS users) and "learning from the experiences of others", which was considerably higher with 56% (24/43 wiki users) to 96% (69/75 microblog users). Table 7 highlights that "learning from others' experiences" was valued by more participants, and the range of responses across platforms was narrower (excluding wikis).

Table 7. Percentage (agree-strongly agree) of participants indicating therapeutic value of sharing experiences (one's own vs others').

Platform	One's own, n (%)	Others', n (%)
Social network sites	139 (82)	153 (91)
Discussion forums	50 (74)	69 (92)
Blogs	41 (61)	72 (94)
Microblogs	14 (58)	24 (96)
Video sharing sites	7 (20)	43 (90)
Wikis	7 (18)	24 (56)

Adaptation

"Adaptation" was investigated relative to (1) use changing dependent on stage of illness, which ranged from 52% (23/44 wiki users and 13/25 microblog users) to 71% (121/170 SNS users); and (2) frequency of use during flare-ups of pain or (3) frequency of use during stable pain. Table 8 contrasts the differences in frequency of social media use depending on pain status based on number of cumulated responses. As reported earlier in the results, social media use follows an occasional use pattern rather than often, regardless of disease status. The data in Table 8 show only a small difference in PWCP reporting in favor of using most social media (4/6 platforms) more frequently when pain is flared compared to when stable.

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Table 8. Percentage of participants describing usage frequency of social media platforms (fairly often-very often) according to pain status.

Platform	Flared-up, n (%)	Stable, n (%)
Social network sites	83 (48)	94 (54)
Discussion forums	38 (52)	26 (37)
Blogs	28 (39)	26 (36)
Microblogs	17 (74)	14 (64)
Video sharing sites	10 (23)	11 (24)
Wikis	15 (36)	6 (14)

Association Between Therapeutic Affordances of Social Media and Patient-Reported Outcomes

Figure 4 shows the relationship within the explanatory variables (components of therapeutic affordance) and within the combined platform-health outcomes reported. The color scheme is described in the legend. It ranges from blue to red, showing the strength of the statistical association between affordance components and platform-health outcome (red=strong association). Gray color represents the variables that were not computed because at the macro level no statistical significance was found between therapeutic affordance and health domain. Full statistical analysis can be found in Multimedia Appendix 5.

A trend on the right of the heat map is observed where two particular therapeutic affordances of social media provide the strongest association to reported health outcomes. All three components of the narrative (or, shared experiences) effect showed the highest statistical significance regarding the PROs. However, the effect is strongest for the component “learning from others’ experiences”. This is true for SNS, blog, DF, and microblog use. We note that the statistically significant PROs mirror those reported earlier: cognitive, social, and psychological health (with ADLs also seen in SNS and DF use). Figure 4 also shows that reports of more frequent social media use correlate with positive impact reports of social, psychological, and cognitive health in SNS, blog, DF, and wiki use. This appears to be regardless of whether pain was reported as stable or flared. However, reported “increased use during flares of pain” has a greater number of statistically significant relationships (this includes cognitive health from wiki use).

Notable outliers are also seen in Figure 4. For example, statistical significance is high in DF: preferences for presence of a facilitator correlate with positive reports for cognitive health. In microblog use, positively impacted components of social health correlate with positive reports for asynchrony and geographic freedom. Finally, in VSS use, components of identity or self-presentation control are strongly correlated with positive reports for ADLs and cognitive health (in particular, the ability to interact anonymously and to control the amount and sorts of information people know about them).

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Figure 4. Relationship between therapeutic affordances and patient-reported outcomes.



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Discussion

Principal Findings

Overview

The results presented in this paper provide a detailed representation of social media use in chronic pain management. Using a systematic approach to survey design, we have been able to gain a clearer demographic picture of PWCP who use social media as part of their self-management, typical health outcomes they report, and the therapeutic affordances underpinning these results. We explore each of these areas further.

Demographic Characteristics

This study's first hypothesis was that social media's therapeutic effect on PROs would show statistical significance correlating to particular demographics. While results did not confirm this hypothesis, they did corroborate findings in academic literature. With health status controlled for, the results show that users tend to be well-educated females, in relationships, aged 30-60 years. This finding has been reported elsewhere [19,32], and our study validates findings of a systematic literature review [11]. Notably, Figure 3 shows that "reason not working" (due to ill health in 76% of cases) was most closely associated with PROs and suggests that PWCP who are not working due to ill health may be well suited to report benefits from social media use. Disease diagnosis was another area flagged. Various conditions were reported. The number of PWCP with fibromyalgia was more than double most other reported conditions, with arthritis second. These are two major chronic diseases commonly reported in academic literature [32-36]. However, no statistical relationship was observed linking diagnosis, health outcomes, or platforms used.

Social Media Use—Platforms Used, Frequency of Use, and Nature of Interactions

Participants indicated a clear propensity for SNS. Several factors may contribute to this finding. First, SNS are often synonymous with Facebook and while we defined SNS as "online community platforms that allow users to connect and share interests and/or activities", we also provided examples to respondents, such as Facebook, MySpace, PatientsLikeMe, and Daily Strength. This may have biased responses in favor of Facebook. However, Facebook boasts hundreds of millions of users globally and hosts several disease-specific support groups, thus is an accurate representation of social networking [37]. Blogs, DF, wikis, and VSS were the next most used platforms.

Use of DF highlights an ongoing debate. Social media are recognized as services that allow for the principles of Web 2.0 to be realized and include SNS, blogs, VSS, and wikis [38,39]. However, discussion forums reside in a gray area. Despite being inherently social in nature, their architecture goes back to the early days of the Internet [40]. Although these forums have been surpassed by advances in social media, chronic disease sufferers and PWCP continue to show a propensity to use them (DF were the second most reported platform used: 48%, 86/180). This suggests that PWCP people may not be using social media to their full potential.

Findings regarding optimal frequency of social media use to positively impact PROs were inconclusive. Previous studies investigating frequency of Internet use by people with chronic disease hypothesized that health-related Internet use would show a pattern of relatively high frequency; however, their findings showed a much more occasional usage pattern [32]. This study supports these findings, with most people reporting weekly to monthly (or less) use. However, SNS and microblogs had the greatest amount of weekly to daily use reported. We did note that regardless of whether pain was flared or stable, increased usage frequency correlated to a greater number of positive PROs. This finding was replicated for all platforms and all health outcomes and thus is worthy of further attention.

Ongoing debate in academic literature surrounds whether health social media users are more likely to be active participants or passive users (posters or lurkers). Reports lean towards seeking of information or "lurking" over communication and engagement [32,41]. The results of our study go some way to support this, with a clear trend favoring passive use of social media (ie, reading or liking others' comments or posts). Earlier reports have suggested that active use is positively correlated to greater improvements in PROs, such as emotional health, compared with passive use [41]. However, the same study also iterates that lurkers also gained support through online activity (particularly through increased insight). Our study provides evidence that both active and passive social media users report positive impact on health outcomes.

Patient-Reported Outcomes From Social Media Use

The graphs in Multimedia Appendix 3 indicate similar patterns of positive impact on psychological, social, and components of cognitive health across each platform. This provides further validation of previous research PROs findings from social media use [11] and thus warrants further attention by patients and clinicians.

Positive impact on "emotional burden" was the most reported health outcome in our survey (most evident with SNS use). Psychological well-being is often the focus of chronic pain literature and given the emotional burden chronic pain can place on individuals, it is not surprising that interventions often target this [42]. Our results suggest that "enjoyment of life" and "relationships with other people" are the most notable social well-being outcomes reported. This is also consistent with several other studies that have reported improved social well-being from social media interventions, often presented in the same context as improved "empowerment" [35,43-45]. Finally, observations for cognitive health in our study suggest "ability to take in new information" is the primary cognitive variable positively impacted by social media use. This is often used interchangeably with "disease-specific knowledge" in the literature, with earlier reports from SNS use in chronic pain management indicating that disease-specific knowledge can improve and can lead to better self-management [42]. In this survey, the greatest number of positive reports for "ability to take in new information" was by VSS users, and this was also the most noteworthy outcome reported by wiki users. This

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speaks positively for the potential of using video platforms and wikis to impact "disease-specific knowledge".

Therapeutic Affordances

Hypothesis 2 was that health outcomes from social media use might be explicable according to therapeutic affordances underlying use across each platform.

Regarding the therapeutic affordance of "identity", participants were most concerned with "preference to control the amounts and sorts of things they share with others". Statistically, this was only significant for VSS use but was also noted within free-text survey responses.

"Flexibility" was observed via preferences for asynchronous communication (interacting at a time that suits). In microblog use, statistical significance was seen through positive reports for components of social health. The asynchrony provided by most social media has been well documented previously [33,46].

"Structure" measured via guidance to information and/or facilitated social media use showed varying levels of positive reports. While the trend was similar for all platforms, only DF use was shown to be statistically significant to positive reports for cognitive health. PWCP were positive about moderated/facilitated social media use, particularly for the involvement of health professionals in online interactions. This supports similar views that professional or facilitated online interactions diminish the risk of patients ending up with poor or misleading information [47]. Complementary reports suggest that moderation/facilitation increases engagement/participation and decreases attrition [48]. Given that our study suggested that increased use of social media statistically correlates to PROs, this may be clinically relevant and is worthy of further attention.

"Narration" was very well supported in our study, providing the most statistically significant associations to PROs. The emotionally cathartic effect of sharing experiences online has been widely reported [11,49,50]. Published reports of the power of the narrative effect explain that emotional health management can occur through actively sharing and/or learning from others' experiences [49,50]. Participants reported social media (excluding wikis) were effective platforms to record stories of chronic pain. Figure 4 shows that the narrative effect, in particular the more passive approach of learning from others' experiences, resulted in the broadest and strongest statistical significance, underpinning positive reports of health outcomes from SNS, blog, DF, and microblog use (psychological, social, and cognitive health). Given that "narration" was so statistically significant to the PROs, it appears to be a priority area for further research to validate its potential benefit to health outcomes.

Finally, "adaptation", measuring frequency of social media use relative to the user's circumstances, has already been discussed. "Occasional" use of social media has been most commonly reported in health self-management. However, results showed that reports of increasing frequency of social media use were statistically significant, correlating to reports of positive psychological, social, and cognitive health outcomes, in conjunction with use of SNS, blogs, DF, and wikis. Significance was observed for both flares and stable periods of pain. However, a greater number of statistically significant PROs were seen for increased use when pain has flared up. This provides preliminary evidence that social media use may offer greatest benefits to those experiencing exacerbations of pain.

Strengths and Limitations

Strengths

This survey forms part of a larger research project and framework being refined to generate evidence about health outcomes from social media use in chronic disease management [12]. It is broken down into sections: participant demographics, health/pain status, social media use, therapeutic affordances, and PROs. Standardized, validated, and global outcome measurement was chosen in the form of PROMIS in order to provide other researchers interested in social media for health with the means to generalize findings and apply this survey methodology to study various chronic diseases [18]. It is our belief that, to date, no similar surveys have used PROMIS for outcome measurement in this domain.

The study has provided a much-needed, comprehensive update examining social media use in a chronic disease management context and the health outcomes reported (using chronic pain as an example). Its strengths lie in its global spread of results and coverage of a range of social media compared to previous surveys completed in this domain [43,44,51]. Focus on the role of therapeutic affordances provides a unique perspective not previously applied to this type of research. This provides clinicians and patients with a new way to investigate and explain what may underpin patient-reported health outcomes from social media use.

Also, we have introduced a novel way to extract and analyze a large amount of complex data. Heat mapping is a technique previously unused in this type of research; we have yet to note any other examples of this type of data visualization tool being applied to findings from social media research. This analysis technique is normally reserved for mapping gene expression in more complicated genomics experiments. However, using the same principles of clustering and measuring distance between variables provides a meaningful approach to process and visualize the data from the study. It may be equally useful to show associations between variables in other social media research contexts.

Limitations

Response scale sensitivity was a persisting issue for data interpretation in this survey. Using a 5-point Likert scale, most questions aimed to delineate and grade the differences in perceived value of social media and how each impacts PROs. No previous questionnaires examining PROs from social media use in chronic disease have been formally validated or standardized. Regarding social media use, it was difficult to discern the difference between reports of somewhat/quite a bit/very much, agree/strongly agree, or fairly often/very often. It was for this reason that cumulative percentage of participant responses (ie, somewhat to very much) was used. Validity and reliability testing of survey instruments in social media research is warranted for future research to achieve greater accuracy, particularly to determine sensitivity between scale points.

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Our quantitative data collection methods did not make specific provision for the reporting of perceived adverse effects. Answers biased towards "no help" or "not at all" may actually have been indicative of deterioration or a "negative" impact. Therefore, a lack of reported adverse effects is not necessarily accurate. However, we purposely included the option for participants to provide open commentary free of coercion about each platform they used for chronic pain management [22]. Of all collected free-text responses, only a few suggested that social media may have a negative impact: augmenting sensations of hopelessness, potentiating pain behavior, and disseminating inaccurate information. The free-text responses collected in the survey are the subject of a separate paper, as previously stated [22].

Survey fatigue was another central issue relevant to study design, given that our survey asked questions about a wide variety of social media. This was pertinent for participants who reported using several platforms as part of their chronic pain self-management. Fatigue and concentration may have become factors. In order to attempt to mitigate this and potential attrition, not all questions were marked as mandatory. While this resulted in a good completion rate, it also meant that response numbers to different questions were inconsistent, as can be seen from the results. More recognizable social media (ie, SNS, blogs) received more answers than others (ie, virtual worlds, tagging/bookmarking sites).

It is also possible that not all therapeutic affordances of social media are derived from every platform, thus creating variability in response counts. We also acknowledge that individual interpretation of therapeutic affordances may differ. Refinement and clarification of the therapeutic affordances described in this study is the subject of a separate paper [22]. Missing data for therapeutic affordance related questions might also provide preliminary evidence that some social media are more conducive to certain therapeutic effects and not others. Regardless, missing data created a problem for data analysis and was the primary reason that results reporting centered on descriptive statistics rather than hypothesis testing. Some platforms received a low number of responses, and it was for this reason that formal analysis of photo sharing sites, virtual worlds, tagging/bookmarking sites, and chat rooms did not proceed. Missing data are also the reason that Figure 3 is an analysis of only the three most reported platforms and the two most reported PROs. This is similarly highlighted in Figure 4. Represented by the color gray, further statistical analysis was not conducted for many relationships. The decision was made to deconstruct and conduct more detailed analyses of relationships among only those therapeutic affordances and health domains that showed statistical significance at a macro level (eg, narration and social health). The heat map shows analyses conducted at a micro level, where the individual components of the therapeutic affordances were combined with the individual components of each health domain (eg, "learning from others' experiences" and "relationships with others"). We therefore acknowledge that statistical relationships may have existed but have not been identified and that these may have been significant to small groups. Non-computations should not be deemed to be insignificant purely based on reporting.

Finally, social media use by participants in this study represents a self-selecting population. This has been the subject of various published papers [25,52]. The participants in our survey were avid social media users, already using these tools as part of their chronic pain management. It has been suggested that those willing to participate in social media surveys are already more likely to be enthusiastic about the research in question [53]. Confounding self-selection bias was the fact that we were unable to verify exactly on which platforms participants were made aware of the research. Participants were given the opportunity to tell us through which chronic disease or chronic pain entity they were made aware. However, only 24.7% (57/231) answered this question. This may have created bias skewed towards answering questions for certain social media platforms over others. Representativeness is also relevant to this research. For example, participants were Internet literate and generally well-educated PWCP, which is not necessarily representative of the wider chronic pain population. This limits transferability to other chronic conditions and cautions against generalizing findings on an epidemiological level [25,52,54,55]. However, the cohort studied was the target group for this research. Given that results corroborate evidence of previous studies about the health effects of social media use in chronic disease management, we believe that this is an accurate representation of the reported effects of social media use by PWCP.

Recommendations and Conclusions

This research highlights several key considerations. Approaching social media from the perspective of what it therapeutically affords to users is not only a meaningful way to survey participants but provides a means to examine the underlying factors that may underpin reported health outcomes from use. Further research exploring the nature and impact of those therapeutic affordances is warranted. This chronic pain-focused research further validates previous research into health outcomes from social media use in chronic disease management [11]. However, its broader clinical application, generalizability, and scalability are yet to be confirmed. Questions remain as to whether findings about social media apply only to a niche subset of the chronic pain population or whether they are equally valid and applicable to a clinical-setting demographic of PWCP and people living with a variety of other chronic diseases. Further examination of the efficacy of social media use and their precise therapeutic affordances in clinical settings are an essential next step towards understanding whether and how social media can be targeted and tailored to meet far more individual needs for chronic disease self-management. Clinical work has recently begun and will help build and further strengthen evidence of the role of the therapeutic affordances in impacting health outcomes.

The aim of this study was to improve understanding of health outcomes reported by PWCP in relation to various therapeutic affordances of social media. While many statistically significant findings were observed supporting this aim, we conclude that our results to date do not prove the two hypotheses we formed. Our understanding of social media use to impact health outcomes is not yet mature enough to recommend such definitive use in clinical care. Our study has added to previous research, with findings highlighting positive impact on psychological,

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social, and cognitive health from social media use, and showing that much of the potential of social media for impacting such health outcomes lies in their ability to foster the narrative experience. The results of this study move the research agenda one step closer to a more evidence-based approach to social media use for health.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Survey instrument.

[PDF File (Adobe PDF File), 1MB - jmir_v17i1e20_app1.pdf]

Multimedia Appendix 2

Activities performed when using social media.

[PDF File (Adobe PDF File), 163KB - jmir_v17i1e20_app2.pdf]

Multimedia Appendix 3

Patient-reported outcomes and social media use.

[PDF File (Adobe PDF File), 297KB - jmir_v17i1e20_app3.pdf]

Multimedia Appendix 4

Demographic characteristics and patient-reported outcomes.

[PDF File (Adobe PDF File), 40KB - jmir_v17i1e20_app4.pdf]

Multimedia Appendix 5

Therapeutic affordances of social media and patient-reported outcomes.

[ZIP File (Zip Archive), 8KB - jmir_v17i1e20_app5.zip]

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Abbreviations

ADLs: activities of daily living
DF: discussion forums
HRQL: health-related quality of life
PI: pain interference
PROMIS-PI: Patient-Reported Outcome Measurement Information System—Pain Interference
PROs: patient-reported outcomes
PWCP: people with chronic pain
SNS: social network sites
VSS: video sharing sites

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Original Paper

Picture Me Smokefree: A Qualitative Study Using Social Media and Digital Photography to Engage Young Adults in Tobacco Reduction and Cessation

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Abstract

Background: Young adults have high rates of tobacco use compared to other subpopulations, yet there are relatively few tobacco interventions specifically targeted to this group. Picture Me Smokefree is an online tobacco reduction and cessation intervention for young adults that uses digital photography and social networking.

Objective: The main goal of the project was to determine the feasibility of engaging young adults in participating in user-driven, online forums intended to provide peer support and motivate critical reflection about tobacco use and cessation among this high-use, hard-to-reach population. A related aim was to explore the influence of gender-related factors on participation, in order to determine the need for online interventions to be tailored to the specific gender preferences reflecting young men and women's participation styles.

Methods: A total of 60 young adults ages 19-24 years who self-identified as current cigarette smokers or who had quit within the last year were recruited from across British Columbia, Canada, and participated in an online photo group on Facebook over a period of 12 consecutive weeks. A variety of data collection methods were used including tracking online activity, a brief online follow-up survey, and qualitative interviews with study participants. Data analysis involved descriptive statistics on recruitment, retention, and participation and qualitative (eg, narrative analysis, synthesis of feedback) feedback about participant engagement.

Results: Findings from this study suggest good potential for Facebook as an accessible, low-cost platform for engaging young adults to reflect on the reasons for their tobacco use, the benefits of quitting or reducing, and the best strategies for tobacco reduction. Young adults' frequent use of mobile phones and other mobile devices to access social networking permitted ease of access and facilitated real-time peer-to-peer support across a diverse group of participants. However, our experience of conducting the study suggests that working with young tobacco users can be accompanied by considerable recruitment, participation, and retention challenges. Our findings also pointed to differences in how young women and men engaged the photo-group intervention that should be considered, bearing in mind that in follow-up interviews participants indicated their preference for a mixed gender and "gender neutral" group format.

Conclusions: Tobacco interventions for youth and young adults should be embedded within the existing social networking platforms they access most frequently, rather than designing a stand-alone online prevention or intervention resource. This subpopulation would likely benefit from tobacco reduction interventions that are gender-sensitive rather than gender-specific.

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KEYWORDS

smoking cessation; tobacco use; young adults; Facebook; participatory visual methods

Introduction

Background

In Canada, young adults have the highest prevalence of smoking compared to other age groups. Moreover, the prevalence rate almost doubled from adolescence (11%), with an overall smoking rate of 20% for the 20-24 year olds in 2012, according to the findings of the Canadian Tobacco Use Monitoring Survey. Within these subgroups of tobacco users, gender-related differences in smoking were also notable in that they were consistently and significantly higher among young adult men compared to young adult women (23% and 17% for men and women ages 20-24 years, and 27% and 17% for men and women ages 25-34 years) [1].

While the bulk of tobacco prevention and intervention efforts have been directed toward school-age children and adolescents, less attention has been paid to targeting cessation strategies to young adults [2]. Related to this, young adults have cited the need for relevant, creative interventions that respect their choices and emphasize the positive aspects of quitting [3]. In the absence of targeted efficient cessation interventions, young adults who smoke have remained a subgroup at higher risk for continued smoking [4]. Likewise, while tobacco researchers have prioritized investigations of how gender-related factors influence smoking cessation [5], very little is known about how gender influences tobacco use by young adults. In the current study, we set out to address this knowledge gap by distilling how best to support the reduction and cessation efforts of young adults ages 19-24 years through the trialing of social networking and digital photography as novel tobacco intervention tools with this subgroup. Our aim was to utilize capacity from an existing social network platform to develop a user-driven, online community that supported and promoted cessation and being "smokefree" based on users' photo posts and dialogue.

Prior Research and Interventions

Social media and social networking sites (SNS) may provide opportunities to engage young adults in tobacco reduction and cessation through the use of accessible and scalable technologies that enable user-driven participation and interaction. Using the Internet to deliver innovative cessation programming has a longstanding history in Canada where, in 2004, the term Web-Assisted Tobacco Interventions (WATI) was coined to refer to smoking cessation delivered online and through personal mobile and wireless devices. In 2004, the WATI Initiative was formed to support the research, development, and delivery of tobacco cessation interventions across Web-based and mobile platforms [6]. Recognizing the potential to move beyond the delivery of "static" educational materials or didactic online resources, the WATI initiative in tobacco control anticipated what has now become standard in the delivery of eHealth programming, as it emphasized the need for interactive, user-driven technologies in order to engage people in health promotion interventions. Yet in a review of WATI, it was suggested that tobacco intervention websites had underutilized online capacity in terms of harnessing the potential for interaction and for personalizing cessation and reduction treatments for users [7].

The United States has provided additional, prominent examples where online presence and social media were used to engage youth on tobacco issues, such as the American Legacy Foundation's longstanding "The Truth" [8] initiative, which mobilized young people in advocacy against tobacco corporations, and the more recent "Smokefree Teen" [9] cross-platform, online initiative for adolescents from the US National Institutes of Health and the National Cancer Institute. In both the United States and Canada, tobacco control and health promotion organizations have regularly sponsored online contests where youth create their own anti-smoking visual media, by making and sharing photos or videos, such as the "Let's Talk Tobacco" [10] project from the Canadian Cancer Society. In British Columbia, Canada, the context for the current study, the province's young adult tobacco prevention initiative, Quitters Unite [11] (funded by Health Canada and the Heart and Stroke Foundation), successfully ran a photo contest in 2011 based on the theme "My Smoke-free Lifestyle", [12] where over 150 entries were received for a CAN $300 cash prize, the approximate cost of buying cigarettes for 1 month. Specific to young adults and SNS capacity, in 2014 the Canadian Cancer Society (in partnership with Health Canada) launched a website, a cross-platform social media campaign, and mobile app under the banner "Break It Off" [13] to encourage young women and men to "break off their relationship with smoking and stay smoke-free" [14]. Specific to SNS, a unique feature of Break it Off was an add-on app for use within Facebook, which participants could use to change their "relationship status" and announce to their Facebook network that they had ended their relationship with smoking (similar to the feature where Facebook users indicate a change in their romantic relationships by linking or de-linking to another user), as a way to lobby social support for sustaining their quit [15]. Also targeting young adults, the Crush the Crave mobile phone app for young adult cessation [16] (a partnership between tobacco researchers at the Propel Centre for Population Health Impact at the University of Waterloo in Ontario and the post-secondary anti-tobacco initiative "Leave the Pack Behind" from Brock University, Ontario) has been aimed at providing young adults with tools to track and log their cessation attempts, in addition to ways to share their successes and receive support and reinforcement from friends and family via SNS. An analysis of the content posted to the Facebook page promoting the Crush the Crave app has suggested that people who commented on posts (ie, replies) were highly engaged with the visual content and images posted (posts were made almost entirely by page moderators) and that the majority of comments (77%) were themed around showing support for cessation [17].

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Consumer research on social media use in the province where this research project was carried out has suggested that among British Columbians ages 18-29 years, 76% have used Facebook on a daily basis [18]. Facebook's own statistics on usage by Canadians suggest that they are the most active users of the platform globally, with over 14 million users logging into their accounts daily and 9.4 million of those doing so from mobile devices [19]. There is also evidence to suggest differences in how women and men engage online and that gender norms shape how they participate in SNS. For example, women have been shown to be more active users of social media for staying connected with others and for "relationship maintenance" when compared to men [20-22]. Relevant to our project, age and gender differences are also seen in SNS use where "women and the young drive Facebook usage" [23]. Studies with Facebook users have shown that women posted more photos of themselves on Facebook as well as updated their status, commented on posts, and endorsed posts by others more often than did men [24,25]. These differences in use are seen on other SNS platforms; for example, women also far outnumber men as users on the image-based platform Pinterest (72%), whereas men outnumber women on YouTube, with 68 million more monthly visits [25-27].

While there is sizable research on delivering online and mobile phone cessation supports for adult populations, review studies have shown inconsistent evidence for effectiveness [28,29]. Similarly, studies have suggested that text messaging [30,31] and peer-based email support [32] for cessation have had good potential for engaging young adults and have been effective for reducing tobacco consumption [33,34] and for smoking cessation in the short term [35]. In their systematic review of WATI for young adult health behavior change, Crutzen et al [36] considered 26 studies of Web-based interventions for adolescents or young adults ages 12-25 years, with 8 of 26 studies that were specific to smoking cessation. An important conclusion of this review for Picture Me Smokefree was that strategies for generating online peer-based support such as discussion boards were only moderately used, yet overall it is still difficult to ascertain the effectiveness of various methods used to increase exposure to online interventions because tracking and reporting exposure measures was inconsistent or non-existent [36].

We are unaware of any studies where the primary delivery of a WATI is through an existing SNS platform such as Facebook, especially where the content is generated by participants (ie, rather than delivered "to" them by researchers on "intentionally created" websites or intervention communities) [37]. Despite the belief that delivering tobacco interventions through SNS may be well suited to a demographic where using sites such as Facebook has been woven into daily life for many, to date, there has been little research specific to young adults and the delivery of SNS-based cessation interventions [38]. A systematic review of randomized controlled trials (RCTs) of WATI from 2011 concluded that Web-based interventions had the potential to offer low-cost, wide-reaching treatment [39]. Yet Hutton et al [39] identified only one RCT carried out with young adults [40], which had multiple components that made it difficult to evaluate in terms of isolating the efficacy of the Internet for tobacco cessation. The RealU online intervention for college students sent weekly emails to participants inviting them to the intervention website where they were asked to report on their health behaviors of the previous week, take an interactive quiz related to smoking dependence, and read online general interest articles [40]. The authors reported higher 30-day abstinence rates in the control group, but not continuous 6-month abstinence rates. Another feasibility study with 46 college students in the United States evaluated a mobile phone text-messaging smoking cessation program [41]. The text messages were individually tailored, based on personal smoking information that the participants provided by answering assessment questions on a website. Participants recorded their daily smoking behaviors on a website and could access quitting information there. Although 22% quit smoking after 6 weeks in the study, the attrition rate was 33%. The authors replicated this study in 2008 with 31 college smokers who wanted to quit, concluding that phone text messaging held good potential as a tobacco intervention with young people [42]. A larger RCT with 1705 smokers (mean age 25 years old) also tested the effectiveness of mobile phone text messaging as a cessation tool [43], reporting that 28% of the intervention group had quit at the 6-week mark. Indeed, at 26 weeks there was little difference between the intervention and control groups, because the control group began reporting increasing quits. In all these studies, the intervention was delivered without communication or support being generated among youth or young adult participants, and smoking abstinence, as distinct from tobacco reduction, was the measured cessation outcome.

Research Questions and Feasibility Indicators

To determine the feasibility of using digital photography and SNS as a smoking cessation and reduction intervention for young adults, the current study was guided by three core elements of the framework developed by Bowen et al [44], summarized in Table 1.

Given the presence of gender-related influences in smoking prevalence for this age-based subgroup, we also collected findings disaggregated by gender, to provide a preliminary assessment of the extent that gender-related factors may have influenced participants' use of our online and photo-based intervention.

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Table 1. Study feasibility foci and outcomes of interest (adapted from Bowen [44]).

General areas of focus	Specific areas of focus	Outcomes of interest
Acceptability: To what extent was the intervention suitable for attracting the target audience?	Clarity and suitability of the study recruitment strategies and eligibility criteria	Number of inquiries vs number of sign-ups
		Number of inquiries outside the eligibility criteria
		Findings disaggregated by gender
Implementation and practicality: To what extent could the intervention be implemented given possible resource constraints?	Ease and cost of recruitment and participation	Count of participants recruited weekly
		Recruitment sources and cost analysis
		Remuneration costs
		Findings disaggregated by gender
Demand: To what extent were aspects of the intervention actually used by participants?	Participant engagement	Level of photo group activity
		Completion and retention rates at 12 weeks
		Survey responses and rates
		Participant interviews
		Findings disaggregated by gender

Methods

Study Design

A prospective, non-comparative design was used. This design is appropriate for feasibility studies that aim to determine whether the intervention is appropriate for further testing and estimate important parameters that are needed to refine the design of a full scale study [44,45]. The study protocol was approved by the ethics review board at the University of British Columbia, Vancouver, Canada.

Picture Me Smokefree Intervention—Rationale and Implementation

To facilitate user-driven peer support and interaction within the context of an online group, the design of our project adapted Photovoice [46,47], a visual method that is well established in health research, tailoring it for use with digital photography and an SNS platform. The broad intent of using what we have termed "participant-driven" photography methods in public health research has been to mobilize participants' creativity and community engagement beyond what is possible through using narrative-based methods (ie, interviews and focus groups). Conventionally, participant-driven photography projects have been community-based in neighborhoods or other physical settings for health promotion, aiming to collectively empower research participants using photography to document local health issues. In "true" Photovoice research, there is an active community advocacy component where participants work together and make collective decisions about the photo-based findings and themes they want to share with stakeholders and other decision makers at the project's conclusion. Participant-driven photography has also been used to engage participants in critical reflection about health behaviors and illness experiences at an individual level, through integrating discussions about photographs within interviews conducted between participants and researchers [48,49].

The investigative team for this project had previously conducted several participant-driven photography studies to understand the experiences of people that smoke, focusing specifically on how gender-related factors influenced tobacco use and the need to prioritize gender considerations in cessation and reduction interventions [50-52]. Departing from the usual approach in participant-driven photography research of providing participants with disposable cameras, Picture Me Smokefree was designed to assess the potential for adapting photo methods to a social networking platform, capitalizing on young adults' familiarity with documenting and sharing daily activities through digital photography (camera and mobile phone). A key difference in the research process for Picture Me Smokefree compared to our past participant-driven photography studies was that by asking young adults to take pictures using their own digital cameras or mobile devices and to caption them online, the balance of power shifted to the participants and the researchers' involvement in assisting them with the process of taking and sharing photographs was minimal. As a result, interactions between project participants were instantaneous and for the most part unfiltered between members of the online photo group created for the project, and the researcher participated as a group member rather than moderator (Figure 1). Most topics were user-initiated, but occasionally the researcher-moderator posted photo challenges, topics, or "mini-contests" to engage participation during periods of low activity within the photo group.

Instead of creating a standalone website specific to our photo-based intervention, we chose to host our project on Facebook as a low-cost option with the potential to engage young adults who have been the most frequent users of this SNS. The built-in features of Facebook allow users to post and comment on photos in a variety of spaces (ie, pages, groups, and walls), creating spaces for dialogue, debate, and online support. While we initially planned for the Picture Me Smokefree photo-posting group to be open for viewing by the public, once recruitment was underway we elected to create a private "members only" group on Facebook. This decision was based on users' stated preferences for sharing their photos about smoking and cessation in a limited capacity, so that posts and other content they shared could not be seen by their network of

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Facebook contacts or be viewed publically (ie, especially family or employers who may not be aware of their smoking status).

Figure 1. Screenshot from the Picture Me Smokefree photo group on Facebook.



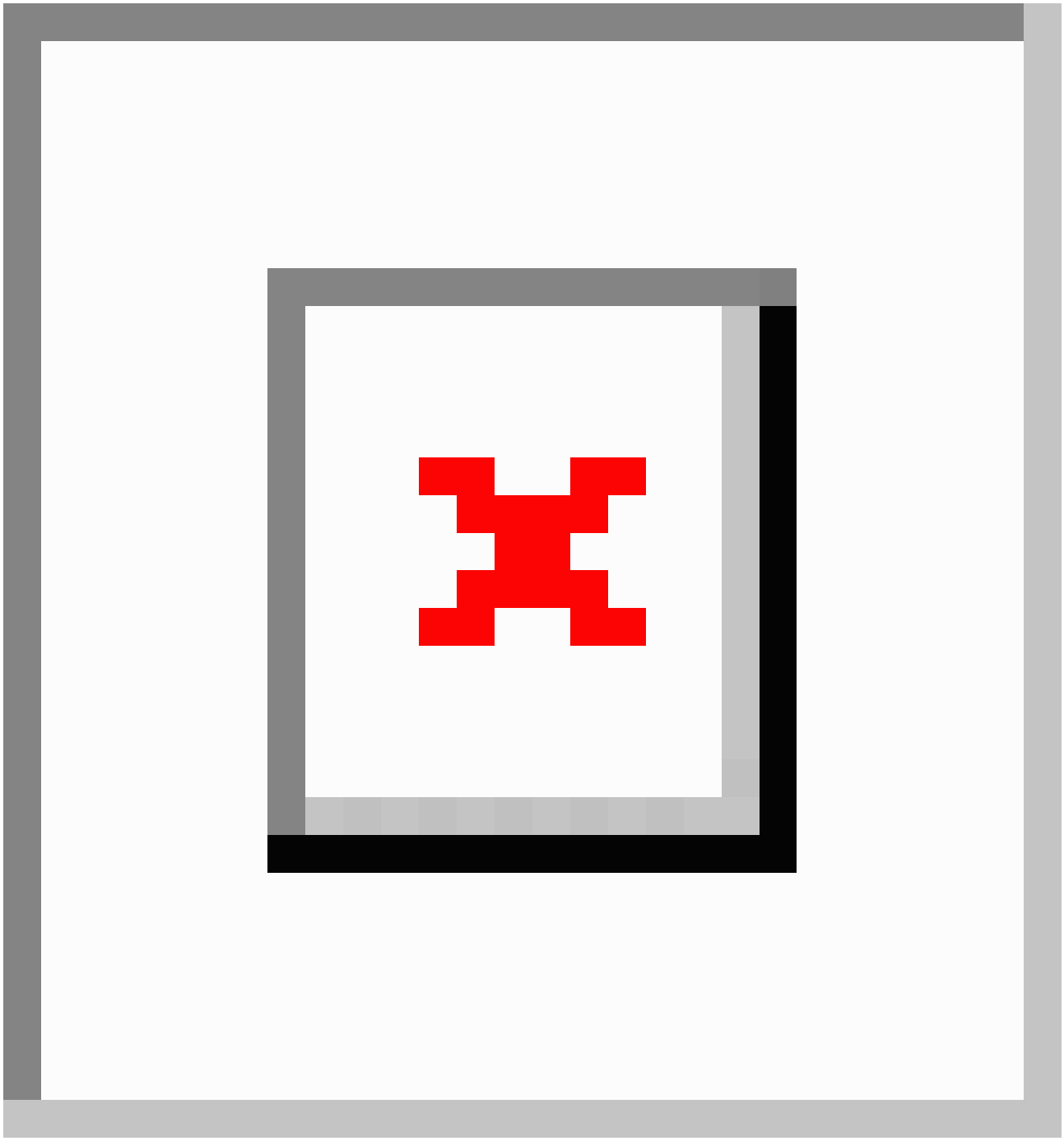
Recruitment

The target for recruitment was 60 young adults. The eligibility criteria included being a man or woman aged 19-24 years, living in British Columbia, having English literacy, and having Internet and camera access. Although we had resources to provide participants with cameras, only 3 people required this. Recruitment was open to active smokers (with some interest in quitting) or those who had quit within the last 12 months. We used a variety of recruitment strategies beyond social media, although a recurring Facebook ad garnered the majority of inquiries. Separate from the photo-group space, we created a Facebook "landing page" (Figure 2) for the study, which provided general information and a way to promote recruitment. In addition to the standard Facebook features of the public wall or timeline where posts could be shared, our Facebook page included an online Web form where participants could sign up for the study (responses were pushed to us via email). Additionally, we contracted the services of a youth-friendly social marketing firm to develop a consistent brand identity (ie, logo, color scheme) for the project and to promote the study through online and offline channels (Figure 3).

We also worked with a team of community-based health promoters to distribute flyers, posters, and magnets advertising the study to young adults in their local communities across the province. A Twitter page for the study was created to promote the study and to interact with other local tobacco control and health promotion initiatives geared toward youth and young adults. Other recruitment activities included flyers posted on post-secondary campuses and at youth-serving health and social service agencies, print ads in campus newspapers, participants' referrals, posts on craigslist, and email group "blast" messages sent through professional mailing lists.

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Figure 2. Picture Me Smokefree Facebook landing page.



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Figure 3. Picture Me Smokefree intervention logo and social media branding.



Data Collection and Analysis

To be participants, individuals had to join the Facebook photo group, which first involved brief contact with the study investigator by telephone or in person to provide their informed consent and to receive a brief orientation to the project. Because we know that smoking status may fluctuate often for young adult tobacco users, participants were asked to post to the group for 12 weeks and to make a minimum of one posting per week, preferably by posting an original photo and caption about their experience of smoking or quitting. We defined a participant as active as soon as they had completed one action in the Facebook photo group, posting a photo or comment, sharing a link, or "liking" other posts (Facebook's "thumbs up" endorsement action). For each week that a participant was active, they received a CAN $10 credit, which was paid out to them at the end of the 12-week consecutive period. Research staff enrolled participants and monitored their activity in the photo group on a weekly basis, manually tabulating the number of posts to the group made by each person. Weekly reminders to post and updates on their current status (ie, credits and weeks remaining) were sent to participants via Facebook and by email. As recruitment was ongoing and participation was staggered over the course of the 10 months that the study was running, the numbers of people within the photo group varied at any given point. The largest number of members in the group was 46, keeping in mind that some people signed up but failed to join the group, and others joined but never posted (study dropouts).

Other data collection measures included a smoking history and demographic form completed at sign-up. At the end of the 12-week participation period, participants were also asked to complete a brief (10 question), anonymous, online evaluation survey, and invited to provide additional feedback about their experience of participating in Picture Me Smokefree in a feasibility interview (face-to-face or by phone). The interview was optional but was offered to all participants who were active in the photo group for at least 1 week and was completed by 22 people (12 men, 10 women). Data analysis involved descriptive statistics on recruitment, retention, and participation and qualitative (eg, narrative analysis, synthesis of feedback) feedback about participant engagement. Multimedia Appendix 1 (slideshow) provides further detail about the recruitment materials, study procedures, and the study results.

Results

Acceptability

There were 134 inquiries about participation in the study received: 78 (58.2%) from men and 53 (39.6%) from women. Three inquiries (2.2%) were received by email, and the sender's gender was not specified. Only 20 (14.9%) of inquiries were outside of the advertised eligibility criteria, suggesting that the recruitment materials and strategies were clear and appropriately targeted to our population of interest. For those instances where the person who inquired was deemed ineligible to participate, the most frequent reason was being outside the age range (n=13), with 1% under age 19, and 11% older than 24. As participants ranging in age from 31-70 years inquired about signing up, this possibly suggests that a photo group on Facebook may also be attractive to adults who smoke or who want to quit. Only a few people that contacted us about the study (n=6) booked an appointment to sign up but did not follow through. For other inquiries lost to follow-up, we assumed general disinterest. Only one person who contacted us explicitly declined to sign up because they did not have a Facebook account.

Through the recruitment process, an unanticipated issue arose regarding confidentiality and privacy. Although the study was targeted directly to young adults, we received a few inquiries from parents, relatives, and service providers seeking to sign up on behalf of a young adult who smoked (n=5). This speaks to the need for greater clarity in our recruitment materials regarding participation as voluntary and direct and to have explicit guidelines in place for research staff when third-party inquiries are received. Another issue was that one-quarter of

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our participants (8 women, 7 men) opted to create an anonymous profile or "Facebook alias" user account—an option that we encouraged as part of our informed consent process—due to privacy concerns and to ensure that their identities would not be associated with a study about tobacco use.

Implementation and Practicality

We enrolled 60 individuals aged 19-24 years (mean age 21 years) into the study over a period of 10 months in late 2011, through until the summer months of 2012. With 34 men (57%) and 26 women (43%) signing up for the study, the gender split reflected patterns seen for the study inquiries. Recruitment occurred more slowly than we anticipated, which posed a significant challenge for meeting the pre-determined feasibility targets for signing up 5 new participants per week. Since we attracted very few participants (≤3) in the first months of the study, we refined and expanded our initially proposed strategies for reaching young adult tobacco users. To this end, the first few months constituted a "soft launch" on Facebook, while we determined the best combination of online and offline approaches to use. Recruitment ceased in July 2012 when we reached our sample target (N=60). There were only 3 months when there were more than 5 new participants that signed up: March (19), February (11), and June (10). While these increases in recruitment were arguably tied to intensification and diversification of our efforts, we hypothesized that they may also be tied to events in the local post-secondary academic calendar (ie, vacation, mid-term examinations), as many of our participants were students.

Overall, about half of the total inquiries (68/134, 50.7%) received about the study came through targeted Facebook ads, which we set to be shown to all Facebook users that met our age and geographic inclusion criteria; to a lesser extent targets to users with profiles associated with post-secondary institutions and terms referencing tobacco use or cessation were also used. After Facebook, the top three *referral sources* (ie, how potential participants heard about the study) were from a friend participating in the study (21/134, 15.7%), from a mass email message they received about the study (9/134, 6.7%), or from a flyer posted at a youth-serving agency (9/134, 6.7%). Considering only those inquiries that progressed to sign up as participants, recruitment from Facebook (17/60, 28%), friend referral (17/60, 28%), and posted flyers (16/60, 27%) accounted for most (50/60, 83%) of our final sample. Male participants were more likely than female to be referred to the study by a friend who had signed up to participate (11/34, 32% vs 6/26, 23%). It is also noteworthy that there were 10 participants (5 couples) who signed up and had a partner also participating, which may speak to the importance of considering intimate partners as a source of support for young adult smoking cessation, in light of studies suggesting that gender relations are key influences on cessation for adult heterosexual couples and families [53-55].

In terms of the *referral type* (ie, the method used for contacting us), most participants used the online contact form on our Facebook landing page (25/60, 42%), sent a direct email (13/60, 22%), or telephoned (10/60, 18%). For those who signed up for Picture Me Smokefree, there were some gender differences noted in the contact methods used, however, as men where 3.5 times more likely to communicate initially by text messaging, and women were twice as likely to use email.

The major costs associated with recruitment were graphic design services, printed materials, newspaper advertising, Facebook ads, and contracted social marketing and community recruitment services. At approximately 15% of the total budget, recruitment costs were reasonable, although perhaps higher than typical given the relatively small number of participants recruited. Yet given that our population of tobacco users is seen as a "harder-to-reach" group, we believe the expense was justified, while recognizing that as recruitment occurred as a process of "trial and error", these costs could most certainly be streamlined in the context of future studies.

Demand

To ascertain demand and participant engagement, it is useful to consider the characteristics of those who signed up (smoking status, gender), how they participated in the group (type, frequency of their activities), and 12-week study completion rates (attrition). Finally, we considered the findings from an anonymous survey at the conclusion of the participation period, in order to summarize user feedback on the experience of being a participant in Picture Me Smokefree.

Picture Me Smokefree attracted individuals with a wide range of self-reported smoking patterns at the point of signing up: from light to heavy daily smokers, weekly and occasional social smokers, as well as a few who were attempting to maintain their quit. Almost half (25/60, 42%) of the participants reported being daily, light smokers and consuming 5 cigarettes or less per day. Those who were classified as heavier smokers, at between 15-20 cigarettes per day, comprised 15% (9/60) of participants. Like the range in their daily smoking frequency, the length of time participants had smoked varied widely; the most common length of time participants reported having smoked was from 3-5 years. Additionally, Picture Me Smokefree participants reported that their smoking status changed over the course of the 12 weeks they participated. For example, among the participants who completed the online follow-up survey (39/60), 10% (4/39) reported they had quit during their participation and 51% (20/36) had reduced their smoking during the course of the study. For another 24% (9/36), there were no reported changes, and 5% each (2/39) stated they had relapsed, increased tobacco use, or had already quit prior to the study. Overall smoking status among the women and men recruited was similar: 27% (7/26) of women and 29% (10/34) of men characterized themselves as actively quitting, and 73% (19/26) of women and 71% (24/34) of men were smokers at their sign-up. As the final survey was anonymous, we did not collect findings about gender in regards to changes in smoking status over the 12 weeks.

Although Picture Me Smokefree attracted more men than women to participate, overall women participated more frequently and posted more content to the photo group than did men. We tracked the level of study participation and learned that women were more likely than men to complete more weeks of the study and post to the group at least once during each of the 12 weeks. Table 2 shows the differences in the level of participation for men and women, with reported percentages

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weighted by gender. While women were more likely than men to be high participators, more men than women were seen in the medium participator group. However, collapsing the medium/high distinction, any differences all but disappear, with 70% (24/34) of the men and 69% (18/26) of the women participating in the Picture Me Smokefree photo group for between 5-12 weeks. Low participation in the study and dropping out of the study was not very different for men and women. In terms of attrition, we classified one-fifth of participants as study dropouts (19% of women and 21% of men) as they either failed to join the Facebook group after signing up with the study investigator, or joined the Facebook page and posted only once or not at all. Although the retention rate was better than our pre-set target of 75% and suggests that engagement in the photo group was strong, a greater number of both men and women in the high participation group would have been more desirable.

Table 2. Study participation of men (n=34) and women (n=26).

Participation	Men, n (%)	Women, n (%)
Percentage of Picture Me Smokefree participants	34 (57)	26 (43)
Participation rates		
High participation (9-12 weeks)	15 (44)	17 (65)
Medium participation (5-8 weeks)	9 (26)	1 (4)
Low participation (1-4 weeks)	3 (9)	3 (12)
Study dropouts	7 (21)	5 (19)
Total	100	100

Posts to the photo group were tracked both manually by a research assistant and electronically through NVivo NCapture software, which was used to export Facebook data at the completion of the study. In total, there were over 1800 actions (including photos, comments, “Likes”, and “shares”) to the photo group by participants, which indicates reasonable engagement for a group of this size. Picture Me Smokefree participants posted 283 photos, with 94 photos posted by men and 189 by women. This difference holds when looking at the number of postings by individuals, with a mean of 9.45 photos for women and 4.27 photos for men. Of the 18 participants who did not post any photos (but commented and endorsed other content in the group), 6 were women and 12 were men, indicating the same trend: overall women were more likely to post photographs. While we saw rates of activity that were comparatively higher for women than for men, quantity of interactions should not alone be the markers of significant engagement. For instance, although some men posted less frequently, this did not appear to be related to a lack of interest in sharing or “connecting” online. Both women and men posted photos and captions about their experiences with tobacco use and cessation that were reflective and deeply personal, often sharing details about tobacco use and their struggles with quitting in the context of their family life and relationships, and as linked to work and school settings. Two examples illustrating this point are provided by Figures 4 and 5.

The response rate for the brief, online follow-up survey at study completion was adequate at 65% (39/60). When asked to rate their “overall experience” on a scale of 1 to 10, many participants (31/39 or 79%) provided a rating of 8/10 or higher (Figure 6). Similarly, when asked “would you participate in a project like this again?”, all but 1 respondent predicted they would (38/39). Completion of the survey also appeared to be tied to higher levels of participation and engagement in the study, as most of those who completed the survey (32/39) indicated that they had participated between 9-12 weeks. Respondent recall for this number is likely accurate, given that all participants were provided with a report on the number of weeks they were active in the study, as this was linked to their weekly credits and the amount of their final honorarium payment.

To briefly summarize narrative (qualitative) feedback from the online survey and the one-to-one interviews (22/60), most men and women indicated that what they viewed was positive, non-judgmental, and endorsed the supportive tone of the group, especially as it was presented in the context of interactions between moderator and participants, between group members who had quit and those who were still actively smoking, and also as it was expressed toward those who had relapsed (see Textbox 1). Yet a small number of those who had quit or were planning to do so expressed that they would have preferred an “all quitters” group because they found that some of the posts by active smokers were “too pro-smoking” and shifted the tone away from reduction and cessation.

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Textbox 1. Themes in participants' feedback (survey and interviews).

Picture Me Smokefree participants liked:

- support and connections with peers
- new information and diverse views represented
- freedom/creativity in posting
- honesty/non-judgment
- private group (smoking status not visible to public)
- easy: "only a mild hassle", "easy money"
- reinforcement for cessation (alerts creates daily reminders)

Picture Me Smokefree participants' suggestions for improvement:

- more interaction between members in the group
- more interactive and structured activity (eg, surveys, contests)
- alerts or reminders to post
- too busy/lost interest (increase engagement)
- dislike Facebook (provide other online options)
- add offline support meetings
- help with ideas for creating photo posts

In regards to how Picture Me Smokefree might have positively influenced their movement toward tobacco reduction or cessation, participants provided the following qualitative feedback:

> *Um, I thought it was a really great experience, it really opened my eyes to what other people think and associate with smoking…And I think it was great to see what everybody else's ideas and their pictures and stuff and it really made me personally think of why I smoke and what the reasons are and what else I associate with smoking as well.* [woman, age 23]
>
> *I liked having a place where a lot of people might come and put why they still smoke and the triggers that make it harder for them to quit and just kind of bringing more of a general knowledge of the struggle people have when they try to quit smoking.* [woman, age 24]
>
> *I think the best part of about it was the fact that there was a group of smokers or ex-smokers that kind of worked together to help bend or quit the habit and uh it kind of served as a motivation…There was a mini-community thing going on and I really liked that. I liked seeing others and their photos and how they're dealing with it or what problems they have associated with smoking which, which kind of gives you broader understanding of why people smoke which is really interesting.* [man, age 19]

Even after the study had ended, participants' provided feedback (sometimes months later) that Picture Me Smokefree helped motivate them to quit: "I have quit Facebook for the time being. I have also quit smoking" (woman, age 23), "Haven't smoked since my twelve weeks wrapped up. Instead, I've been eating way healthier, working out, and getting a ton more work done towards my career. Off to a great (re)start" (man, age 21), and "I am going to attempt what I believe to by (sic) my first serious attempt to quit smoking. I think the seed of quitting was planted in my mind this year when I took part in your project" (man, age 21).

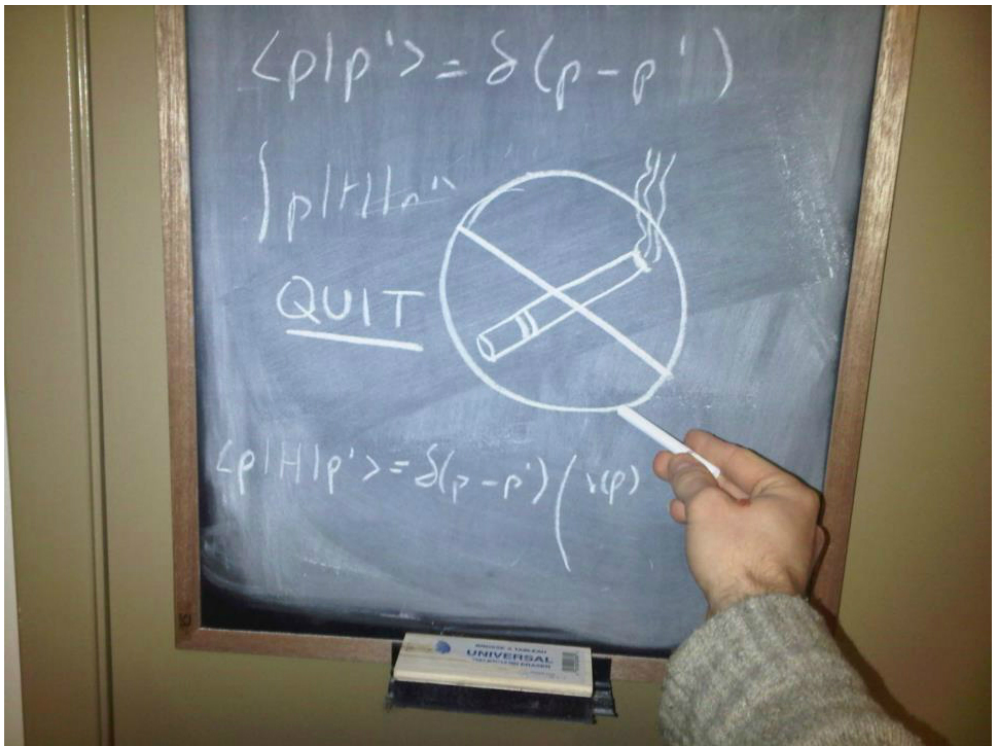
A further key issue associated with assessing the feasibility of participation in our intervention pertains to practicality and the costs of remunerating participants. For this feasibility study, our costs were relatively low in terms of equipment purchases and payments made to participants. With only three cameras purchased for those without access, under CAN $500 was spent on equipment. It is also notable that Internet access was not a barrier to participation—even for the participants that were marginally housed and recruited from youth shelters and transitional housing, Internet and computer access was readily available to them at these agencies. The total amount spent to remunerate participants was just under CAN $5000 over the course of 10 months, and keeping in mind that not everyone participated on a weekly basis, on average these costs were about CAN $109 per person. There were also 6 participants we repeatedly contacted that did not collect their final payments, for amounts ranging from CAN $10 to $110.

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Figure 4. Example of a participant photo and caption about tobacco use, health, and quitting (Woman): “This is why I hate smoking. They said his heart is inflamed and smoking is contributing to it. I know that if we kept smoking this is where we will end up. I just keep asking why would I do this to myself?”.

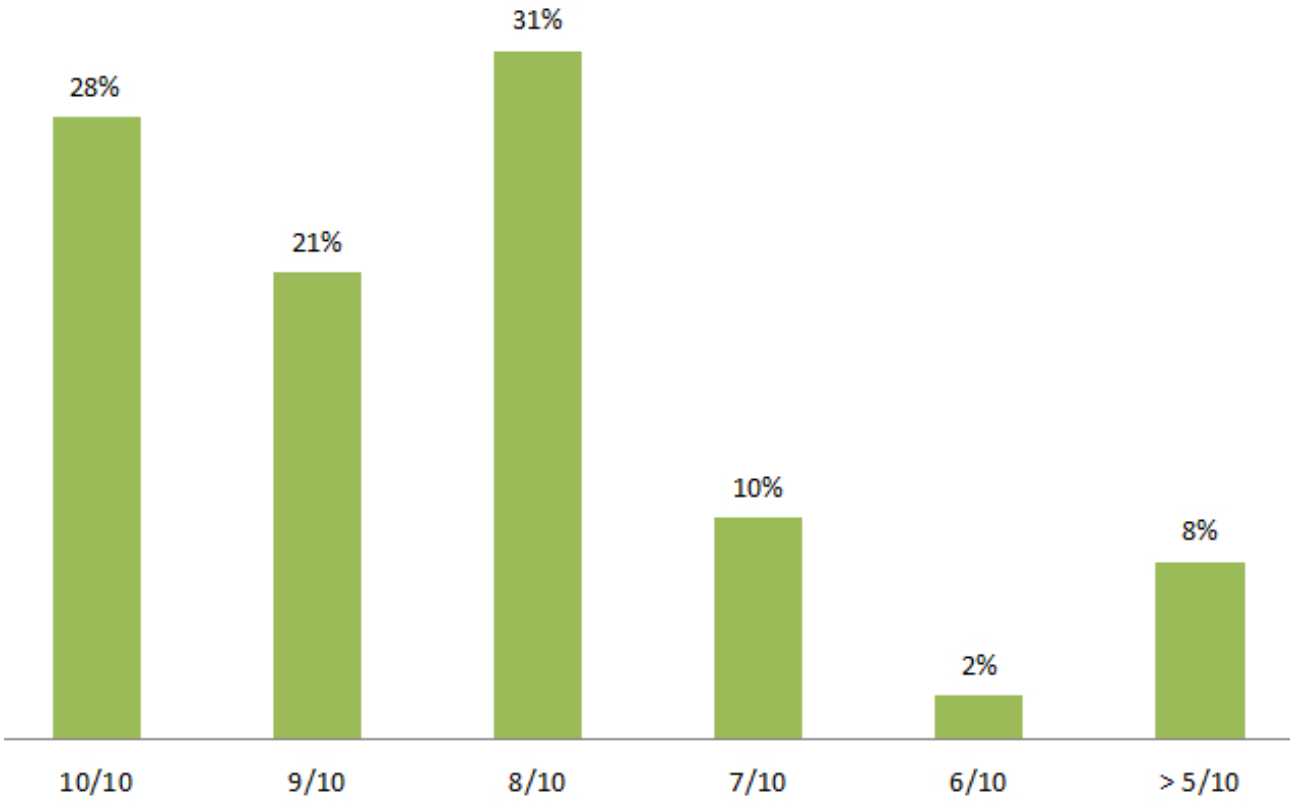


Figure 5. Example of a photo and caption about tobacco use, health, and quitting (Man): “Sometimes smoking gets in the way of my academic pursuits. I take too many breaks, I put off time for studying by adventuring to the local mini mart of gas station, I relax with the subtly deadly nature of tobacco. I feel that if I don’t quit soon, it’ll harm me in the long run, and my pursuit of becoming a professor will die off quit quickly (and literally). As soon as exams are out of the way, I will return to my non-smoking ways. But until then, I must cope”.



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Figure 6. Follow-up survey question: "On a scale of 1-10, please rate your overall experience as a participant in this project".



Discussion

Principal Findings

The current study findings support the feasibility of adapting photo research methods to an SNS to form a user-driven, online intervention that can provide an opportunity for young adults to reflect critically about their tobacco use and access peer support for cessation. Picture Me Smokefree demonstrated that embedding a tobacco intervention within social media platforms has potential to engage young adults in cessation or reduction plans by drawing on their familiarity and experiences in using Facebook. The strength of this approach appears to be the interactive quality and peer contact provided by social media that is not only engaging but offers young adults the opportunity to learn from each other's experiences and to provide mutual support, regardless of their smoking or quitting status. However, even when an intervention is hosted in an online context where young adults are frequent and fluent users, we found that recruiting current and former tobacco users from this subgroup can be difficult and time-consuming. A key conclusion of our study is that recruitment efforts need to be creative and multi-pronged (taking place both online and offline), and that this type of tobacco cessation intervention may require considerable resources to attract and retain participants. In this case, reaching our (relatively small) target of 60 participants to an online group required 10 months of experimenting with various recruitment efforts, but we anticipate that in a future study the lessons learned from this preliminary research would likely reduce the time period to attract sufficient numbers considerably. However, any assessment of feasibility must seriously consider that this particular subgroup of smokers might be considered "hard to reach" from an age and cessation-based perspective, and therefore perhaps less likely to join an intervention, regardless of the format.

The design of this study does not permit us to claim generalizability about changes in smoking outcomes associated with our intervention. Nevertheless, the qualitative and self-report findings on how smoking status changed during participation—in particular that over half of the participants reported reducing their tobacco use—suggest that a user-driven photo-group intervention like Picture Me Smokefree shows promise and warrants further study to determine its effectiveness in supporting cessation and tobacco reduction.

Suggestions for Future Studies

It is clear that some young adults found the online group useful for reducing or quitting smoking, while others may have participated without influence on their smoking status. While most found the context and the content of a group open to participants from a range of smoking statuses to be positive and supportive, there were at least a few participants who expressed a desire for a "quitters only" group, so that they would be exposed only to interactions and content that reinforced their decision to be smokefree. To this end, future comparative studies might compare outcomes when participants are assigned to an "active smoker", "active quitter", and to mixed status groups. Although a more detailed analysis of the visual and narrative themes within the photos is beyond the scope of this initial

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feasibility report, the findings have provided valuable background to inform additional group content and activities (ie, assigning weekly topics or themes for photo posts) that might assist in sustaining engagement in the photo groups and for increasing young adults' motivation toward tobacco reduction and cessation.

As our study was structured to include weekly credits for participation, it would be particularly important for future research to test alternate mechanisms for incentivizing participation and retention. For instance, a comparison of the weekly payment credit system used by Picture Me Smokefree with that of a photo contest format or another more cost-efficient mechanism of remuneration would be useful. Where regular incentive strategies are generally seen as cost prohibitive when rolling out an online intervention at the population level [36], a virtual reward or contest system (eg, one contest entry per week of activity) would likely be the most appropriate and cost-effective strategy to encourage participation. Still, based on our findings that several participants did not collect their final payments, it is perhaps also the case that monetary incentives were not the prime motivation for participation by all young adults in this study.

This study also provided some preliminary findings to suggest support for interventions that are sensitive to or tailored to gender-related influences, as indicated by some of the variations observed in the online participation by young men and young women in Picture Me Smokefree. Although men and women may have used the group in different ways and with different levels of participation, the follow-up surveys and interviews with participants indicated that both men and women experienced Picture Me Smokefree as helpful because it provided a supportive, non-judgmental online space where they could share quitting and smoking experiences and struggles. The men and women used the online group and the process of posting photos to reflect on their smoking, their habits related to continued smoking, and the benefits of and reasons for quitting. Rather than suggesting support for segregating users into gender-specific cessation or reduction groups, this population may benefit more from reflecting on their own smoking behaviors and from supporting others in a mixed-gender setting.

In an effort to be credible and appropriate for youth and young adults involved with tobacco, there are several other popular image-based social media platforms such as Instagram or Tumblr where an eHealth intervention component might be embedded. Based on feedback from our participants, future revisions for a larger study should include more interactive features in an online group (eg, a group chat feature, weekly group photo topics or assignments). These kinds of interactive activities, supported by social media platforms, encourage the "everyday embedding" of reduction and cessation in the context of digital activity, providing tools that may promote self-reflection on smoking behaviors, increased self-awareness of the reasons for continued smoking, the benefits of quitting, and tips for successful cessation.

Comparisons With Prior Work

To the best of our knowledge, there have not been previous studies of photo-based methods deployed as online tobacco interventions in the context of Facebook or other SNS. As such, there are several areas in which the current study findings provide unique contributions to the young adult tobacco cessation and eHealth intervention literatures. First, as participant-driven photography and other photo-based methods have seen increased prominence in health promotion research, a project like Picture Me Smokefree helps to make a case for innovation in the use of visual methods, in order to capitalize on widespread use of online platforms for uploading and sharing photos online, particularly among young people. While some youth-based tobacco control campaigns have incorporated user-created photos and video in innovative ways, this occurs primarily in the context of online contests and is typically not directly linked to measuring cessation outcomes or behavioral changes. While there may be high levels of user engagement and interactions that result from this digital content (eg, online voting), there remains a need for evaluation components that go beyond assessing short-term engagement. Likewise, as the results of participant-driven photography and other visual research have been descriptive, our project provides preliminary support for shifting participant-driven photography from a visual method that chronicles health problems, toward a scalable, sustainable intervention.

While we have emphasized that a unique aspect of this research project was that it included both active tobacco users and those who were in the process of, or had been successful at smoking cessation, the idea of bringing together these groups is not our invention. This strategy has been used by some of most successful youth anti-tobacco campaigns, including the US-based Truth initiative, which has from its inception been inclusive of youth that are actively smoking. For example, their online campaign materials have stated that "We are here to empower not to judge" and "This is about getting everyone on the path to ending smoking. It's not about making fun of smokers. Or leaving them out. We love smokers. The more of them we can get on board, the closer we can get to ending teen smoking once and for all" [8]. Likewise, Canadian campaigns such as Quitters Unite have also positioned their online materials to be inclusive and welcoming to youth who may be actively smoking or resistant to quitting (eg, "Whether you smoke, have quit, or just want to support someone else to quit, there's something here for you") [56].

Limitations

While these preliminary findings show good evidence for engagement, efficacy will need to be evaluated in a future controlled study to determine if this strategy leads to significant changes in smoking behavior and cessation outcomes pre- and post-intervention. The self-reported feedback from participants about changes in their smoking during and following their participation suggests that there is potential for this approach to motivate movement toward cessation for those who are still smoking and to reinforce being smokefree for young adults who had taken steps to quit tobacco.

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An aim of this study was also to consider gender-related influences, and while we noted some apparent trends in how men and women participated in the intervention, further study is still needed. In the context of gender-specific groups, it is quite possible that we might observe different styles of interaction, support, and sharing between users if assigned to men-only, women-only, and mixed-gender photo groups. This is an area where the eHealth literature is nascent, albeit based on findings about how gender influences face-to-face support groups in health, prioritizing gender in digital and online health research is critical to determining how "gender matters" interconnect with people's engagement and participation in the context of the virtual/online world.

Conclusions

Picture Me Smokefree suggests that for young adults who smoke, an online context might provide the awareness of smoking behaviors that serves as the motivation for their beginning to contemplate quitting, even if the expectation of being completely and permanently smokefree may not yet be the priority for some people in this age group. Bringing together those who are actively smoking with those who are thinking about, or who have committed to quitting, to regularly share their experiences may be more appropriate for this age group as it more closely mirrors their social interactions in the "real-life" offline world, where those who smoke and those who do not frequently socialize. Likewise, in terms of gender, our participants expressed no preference for gender-specific groups or online communities, but rather stated that mixed-gender group mirrored their social interactions and relationships with other tobacco users who may be their partners, friends, and family.

Acknowledgments

RHS designed the study and carried out data collection and analysis, and with MK, shared responsibility for conceptualizing and drafting the first version of this manuscript. JO and JB contributed to conception and design of the study, as well as the writing, editing, and conceptual development of subsequent versions. All authors approved the final version of the manuscript.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

PowerPoint presentation on the Picture Me Smokefree intervention (2013).

[PDF File (Adobe PDF File), 2MB - jmir_v17i1e27_app1.pdf]

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Abbreviations

RCT: randomized controlled trial
SNS: social networking site
WATI: Web-assisted tobacco interventions

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Original Paper

Enhancing Web-Based Mindfulness Training for Mental Health Promotion With the Health Action Process Approach: Randomized Controlled Trial

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Abstract

Background: With increasing evidence demonstrating the effectiveness of Web-based interventions and mindfulness-based training in improving health, delivering mindfulness training online is an attractive proposition.

Objective: The aim of this study was to evaluate the efficacy of two Internet-based interventions (basic mindfulness and Health Action Process Approach enhanced mindfulness) with waitlist control. Health Action Process Approach (HAPA) principles were used to enhance participants' efficacy and planning.

Methods: Participants were recruited online and offline among local universities; 321 university students and staff were randomly assigned to three conditions. The basic and HAPA-enhanced groups completed the 8-week fully automated mindfulness training online. All participants (including control) were asked to complete an online questionnaire pre-program, post-program, and at 3-month follow-up.

Results: Significant group by time interaction effect was found. The HAPA-enhanced group showed significantly higher levels of mindfulness from pre-intervention to post-intervention, and such improvement was sustained at follow-up. Both the basic and HAPA-enhanced mindfulness groups showed better mental well-being from pre-intervention to post-intervention, and improvement was sustained at 3-month follow-up.

Conclusions: Online mindfulness training can improve mental health. An online platform is a viable medium to implement and disseminate evidence-based interventions and is a highly scalable approach to reach the general public.

Trial Registration: Chinese Clinical Trial Registry (ChiCTR): ChiCTR-TRC-12002954; http://www.chictr.org/en/proj/show.aspx?proj=3904 (Archived by WebCite at http://www.webcitation.org/6VCdG09pA).

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KEYWORDS

Internet-based intervention; online intervention; mindfulness; Health Action Process Approach (HAPA); mental health promotion

Introduction

Background

According to the World Health Organization [1], mental health is essential to contributing to the overall well-being of every individual. However, approximately 450 million people worldwide suffer from mental health problems, and they represent 15% of the total disease burden as assessed by disability-adjusted life years (DALY) [1-3]. Based on the Global Burden of Diseases, Injuries, and Risk Factors Study 2010 [4], depressive and anxiety disorders account for 55.1% of DALYs

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caused by mental and substance use disorders [5]. Given the tremendous burden on affected individuals, family, and society, it is critical for mental health promotion and prevention of mental illness to be incorporated into public health initiatives [6].

Benefits of Internet-Based Interventions for Public Health Promotion

Considering that, in both primary and secondary care settings, there are tremendous service gaps between supply and demand for psychological services and the costs of treatment are large, Internet-based intervention is a viable option to reduce stress—which is a significant risk factor for poor mental health—and to promote mental well-being for adults in the community [1]. It provides an effective, low-cost, convenient, and anonymous alternative and makes health promotion more accessible to those who would otherwise not seek help due to cost, inconvenience, stigma, and other barriers to help-seeking [7,8]. In Hong Kong, the Internet is a convenient and accessible portal for providing health promotion and universal preventive measures, as 77.9% of households have Internet access and 72.8% of individuals over 10 years old have used the Internet in the past year [9].

Internet-based interventions have been shown to be effective in the prevention of depression and anxiety for both research trial participants and public registrants [10-16]. The effectiveness of Internet-based mental health promotion was also demonstrated in community samples in Western countries [10,12-14,16]; however, no study to date has evaluated Internet-based mental health promotion programs in Asia.

Mindfulness as Means of Promoting Mental Health

In addition to the prevention of mental illness, mental health promotion involves tackling risk factors and promoting positive aspects of individuals' lives and their overall quality of life [1]. In recent decades, mindfulness has gained attention in the domain of mental health promotion and psychological intervention. Many well-researched therapeutic approaches have incorporated mindfulness into their intervention, including acceptance and commitment therapy, dialectical behavior therapy, mindfulness-based cognitive therapy (MBCT), and mindfulness-based stress reduction (MBSR). Although these approaches may vary in terms of therapeutic techniques and emphasis, the core philosophy on present moment awareness with compassion remains the same. Traditionally, mindfulness is a systematic training to develop sustainable attention and awareness with the aim to glean insight from direct experiences [17]. It is part of the comprehensive Buddhist teachings at attaining genuine and sustainable well-being.

Mindfulness is an approach that focuses on the cultivation of conscious, non-judgmental awareness in the unfolding of events in the present moment [18]. It emphasizes the transience of all experiences. It involves self-regulation of attention and orientation towards the present moment with curiosity, openness, and acceptance [19]. Developed in the behavioral medicine setting for people with stress-related disorders, MBSR was the first manualized mindfulness-based training program. It was later adapted into MBCT [20]. During the 8-week program, mindfulness is cultivated through exercises such as sitting meditation, body scan, and stretching exercises [18]. In addition to formal practices, participants are encouraged to practice mindfulness during daily activities (eg, walking or eating).

Empirically, mindfulness-based approaches have demonstrated effectiveness in treating depression, anxiety disorders, and a host of other physical and mental health conditions in both non-clinical and clinical populations [21-25]. The approach also reduced psychological and physical symptoms among community adults [26-28]. A study conducted among adults in the wider community showed that, compared with cognitive-behavioral stress reduction, MBSR demonstrated larger effects across indices including energy, pain, well-being, and perceived stress [27]. In a randomized clinical trial comparing mindfulness with relaxation training among community adults, although both programs showed similar effects in reducing distress, mindfulness showed greater effects in enhancing positive states of mind [29]. Thus, a mindfulness-based approach has the potential not only to prevent mental health problems, but also to promote positive well-being and overall health.

Health Action Process Approach as a Means to Enhance Mindfulness Practice

Given that mindfulness-based training is traditionally delivered face-to-face and requires participants to diligently practice mindfulness daily throughout the training period, adherence to mindfulness practice may be a concern if delivered over the Internet. In this study, in addition to investigating the efficacy of Internet-based mindfulness programs for mental health promotion, we also evaluated the utility of applying principles set out in the Health Action Process Approach (HAPA) in enhancing the effect of mindfulness on mental health outcomes. This was done by comparing its effects on (1) an Internet-based mindfulness program, (2) an Internet-based, HAPA-enhanced mindfulness program, and (3) a waitlist control group. Results were assessed at the end of the 8-week program and at 3-month follow-up.

The HAPA stresses the importance of post-intentional mechanisms in making behavior change. It has been widely applied across many different health behaviors and across a wide range of health conditions to promote behavioral change, including adherence to physical exercise after cardiac rehabilitation [30,31], breast self-examination [32], dietary behaviors [33-36], vaccination adherence [37], and physical activity [35,38].

Given that mind wandering (the opposite of a mindful state) is a habitual tendency in most individuals, it is not uncommon for people new to mindfulness training to become frustrated and confused by the nature of the exercises. Therefore, in the HAPA-enhanced mindfulness condition, we incorporated specific guidelines to enable participants to anticipate difficulties in keeping up the routine and to develop their own corresponding mitigation strategies. Messages on acknowledgment of potential difficulties and encouraging resumption (despite temporary disengagement) were incorporated in the lesson content. Thus, the HAPA-enhanced condition aimed to increase participants' planning of and

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effectiveness in their daily exercises, as well as development of coping strategies towards daily obstacles and resumption of practice after setbacks.

Despite a wealth of evidence being established for Internet-based interventions and mindfulness separately, researchers are still at an early stage in empirically evaluating the efficacy of online mindfulness program (eg, [39]), which can potentially be a cost-effective promotion and universal prevention option for adults in the community. This study sought to evaluate such programs in a randomized controlled trial (RCT). We hypothesized that the HAPA-enhanced mindfulness group would demonstrate better outcomes than the basic mindfulness group, and both groups would attain better well-being than waitlist control.

Methods

Participants, Design, and Procedure

Participants were recruited from seven local universities in Hong Kong through mass emails, newsletters, and online forums. The general public was welcome to join. All participants were above age 18 and were computer literate. In total, 321 university staff and students signed up for the program. We randomly assigned them into three groups based on a random digit generated by the computer program: HAPA-enhanced mindfulness, basic mindfulness, and waitlist control. The study was approved by the institutional review board of the investigators' university. See Multimedia Appendix 1 for the CONSORT-EHEALTH checklist [40].

While 105 participants from the HAPA-enhanced group and 104 from the basic mindfulness group completed the pre-program survey, only 73.8% (79/107) of participants from the control condition remained to give informed consent. Our sample had a mean age of 22.8 (SD 6.504); the majority (191/286, 66.3%, with 2 missing data) was female. Less than one-fifth (15.6%, 45/285, with 3 missing data) reported having previous experience on mindfulness and related practice. About one-third (34.7%, 100/287, 1 missing data) reported having a religious belief, with most of them being affiliated with Christianity (14%, 40/63), followed by Catholicism and Buddhism, with each accounting for 4% (10/63); 1 person reported to be affiliated with Taoism, and 2 were affiliated with other religions. Chi-square analysis revealed no cross-group differences on previous mindfulness practice and religious affiliation. For age, analysis of variance (ANOVA) indicated that control participants (mean age 21.4, SD 6.04) were significantly younger than the basic mindfulness groups (mean age 24.1, SD 7.61) but not the HAPA-enhanced group (mean age 22.4, SD 5.36; $F_{2,276}$=3.99, P=.02). As for retention rate at post-program and 3-month follow-up (see Figure 1), the overall retention rates were 51.1% (164/321) and 32.7% (105/321) at post-assessment and 3-month follow-up, respectively.

Participants assigned to the HAPA-enhanced and basic mindfulness groups were invited to attend a 3-hour workshop to provide a basic overview of mindfulness and other logistic details concerning website usage. On a set date, all participants started the online programs, which were similar to the traditional MBSR structure, with the exception of the full-day retreat. The program content and exercises were prepared by the research team based on the MBSR materials used locally by a certified mindfulness trainer with granted permission on usage. The final contents were reviewed by a certified MBSR trainer. New online lesson material was made available weekly, with a total of eight lessons.

Participants logged into the assigned website using a unique user identity and password, and their progress was tracked by the system. They were expected to spend an average of 30 minutes per week viewing each lesson, which consisted of an overview of various mindfulness topics, in addition to downloadable meditation audios and videos for mindful stretching exercises, lasting 20-30 minutes each (see Figures 2-4 for screenshots). Participants were asked to conduct formal mindfulness practice for 20-30 minutes daily for 6 days a week. Participants were also encouraged to engage in various mindfulness practices on a daily basis and to report their progress weekly using a log sheet. All materials were presented in Chinese, which was the native language for all participants. Automated emails were sent to participants once a week to remind them about their weekly attendance and regular practice.

All course materials related to teaching mindfulness were identical between HAPA-enhanced and basic mindfulness groups, except that the HAPA-enhanced participants received additional guidance derived from the HAPA model to help them translate intention into action and keep up the exercises despite setbacks. These included:

1. Action and maintenance self-efficacy. Additional self-efficacy statements (eg, "You only have to practice for 20 minutes a day; you can do it!" and "Believe in yourself; keep practicing") were incorporated in the course materials to motivate participants to turn motivation into action.
2. Action planning. In the weekly homework log sheets, participants had to write down when, where, and how they planned to engage in the assigned mindfulness practice to concretize their practice plan. Statements related to planning (eg, "Mindfulness practice only takes 20 minutes a day; try to plan ahead") also appeared in the session content to improve their planning.
3. Coping planning. Participants were asked to envisage potential obstacles that might hinder their practice, followed by concrete strategies that they would use to overcome them.
4. Recovery self-efficacy. Reminder statements were added to emphasize the importance of resuming practices when participants lapsed. For example, "If you fell asleep during practice, don't be discouraged. Just learn to feel your body; you can do it!" Participants were also asked to write down their successful experiences, which served to further reinforce their regular practices.
5. Based on the participants' responses about their last session's practice, a variety of pop-up messages appeared in the following session to increase their efficacy. For example, if the participant had practiced only 1-2 days a week, the message was "Keep working hard; you will feel the changes if you practice mindfulness regularly. Using the action and coping planning worksheets and your

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self-efficacy, you can practice more!" The message for daily practitioner was "Well done, it is great that you are keeping up with your daily mindfulness practice. You have worked hard to beat the odds and difficulties in your practice. Keep believing you can carry on. Well done and continue practicing mindfulness."

Figure 1. Flowchart of randomization and retention of participants.

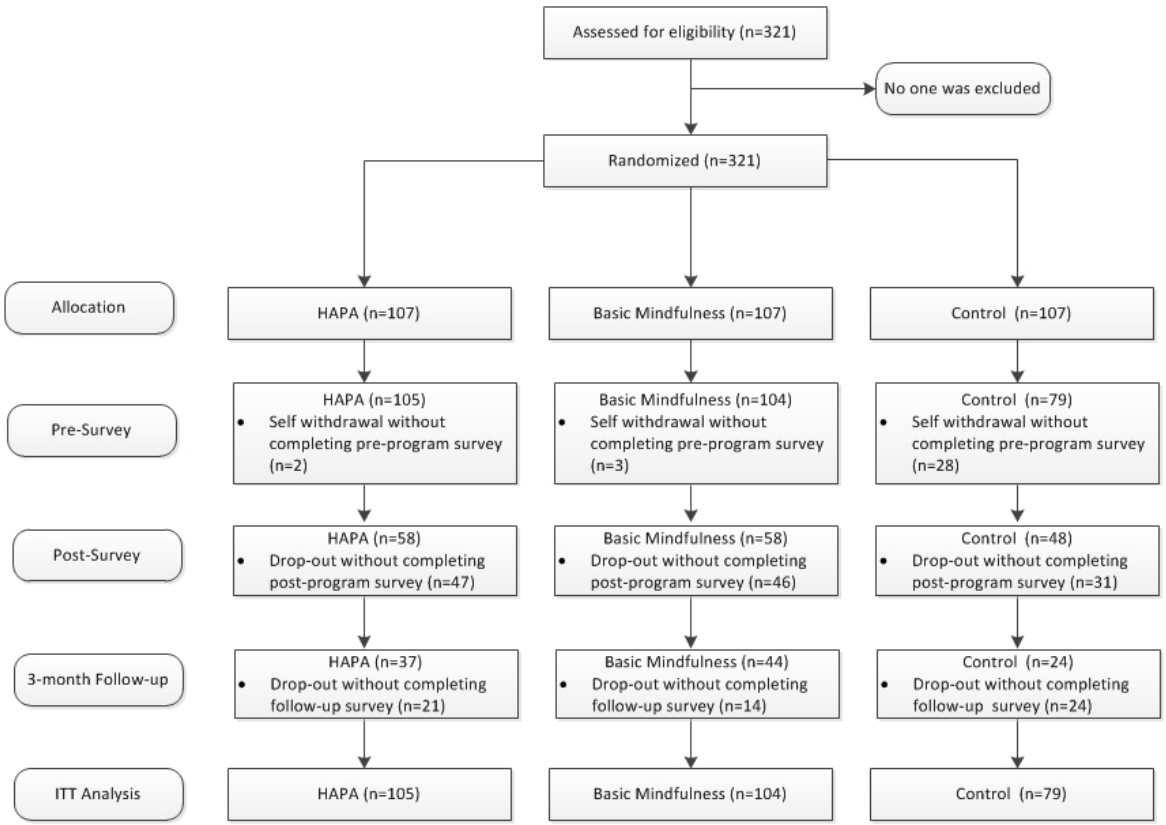


Figure 2. MindfuLiving login page.



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Figure 3. MindfuLiving lesson content.



Figure 4. Suggested off-class mindfulness practices.



Measures

Mindfulness

The 39-item Five Facets Mindfulness Questionnaire was used to examine participants' changes in mindfulness level over the course of our program [41]. Participants gave a rating from 1-5 ("never or rarely true" to "very often or always true") on items covering five mindfulness aspects: non-reactivity, observing, acting with awareness, describing, and non-judging. Sample items include "I perceive my feelings and emotions without having to react to them" (non-reactivity), "When I am walking, I deliberately notice the sensations of my body moving" (observing), "I find it difficult to stay focused on what's happening in the present" (acting with awareness), "I am good at finding the words to describe my feelings" (describing), and "I criticize myself for having irrational or inappropriate

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emotions" (non-judging). Cronbach alpha was .88 at baseline, .91 at post-assessment, and .90 at 3-month follow-up.

Mental Well-Being

The 5-item World Health Organization Well-Being Index was used to assess participants' global mental well-being [42]. Sample items included "I have felt cheerful and in good spirits" and "I woke up feeling fresh and rested". Participants rated on a 6-point Likert scale from 0-5 ("at no time" to "all of the time"). Cronbach alpha was .89 at baseline, .93 at post-assessment, and .93 at follow-up.

Life Satisfaction

The Satisfaction With Life Scale [43], together with one item from the Delighted-Terrible (D-T) scale [44] was used to assess participants' cognitive and affective evaluations of their life. It had a 7-point Likert scale from 1-7 ("strongly disagree" to "strongly agree") on items such as "In most ways my life is close to my ideal" and "I am satisfied with my life". Cronbach alpha was .90 at baseline, .91 at post-assessment, and .94 at follow-up.

Perceived Stress

To understand the extent to which participants' personal life situations were perceived as stressful, the 10-item Perceived Stress Scale was used [45]. Participants rated from 0-4 ("never" to "very often") on items such as "In the last month, how often have you been upset because of something that happened unexpectedly?" and "How often have you felt things were going your way?". Cronbach's alpha was .87 at baseline, .80 at post-assessment, and .82 at follow-up.

Psychological Symptoms

The short version of the Depression Anxiety Stress Scales (DASS 21) was used to gauge the severity and frequency of symptoms related to depression, anxiety, and stress [46]. It has a 4-point Likert scale ranging from 0-3 ("not applied at all" to "applied very much or most of the time"). Cronbach alpha for each subscale at baseline, post-assessment, and follow-up was as follows: .83, .86, and .87 for the depression subscale, .77, .76, and .85 for the anxiety subscale, and .86, .86, and .88 for the stress subscale.

Statistical Analyses

Intention-to-treat analysis, with the last observation carried forward, was adopted as a stringent test of efficacy. Repeated measures ANOVA was used to examine outcome changes over time across groups; when the assumption of sphericity was not met, we either adopted the Greenhouse-Geisser adjustment (when epsilon is <.75) or the Huynh-Feldt adjustment (when epsilon ≥.75) to examine the result [47]. Post-hoc analysis was conducted to explore how each group changed over three time points.

Results

Effects on Mindfulness

A marginal significant time x group interaction on overall mindfulness was found ($F_{4,568}$=2.86, partial eta square=0.02, P=.05; the effect was small). While there was no significant main effect of time for control and basic mindfulness groups ($F_{1.67,130.38}$=2.66, partial eta square=0.03, P=.083; $F_{1.39,142.66}$=1.29, partial eta square=0.01, P=.27, respectively), the HAPA-enhanced group showed significant improvement from pre- to post-, and such improvement was sustained at 3-month follow-up, with an overall medium effect size, ($F_{1.45,150.72}$=7.67, partial eta square=0.07, P=.002). No significant interaction effect of individual mindfulness facets was found.

Effects on Mental Well-Being

Significant time x group interaction was found ($F_{3.76,481.13}$=3.13, partial eta square=0.024, P=.02). Both basic mindfulness ($F_{1.86,191.14}$=10.09, partial eta square=0.09, P<.001) and HAPA-enhanced groups ($F_{1.77,184.52}$=11.38, partial eta square=0.10, P=.001) demonstrated significant improvement from pre- to post- with medium effect size, and improvement was sustained at 3-month follow-up. No significant changes were observed among the waitlist controls across time ($F_{1.39,68.19}$=0.254, partial eta square=0.005, P=.69).

Effects on Life Satisfaction

No significant time x group interaction, but a significant main effect of time ($F_{1.61,453.04}$=8.58, partial eta square=0.03, P=.001) was found. Post-hoc analysis indicated that only the HAPA-enhanced group exhibited a significant main effect of time, with a medium effect size of significant increase in life satisfaction over time, $F_{1.45,150.79}$=9.97, partial eta square=0.09, P<.001.

Effects on Perceived Stress and Psychological Symptoms

No significant time x group interaction was found in perceived stress ($F_{3.26,463.89}$=1.72, partial eta square=0.01, P=.16), depression ($F_{3.52,500.81}$=0.60, partial eta square=0.004, P=.64), anxiety ($F_{3.56,505.04}$=1.71, partial eta square=0.01, P=.16), and stress ($F_{3.48,494.74}$=1.68, partial eta square=0.012, P=.16). Mean scores of depression, anxiety, and stress for all groups across three time points all fell within the normal range of DASS [46]. See Tables 1 and 2 for the comparison of outcomes across three groups.

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Table 1. Mean (SD) among basic mindfulness, HAPA-enhanced mindfulness, and waitlist control groups on outcomes.

	Basic mindfulness			HAPA-enhanced mindfulness			Control		
	Pre	Post	Follow-up	Pre	Post	Follow-up	Pre	Post	Follow-up
Overall mindfulness	3.13 (0.52)	3.19 (0.53)	3.16 (0.49)	3.08 (0.48)	3.18 (0.49)	3.18 (0.48)	3.18 (0.42)	3.15 (0.43)	3.22 (0.41)
Non-reactivity	3.08 (0.71)	3.01 (0.93)	3.08 (0.73)	3.02 (0.62)	3.07 (0.64)	3.07 (0.63)	3.08 (0.71)	3.02 (0.81)	3.12 (0.69)
Observing	3.11 (0.78)	3.20 (0.91)	3.21 (0.84)	3.20 (0.71)	3.33 (0.76)	3.31 (0.79)	3.21 (0.76)	3.17 (0.82)	3.27 (0.86)
Acting with awareness	3.25 (0.81)	3.30 (0.81)	3.19 (0.76)	3.15 (0.88)	3.22 (0.78)	3.23 (0.79)	3.33 (0.88)	3.29 (0.93)	3.30 (0.88)
Describing	3.17 (0.89)	3.18 (0.79)	3.12 (0.77)	3.10 (0.91)	3.22 (0.84)	3.21 (0.83)	3.25 (0.76)	3.20 (0.73)	3.27 (0.67)
Non-judging	3.00 (0.79)	3.18 (0.88)	3.19 (0.81)	2.91 (0.73)	3.05 (0.75)	3.09 (0.81)	3.03 (0.75)	3.04 (0.75)	3.08 (0.75)
Mental well-being	13.22 (5.07)	15.17 (5.31)	14.47 (5.21)	12.76 (5.65)	14.25 (5.50)	14.51 (5.05)	16.58 (5.29)	16.56 (5.36)	16.22 (5.74)
Life satisfaction	4.16 (1.34)	4.46 (1.32)	4.37 (1.40)	3.96 (1.40)	4.24 (1.36)	4.33 (1.38)	4.55 (1.16)	4.57 (1.30)	4.64 (1.32)
Perceived stress	1.72 (0.60)	1.65 (0.53)	1.70 (0.53)	1.80 (0.63)	1.70 (0.61)	1.67 (0.62)	1.63 (0.70)	1.62 (0.70)	1.63 (0.70)
Depression	6.10 (6.33)	5.69 (6.75)	6.81 (7.16)	6.95 (7.67)	6.51 (7.37)	6.88 (7.70)	5.47 (7.55)	5.85 (7.74)	5.90 (8.12)
Anxiety	6.70 (5.21)	6.56 (5.40)	7.29 (6.36)	7.49 (6.63)	6.27 (6.63)	6.46 (6.60)	6.20 (8.02)	5.67 (7.26)	5.72 (7.64)
Stress	11.43 (8.51)	10.29 (8.74)	11.50 (8.93)	12.44 (9.21)	10.55 (9.05)	10.72 (9.01)	9.52 (9.45)	9.44 (9.23)	9.19 (9.35)

Table 2. Effect size (Cohen's *d*) among basic mindfulness, HAPA-enhanced mindfulness, and waitlist control groups on outcomes.

	Basic mindfulness		HAPA-enhanced mindfulness		Control	
	Pre & post	Pre & follow-up	Pre & post	Pre & follow-up	Pre & post	Pre & follow-up
Overall mindfulness	0.08	0.04	0.25	0.19	-0.07	0.10
Non-reactivity	-0.11	-0.06	0.08	0.08	-0.08	0.06
Observing	0.07	0.13	0.24	0.17	-0.03	0.10
Acting with awareness	0.02	-0.13	0.05	0.05	-0.04	0.03
Describing	-0.01	-0.06	0.01	0.11	-0.07	0.03
Non-judging	0.21	0.23	0.27	0.27	0.01	0.07
Mental well-being	0.35	0.20	0.24	0.24	-0.21	-0.22
Life satisfaction	0.18	0.16	0.22	0.26	0.02	0.07
Perceived stress	-0.09	-0.04	-0.20	-0.16	-0.01	0.00
Depression	-0.04	0.10	-0.09	0.02	0.05	0.05
Anxiety	0.00	0.13	-0.20	-0.10	-0.05	-0.05
Stress	-0.64	-0.51	-0.77	-0.68	-0.45	-0.44

Correlation Between the Enhancement of Mindfulness and Mental Well-Being Improvement

After the 8-week program, for both basic mindfulness and HAPA-enhanced groups, significant correlations between the change scores of mental well-being and the change scores of mindfulness were found (r=.55, P<.001 and r=.58, P<.001, respectively). However, no significant correlation was found for waitlist controls (r=.21, P=.14), and the difference in correlations was significant between waitlist controls with basic mindfulness (z statistics=2.29, P=.02) and HAPA-enhanced groups (z statistics=2.55, P<.001) [48]. At follow-up, such correlation remained significant for HAPA-enhanced (r=.59, P<.001) and basic mindfulness groups (r=.43, P<.001) and became marginally significant for waitlist controls (r=.28, P=.051). However, the difference in correlations at follow-up between waitlist controls was not significant with basic mindfulness (z statistics=0.99, P=.32) but remained significant with HAPA-enhanced groups (z statistics=2.25, P=.02).

Mindfulness Practice Between Groups

In terms of time commitment on practices, based on the number of days people spent on their home practice during the 8-week program, no significant difference was observed between the basic mindfulness (mean 4.34, SD 3.78) and HAPA-enhanced groups (mean 4.18, SD 2.55); t_{81}=0.24, P=.81.

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Discussion

Principal Results

This study demonstrated the effectiveness of Internet-based mindfulness intervention in promoting mindfulness and mental well-being of adults in the community, particularly when the program was primed with efficacy and planning components from the Health Action Process Approach. Consistent with previous research that demonstrated the benefits of face-to-face MBSR programs for the general populations [49,50], and recent studies on preliminary evidence and feasibility of brief, online mindfulness courses [39,51], this study further demonstrated that mindfulness can be cultivated over the Internet and such online training can promote mental well-being in an RCT. With the Internet being highly accessible nowadays, Internet-based mindfulness interventions can be a convenient and effective means of promoting public mental health.

Unlike the traditional face-to-face mindfulness-based training programs (eg, MBSR) that pose a heavy time demand on the participants (ie, eight weekly 2.5 hour sessions, 45 minutes daily of formal mindfulness practice for 6 days a week, and a full-day retreat), this program required participants to complete eight 30-minute online sessions, in addition to having 30 minutes of formal mindfulness practice daily for 6 days a week. Previous meta-analysis has found no significant correlation between in-class contact hours and effect sizes of psychological outcomes for both non-clinical and clinical populations and has suggested the possibility of adapting the class time for future practice [52]. Our findings supported the reduction of time commitment for mindfulness practice in providing promising effects on mental well-being of adults in the wider community. In light of the fact that the general public may be less motivated and committed to devoting time for their mental health, Internet-based mindfulness with reduced time demands may be a viable substitute. Moreover, the accessibility, convenience, affordability, and anonymity of Internet-based mindfulness intervention may be regarded as added values that may be appealing to the public, compared with face-to-face mindfulness programs.

This study's findings also demonstrated that an Internet-based mindfulness program enhanced with HAPA elements could better help participants enhance their mindfulness and mental well-being than its basic form. A slightly stronger relationship between mindfulness with mental well-being was also observed in the HAPA-enhanced group. Results suggested that the supplementary messages intended to increase participants' planning and practice efficacy and the strategies to help them deal with obstacles may enhance the effects of the program for them. Although the HAPA-enhanced group did not spend more time on practicing than the basic mindfulness group, the former seemed to be able to get more out of their practice. Future research should further examine the mediating roles of HAPA components directly (eg, action self-efficacy, recovery self-efficacy, action, and coping planning) in order to tailor the delivery of online mindfulness training to maximize gains for the general public.

Limitations

Because the sample focused on university students and staff, the findings may not be generalizable to the general population. Future studies should extend this program to the general public to investigate its efficacy to a wider population. Second, close to half of the participants were lost at post-program assessment and two-thirds lost at 3-month follow-up. Although high attrition rate has been a perennial problem for Internet-based interventions [53-55], with an average of 74.7% attrition observed, the remaining participants may represent a select and motivated group such that their results may not be generalizable to the general public. Furthermore, research has found that those who participated longer in the program and completed more sessions online were found to have better outcomes [56]. Future studies should obtain feedback from participants, especially from those who have dropped out to elucidate their reasons for dropping out versus completing the program. This information can assist researchers in exploring ways to enhance continued participation in Internet-based interventions. Possible strategies may include the inclusion of online support groups or chat rooms among participants to enhance a sense of membership and interpersonal support or the use of technicians in providing telephone support to minimize attrition [16,57,58]. Finally, we used waitlist control as a comparison group. Given that cognitive-behavioral Internet-based interventions have shown to be effective for various health conditions and populations [59,60], future research could consider comparing online cognitive-behavioral and mindfulness training programs to further investigate their differential effects, mechanisms of change, and suitability for different kinds of participants [61].

Conclusions

Notwithstanding these limitations, this study demonstrated the usefulness of health behavioral theory in enhancing changes in mindfulness and mental well-being among adults in an Internet-based program, and the application of Internet-based mindfulness training in promoting public mental health.

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Authors' Contributions

The study was designed by WM and EC. WM, EC, CL, and KN participated in the development of the materials. AC did the statistical analyses and WM and AC interpreted the data. WM and AC contributed to the final write-up of the manuscript. All authors approved the final article.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT-EHEALTH checklist V1.6.2 [61].

[PDF File (Adobe PDF File), 991KB - jmir_v17i1e8_app1.pdf]

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Abbreviations

ANOVA: analysis of variance
DALY: disability-adjusted life years
DASS: Depression Anxiety Stress Scales
HAPA: Health Action Process Approach
MBCT: mindful-based cognitive therapy
MBSR: mindfulness-based stress reduction
RCT: randomized controlled trial

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Original Paper

Automatic Identification of Web-Based Risk Markers for Health Events

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Abstract

Background: The escalating cost of global health care is driving the development of new technologies to identify early indicators of an individual's risk of disease. Traditionally, epidemiologists have identified such risk factors using medical databases and lengthy clinical studies but these are often limited in size and cost and can fail to take full account of diseases where there are social stigmas or to identify transient acute risk factors.

Objective: Here we report that Web search engine queries coupled with information on Wikipedia access patterns can be used to infer health events associated with an individual user and automatically generate Web-based risk markers for some of the common medical conditions worldwide, from cardiovascular disease to sexually transmitted infections and mental health conditions, as well as pregnancy.

Methods: Using anonymized datasets, we present methods to first distinguish individuals likely to have experienced specific health events, and classify them into distinct categories. We then use the self-controlled case series method to find the incidence of health events in risk periods directly following a user's search for a query category, and compare to the incidence during other periods for the same individuals.

Results: Searches for pet stores were risk markers for allergy. We also identified some possible new risk markers; for example: searching for fast food and theme restaurants was associated with a transient increase in risk of myocardial infarction, suggesting this exposure goes beyond a long-term risk factor but may also act as an acute trigger of myocardial infarction. Dating and adult content websites were risk markers for sexually transmitted infections, such as human immunodeficiency virus (HIV).

Conclusions: Web-based methods provide a powerful, low-cost approach to automatically identify risk factors, and support more timely and personalized public health efforts to bring human and economic benefits.

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KEYWORDS

Information retrieval query processing; epidemiology; self-controlled case series; Machine Learning; Web search engines

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Introduction

The identification of risk factors that contribute to the onset of a medical condition plays a crucial role in public health planning, disease prevention, and the promotion of health and wellness. Such factors can be behavioral, such as the link between smoking and lung cancer, or biological and social, and are often interconnected though not necessarily causal. Traditional investigations of associations between individuals' behaviors and disease rely on analysis of historical medical and public health records (eg, birth and death certificates, hospital admissions), clinical cohort studies, and questionnaires. However, they are often constrained by size, and/or limited information on the full range of diseases, and exposures of interest. Assessing diseases where there are social stigmas is problematic, since they may prevent people from attending clinics, for example, sexually transmitted infections and mental health conditions such as anorexia.

In contrast, anonymized Web search engine query logs facilitate studies with cohort sizes that can include millions of users with many thousands of health events and wide-ranging behavioral information. Every day, millions of people search for information on the Internet and leave electronic traces that can be used to characterize their behaviors and interests. Around 80% of US Internet users seek health information online often before they visit health care professionals [1]. Search engine queries, and user queries in general, have been shown to reflect both the activities of people in the virtual world [2] as well as those in the physical one. For example, Ofran et al [2] found a high correlation between the number of searches for specific types of cancer and their population incidence. Similarly, a high correlation was observed between the number of prescriptions sold for a drug and the number of people who search for it [3]. This has led to a body of work using Internet data to study health, in a burgeoning field also termed "infodemiology" [4] or computational epidemiology [5]. Examples of such work include monitoring of influenza activity [6-9], examining the association between weight and bullying and health [10], exposure to underweight celebrities and the development of eating disorders [11], potential adverse effects of medicines [3], and predicting depression and its appearance [12,13]. Thus, Internet data and especially anonymized search engine query logs provide an unprecedented opportunity to study public health.

The self-controlled case series (SCCS) [14] approach is increasingly used in analysis of large health datasets to investigate the association between a transient exposure and a health event. The method uses only cases (without separate controls), which act as their own controls. SCCS calculates the relative hazard of the health event in the risk period following exposure compared to other time periods. Our work builds on this approach to automatically analyze search engine query logs to identify risk markers for health conditions.

Methods

Overview

Our goal was to identify precursor behaviors associated with specific medical conditions. We refer to the proposed solution as the Search Log Analysis for Precursor Behaviors (SLAPB) method, which involves a three-staged process. First, we identified a population of users who were likely to have a medical condition of interest as well as the date this was first acknowledged. Second, we generalized user queries into categories. Finally, we analyzed users' query streams to find likely precursor behaviors. In the following, we describe the three stages.

Data

We extracted all English language queries submitted to the Bing search engine by users in the United States for the 6-month period starting May 2012. Users agreed to provide their search data as part of the terms of use. Data were anonymized by hashing, before access was granted to the investigators, and aggregated prior to analysis. For each query, we extracted the query text, time and date, a list of pages visited by the user as a result of the query, the zip code of the user (identified according to their IP address), and an anonymized user identifier. A small proportion of users provided information on their year of birth as part of their online profile. No further information, such as gender, were available from these data.

The research was reviewed by the Microsoft Research Institutional Review Board (IRB9672), and was deemed exempt.

Identification of Populations With Specific Health Conditions

Our first task was to discover a population that has a medical condition of interest, given the queries made by users. We note that we did not seek to diagnose users. We assume that they have already sought medical attention to provide diagnosis and that their queries reflect this. Our goal in this stage was to find a group of users for whom precursor behaviors could be discovered.

We obtained a list of medical terms, which included symptoms, disease names, and drug names, in order to identify medical concerns in each user query. We used the list of 195 medical symptoms and their synonyms from Yom-Tov and Gabrilovich [3]. This is a list obtained from Wikipedia entries of ICD-10 (International Classification of Diseases) symptoms, and expanded through behavioral analysis of Web queries. The list was validated by medical professionals as detailed in Yom-Tov and Gabrilovich [3].

We extracted all the diseases and drug names that appear in Wikipedia through their "DBPedia" entries. Additionally, we augmented each disease and drug through their redirection entries, which serve as synonyms for these entries. A total of 5521 diseases and 5195 drugs were found, together with a total of 26,639 disease name synonyms and 30,409 drug name synonyms. Synonyms were mapped to the relevant disease or drug name.

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Using this list, we represented each user by a 10,911-dimensional vector, where each entry is the number of times each symptom, disease, drug, or their synonyms were mentioned in queries made by the user during the data period. Synonyms were counted with the original term.

First, we focused on a subpopulation of users who identified in their queries that they had a specific health condition. Such users queried, for example, "I was diagnosed with HIV [human immunodeficiency syndrome]". We marked as self-identified users (SIUs), those users who queried for a disease name or medical condition in conjunction with one of the following phrases: "I have", "I suffer from", "living with", and "I was diagnosed with". We focused on health conditions with at least 25 SIUs, and thus analyzed a population of 18,859 users who self-identified as having one of 92 medical conditions.

We make two very strong assumptions: (1) such users have the health event, and (2) that the onset or diagnosis of the health event occurred at or very near to the time the user made the first query identifying them as an SIU. Of course, neither assumption is valid for all users. However, we believe that the assumptions are, in the majority of cases, valid.

To investigate the validity of our first assumption, that is, that self-identified users experienced the associated health event, we compared the incidence in the United States of 29 diseases as reported in the scientific literature with the corresponding incidence in the SIU group. Table 1 lists the 29 diseases, in rank order, together with their incidence. Table 1 also lists the corresponding incidence and rank in the SIU group. Comparing the relative incidence produces a Spearman rank correlation of rho=.47 (P=.005). Though this is a relatively high correlation, we note that it was imperfect for several reasons, including the prominence of that disease in the media, the generality of the term ("cancer" versus "gall bladder cancer"), and sample representativeness. The second assumption was previously made, and validated, in Ofran et al [2].

The 18,859 users labeled as SIU (and having one of 92 events) was not sufficiently large to conduct the subsequent analysis. Thus, in order to identify a larger group of users who are very likely to have experienced a health event, we used the set of SIUs as a training set, and trained a linear support vector machine (SVM) to classify other users. We represented each user as described above.

This is a very high dimensional feature vector, comprising the number of times each user queried for one of the 5521 diseases, 5195 drugs, and 195 symptoms or their synonyms. Thus, we performed an intermediate analysis to determine which of these features were most important for determining the health event associated with each SIU. We constructed a classifier based on these features, and attempted to predict the health event of a test set population. We constructed a linear SVM (using the LIBSVM [15] classifier with default settings) to predict the condition identified by the SIUs, and tested its performance using five-fold cross validation [16] on the 18,859 SIUs.

The results of classifying users into their diseases are shown in Table 2. As this table shows, the most informative features are disease names. The performance of the classifier when using only disease names reaches slightly over 88% correctly classified users. This is in line with the observation that SIUs ask about their condition 6.8 times, on average, compared to 2.15 in the general population of users who asked about specific diseases. Adding features describing drugs and/or symptoms adds little to the classifier's performance. This is surprising and may be due to the fact that both symptoms and drugs may map to multiple diseases. Future work will investigate how this mapping might be integrated into the classifier, possibly through a hierarchical classification scheme.

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Table 1. Disease incidence[a] in the United States and in the self-identified user (SIU) population for 29 diseases.

Disease	Percentage of SIUs	Incidence in the United States	Rank of SIU	Rank of incidence in the United States
HIV	6.17E+00	1.53E-04	1	18
Cancer	5.19E+00	5.37E-03	2	3
Diabetes mellitus	4.42E+00	6.13E-03	3	2
Herpes simplex	2.34E+00	2.50E-03	4	4
Arthritis	1.30E+00	4.10E-04	5	11
Atrial fibrillation	1.08E+00	6.45E-02	6	1
Gastroparesis	1.05E+00	2.50E-05	7	28
Heart failure	9.70E-01	1.77E-04	8	15
Schizophrenia	9.44E-01	7.00E-04	9	8
Crohn’s disease	8.38E-01	7.90E-05	10	20
Dementia	7.69E-01	1.51E-03	11	5
Alzheimer's disease	7.53E-01	1.26E-03	12	6
Amyotrophic lateral sclerosis	6.04E-01	1.81E-05	13	29
Parkinson's disease	5.62E-01	1.77E-04	14	15
Breast cancer	5.04E-01	7.51E-04	15	7
Colitis	4.40E-01	8.80E-05	16	19
Asthma	4.19E-01	7.00E-04	17	8
Epilepsy	3.92E-01	4.70E-04	18	10
Lyme disease	3.45E-01	7.00E-05	19	23
Hepatitis C	3.08E-01	5.48E-05	20	25
Spina bifida	2.65E-01	3.49E-04	21	12
Leukemia	2.55E-01	1.69E-04	22	17
Hypothyroidism	2.33E-01	2.86E-04	23	13
Chronic pancreatitis	2.28E-01	4.35E-05	24	27
Celiac disease	2.17E-01	6.50E-05	25	24
Cardiomyopathy	1.96E-01	5.00E-05	26	26
Multiple myeloma	1.59E-01	7.76E-05	27	21
Lymphoma	1.48E-01	2.58E-04	28	14
Brain tumor	1.22E-01	7.54E-05	29	22

[a]Incidence is provided as a fraction of the population.

Table 2. Percentage of correctly classified self-identified users (SIUs) given users’ queries for drugs, diseases, symptoms, and their combinations (n=18,859).

Attribute	Correctly classified, n (%)
Drugs	6751 (35.80)
Diseases	16,652 (88.30)
Symptoms	6695 (35.50)
Drugs and diseases	16,671 (88.40)
Drugs and symptoms	6714 (35.60)
Diseases and symptoms	16,675 (88.42)
All three attributes	16,659 (88.33)

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An analysis of the most common errors in classifying SIUs given the profile of diseases each user queried for, shows that some of the 12% of errors might not be considered actual errors. Table 3 shows the top five errors of the classifier, which account for 30% of the classifier errors. Many are related to precursor diseases to HIV—CHILD syndrome is an early symptom of acquired immune deficiency syndrome (AIDS), as is HIV. Cancer might refer to Kaposi sarcoma, a tumor often associated with AIDS.

Table 3. Five most common errors of the classifier, which predicts SIUs given the disease profile.

Self-identified disease	Predicted disease	Percentage of errors
AIDS	HIV	9.6
AIDS	CHILD syndrome	7.1
AIDS	Pregnancy	6.5
HIV	AIDS	3.6
AIDS	Cancer	3.2

Based on this analysis, we used a much smaller 8-dimensional feature vector (see Table 4) to represent each user. We remind the reader that at this stage our goal was to build a classifier to answer the following question: How likely is the user to be suffering from the health event they most frequently queried for? For example, if a user queried 10 times for “breast cancer” and twice for “flu”, the classifier would give the likelihood that the person is suffering from breast cancer given the disease names “breast cancer” and “flu”, as well as the number of times each was queried. Given this likelihood, we can then determine whether users not in the SIU set have also experienced a health event, and thereby significantly increase the size of the population that has experienced a particular health event. The classifier is trained on the SIU set to distinguish between the 72.2% of cases where the most frequently queried condition is the self-identified condition and the remaining, where this is not the case.

We used five-fold cross validation using the set of self-identified users to test the classifier. Both a linear classifier and a decision tree were tested and both obtained similar performances. Therefore, we report the result of the linear classifier.

The area under the receiver operating characteristic (ROC) curve (AUC) obtained by the classifier using all eight features was 0.851. After running sequential forward feature selection [17], we found that an AUC of 0.855 (not statistically significantly different from the AUC using all the features) could be reached by using only three features, numbered 1, 2, and 5 in Table 4.

Thus, our classifier can accurately predict whether the most frequent disease or medical condition that a user asks about is the one he or she has. However, it may be that the population of SIUs is not representative of the entire patient population. Therefore, we collected from the incidence rates reported in the literature for 29 diseases. Our goal was to tune the classifier such that the relative incidence rate for diseases in the test group would be similar to the relative incidence rates in the general population. By setting a lower threshold of the classifier to decide if a user is suffering from a health condition, larger parts of the user population will be deemed as having a health condition.

Table 4. Attributes used to predict whether the most frequently queried disease is the one afflicting the user.

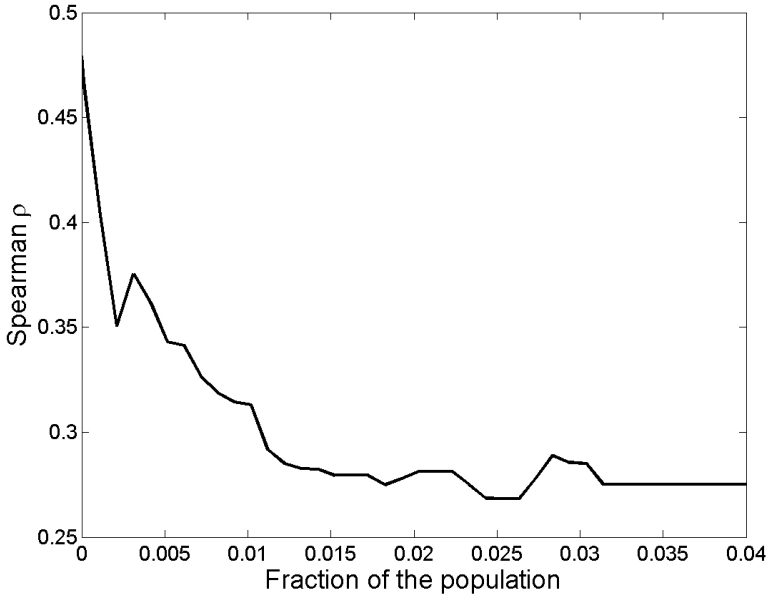
Index	Attribute
1	The number of times queried for the most common diseases.
2	The number of times queried for the second most common diseases.
3	The ratio between the above two.
4	The fraction of users who asked about the most common disease queried by the user.
5	The number of diseases that were asked about more than once.
6	The number of diseases that were asked about more than five times.
7	The number of diseases that were asked about more than 10 times.
8	Indication of queries for drugs related to the most common disease queried by the user: Let M be a matrix of co-occurring diseases and drugs, where Mi,j is the number of users who asked about disease i and also about drug j, and let D be a matrix of queries for each disease, where Dij is whether user i asked about drug j, we compute an indicator of whether the user asked about drugs related to the most common disease they asked about, by multiplying the row vector of D for each user by the matrix M.

The Spearman rank correlation between the SIU population for these diseases and the incidence data is rho=.48 (P=.0055). Figure 1 shows the dependence of the Spearman correlation on the fraction of the population determined to have a health condition. Here, a threshold of zero denotes the use of only the SIU population and, for any threshold greater than zero, all users for which the classifier gave a score greater than the threshold are identified as having the medical condition they most frequently queried about.

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The correlation is strongest for the SIU population. However, a correlation of rho=.32 is achieved for a threshold of around 0.007, with the advantage of having a population of users who are positively classified is 10.6 times greater than the SIU population, thus providing much more data for the next steps of the analysis. Thus, in the paper we use this threshold for identifying populations having specific conditions. We note that the classifier working at this threshold, when applied only to the SIU population, gives a true detection rate of 49.9% and a false alarm rate of 4.5%, that is, 49.9% of the SIU population who queried most often about their self-identified condition are identified as such by the classifier, at the cost of including 4.5% of the SIU population who queried most often about a different condition than their self-identified one.

Figure 1. Spearman correlation between known disease incidence (n=29) and the size of the population identified by the classifier, as a function of the classifier threshold.



Categorization of Web Queries

In this stage of the process we wanted to generalize users' queries so that broader categories of precursor behaviors might be discerned. For example, suppose users query for beaches to find where to go swimming. The hope is that our algorithms will be able to identify that, for example, swimming is a risk factor and not only that swimming at any specific beach is dangerous. Therefore, we required a way to automatically find a general category, for example, for all cigarette brand names and annotate all queries that describe a cigarette brand name with this category.

To categorize a query, we used query log information in conjunction with Wikipedia entries. We proceeded as follows. First, we found all queries (in the entire dataset) that resulted in users clicking on a specific Wikipedia page. We then found those queries that resulted in the same Wikipedia page being clicked on at least 10 times each month. If more than one Wikipedia page was clicked in response to a query, we chose the one clicked most often. The result of this stage is a list of queries and a corresponding Wikipedia page. For example, the query "pre-diabetes symptoms" is thus associated with the Wikipedia page on pre-diabetes [18].

Finally, each Wikipedia page from the above list is annotated by the Wikipedia categories of that page, as obtained from DBPedia. The above-mentioned query would thus be categorized with the following categories: (1) diabetes, (2) medical conditions related to obesity, and (3) nutrition.

Using this procedure, we categorized a total of 2,375,559 unique queries with one or more of 340,947 categories. In the following, each query made by a user is represented by both its text and by the categories associated with the query, if these are available. Note that not all queries could be annotated because in some cases users didn't click on a Wikipedia page when they made the query. In those cases, the query is not generalized and only its text is used as a category by itself.

Discovering Precursor Behaviors: The Self-Controlled Case Series Method

At this point, we have identified users who experienced a health event of interest. We then separately analyzed each health event. For a given health event, we have a corresponding set of users who we have identified as experiencing this event, and, based on their query logs, we have a corresponding set of queries, which we represent by the query text and the associated categories identified in Step 2. For each query text and each category, we then ask whether the specific text/category increases the risk of experiencing the health event. We use the SCCS method to answer this question.

The SCCS method was proposed by Farrington [14] as a method for estimating vaccine safety by measuring the relative incidence of adverse events after a vaccine. As its name suggests, instead of comparing a treated population (for example, one which received a vaccine) against a control population that didn't receive the treatment of interest, SCCS compares the treatment population against itself, albeit at different times.

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In the following, we provide a brief description of SCCS. More details can be found in Madigan et al [19]. Assume N people, denoted by i=1,2,…,N, are treated with a given drug. Some of them develop a medical condition, possibly in response to the drug. Each person is observed over a period of $D_i$days. The number of events (eg, medical condition of interest) on a specific day d is denoted by $y_{i,d}$and the day on which person i was exposed to the drug by $x_{i,d}$. If $x_{i,d}$=1, user i was exposed to the drug on day d.

SCCS assumes that the medical condition arises according to a non-homogeneous Poisson process, modulated by the drug exposure. Each person i has a baseline rate for developing the medical condition, e^{i}. Exposure to the drug causes a multiplicative effect of e^{β}on the baseline rate for a period of time, which is referred to as the risk (or incubation) period.

Assume two users are observed over a given time period ($D_i$equal to 6 months in this paper). Each is exposed to a drug on a day where $x_{i,d}$=1, which causes a possible risk for the development of a medical condition on a day when $y_{i,d}$=1.

The number of events observed for person i on day d has the density as shown in Figure 2. In order to find the parameter of interest, β, the log-likelihood over all people is maximized. Thus, we seek to maximize according to Figure 3. We refer to e^{β}(the parameter we aim to estimate) as the relative incidence or relative hazard of an event [17]. In our work, we used the Nelder-Mead simplex method [20] to maximize L.

We applied the SCCS method to our data by searching for precursor events to the development of a specific medical condition of interest. Rather than begin with a specific precursor event, we estimated the relative incidence of all categories and queries (as described in the previous section) available in the data. Thus, for a particular health event, we examine all individuals, i, that we identified as experiencing this event. For all individuals, the number of occurrences of the event, $y_{i,d}$=1, and is only 1 on the day the individual first self-identified or queried about the event. Then, for each category and query associated with the event, we determined the relative hazard, e^{β}.

One problem that arises in assessing the relative incidence of each category using a relatively limited time span is that transient events may occur that will appear related to the medical condition, when in fact they are related to external factors. For example, news events are known to have a typical spiking behavior with an average length of 3.1 days in search engine queries [21]. If, by chance, the peak of a news event appears close to the time of the medical condition, it may seem to be a precursor behavior.

To reduce this effect, we measured the correlation between the number of times per day that each category appears in the target population (eg, the people who have the medical condition of interest) and the number of times per day it appears in a random sample of users in the entire dataset. We then rejected any category that had a higher correlation than that expected by chance according to the False Discovery Rate (FDR) test [22]. We refer to this step as temporal filtering.

Figure 2. Self-controlled case series (SCCS) density equation.

$$P(y_{i,d}|x_{i,d}) = \frac{e^{-\lambda_{i,d}}\lambda_{i,d}^{y_{i,d}}}{y_{i,d}!}$$

where $\lambda_{i,d} = e^{\theta_i+\beta x_{i,d}}$

Figure 3. Self-controlled case series (SCCS) maximum likelihood equation.

$$L \propto \prod_{i=1}^{N}\prod_{d=1}^{D_i}\left(\frac{e^{\beta x_{i,d}}}{\sum e^{\beta x_{i,d}}}\right)^{y_{i,d}}$$

Results

Summary

We analyzed seven health conditions, termed “events” shown in Table 5. This table further provides the numbers of users classified as experiencing the event, the number of queries, and corresponding categories. The latter were derived from the Wikipedia categories of pages most strongly associated with each query. For each health event, we identified search categories queried for by at least 1% of the population experiencing the event. We applied the SCCS method to our data by estimating the relative incidence of the health event in the 15 days following each of these search category queries compared to other time periods. Precursor search categories or specific query terms that precede the health event with an FDR of <5% and the corresponding relative hazards are shown in Table 6.

Statistically significant precursor behaviors were identified for each of the seven health events. Many of these behaviors are either known or suspected. In some cases, the method raises plausible new behaviors, which need to be confirmed through traditional epidemiology. In some cases, new online behaviors are identified for which there do not appear to be causal relationships. Of course, this is a manifestation of the limits of

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such an analysis in which correlation, rather than causation, is used to generate hypotheses.

The following paragraphs discuss the results for each health event. Note that the last column of Table 6 provides the relative hazard, which is defined above.

The most common medical condition identified was pregnancy and as expected searches indicating interest in pregnancy ("fertility" and "pregnancy symptoms") preceded pregnancy, supporting the validity of our method. The categories "Pregnancy with abortive outcome" and "medical emergencies" may relate to concerns about pregnancy outcomes. Mechanisms for a link with "Teen pregnancy in film and television" are unclear.

The second most common event was allergy. Several preceding search categories associated with allergy are related to household pets (a known allergen for some people) [23]. These include names of pet stores (Petco and PetSmart) and the general category of "pet stores". The broad food category identified may be indicative of specific foodstuffs that are allergenic.

We investigated two sexually transmitted infections: HIV and herpes simplex (genital herpes simplex is sexually transmitted but oral herpes simplex is not). Two of the preceding search categories associated with both diseases were dating websites and the consumption of adult content (RedTube and Xtube). Studies have found a link between accessing adult sites and risky sexual behavior, leading to an increase in the risk of sexually transmitted infections (STIs) [24]. Heterosexual dating websites (eg, Plenty of Fish) were identified as preceding search categories for herpes, while homosexual dating sites (eg, Adam4Adam) were identified for HIV. Online dating has been suspected to be a risk factor for STIs [25], though evidence is inconclusive. Queries related to real estate were linked to herpes and may be plausibly related if having a new sexual partner prompts individuals to move to a new property. Alternatively, reactivation of oral herpes (cold sores) is known to be related to stress and moving house is a known stressor. The links with "military brats" (a term used to describe the child of a parent or parents serving full-time in the United States Armed Forces) and hip hop music may indicate sexual risk behavior in those associated with these cultures. The link with Walmart may reflect that their pharmacies offer advice on self-management of both oral and genital herpes. Mechanisms for links with popular search engines are unclear.

Myocardial infarction was linked to searches related to restaurants. There is some evidence that the availability of fast-food restaurants partially explains cardiovascular disease prevalence [26]. Our method, however, identifies a transient increase in the risk of myocardial infarction following such searches, suggesting that this exposure goes beyond a long-term risk factor and may also act as an acute trigger of myocardial infarction.

Finally, the correlations with mental health disorders including post-traumatic stress disorder and anorexia found statistically significant precursor behaviors; rape and homelessness queries were preceding search categories for post-traumatic stress disorder and are plausible triggers of this condition. Image search was the strongest preceding search category for eating disorders. Images designed to inspire weight loss, also known as "thinspiration", are indeed an important part of anorexic behavior [27]. Depression and bipolar disorder were significant preceding search categories previously associated with eating disorders [28]. "English child actors" might have been identified because one of the young English actors in a major movie, which was released several months prior to the data period, is reported to suffer from eating disorders. The link to "Barnes & Noble", a major Web-based store for books and other media, may indicate content consumed by these users.

Table 5. Medical conditions analyzed for precursor behaviors.

Condition	Number of users	Number of queries	Number of categories
Pregnancy	56,062	3,154,273	1263
Allergy	3739	217,395	1455
HIV	1522	80,537	1008
Herpes simplex	709	45,669	1102
Myocardial infarction	701	36,552	1340
Post-traumatic stress disorder	657	36,986	925
Eating disorder	615	37,948	1671

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Table 6. Precursor search categories and queries associated with the analyzed medical conditions (at FDR rate of 0.05). Queries related to interest in specific people afflicted with the medical condition were manually removed from the list.

Condition	Precursor behaviors	Category or query	Relative hazard
Pregnancy			
	Pregnancy symptoms	Query	3.33
	Birth control	Category	2.74
	Fertility	Category	2.58
	Pregnancy with abortive outcome	Category	2.07
	Medical emergencies	Category	1.84
	Teen pregnancy in film and television	Category	1.59
Allergy			
	Petco	Query	3.88
	Pet stores	Category	3.34
	Crops originating from the Americas	Category	2.88
	PetSmart	Query	2.07
Eating disorder			
	Image search	Category	8.14
	Bipolar spectrum	Category	8.01
	Depression	Category	6.66
	Barnes and Noble (Web-based book store)	Query	4.54
	English child actors	Category	3.85
Herpes simplex			
	WorldStarHipHop (multimedia website)	Query	6.12
	Web-based real estate companies	Category	3.50
	Real estate valuation	Category	3.50
	Military brats (children of parents serving full time in the US Armed forces)	Category	2.52
	Plenty of Fish (dating website)	Query	2.34
	Yahoo	Query	2.13
	Zillow (real estate website)	Query	2.06
	Google	Query	2.03
	Walmart	Query	1.94
	Redtube	Query	1.49
HIV			
	Xtube	Query	5.50
	Same sex online dating	Category	3.54
	Adam4Adam	Query	3.42
	Video game franchises	Category	3.14
Myocardial infarction			
	Fast-food hamburger restaurants	Category	5.28
	Theme restaurants	Category	4.22
Post-traumatic stress disorder			
	Homelessness	Query	14.52
	Rape	Query	14.52

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Additional Evidence for the Accuracy of the Proposed Method

Geographic and Demographic Variability of the Self-Identified User Population

We used the year of birth provided by a fraction of the Bing users to compute their age, and compared the fraction of users at each (computed) age in the SIU population who reported suffering from arthritis to the distribution of ages in patients with arthritis provided by CDC [29]. The correlation between the two distributions is Spearman rho=.83 (*P*=.06), indicating a good match between the two distributions.

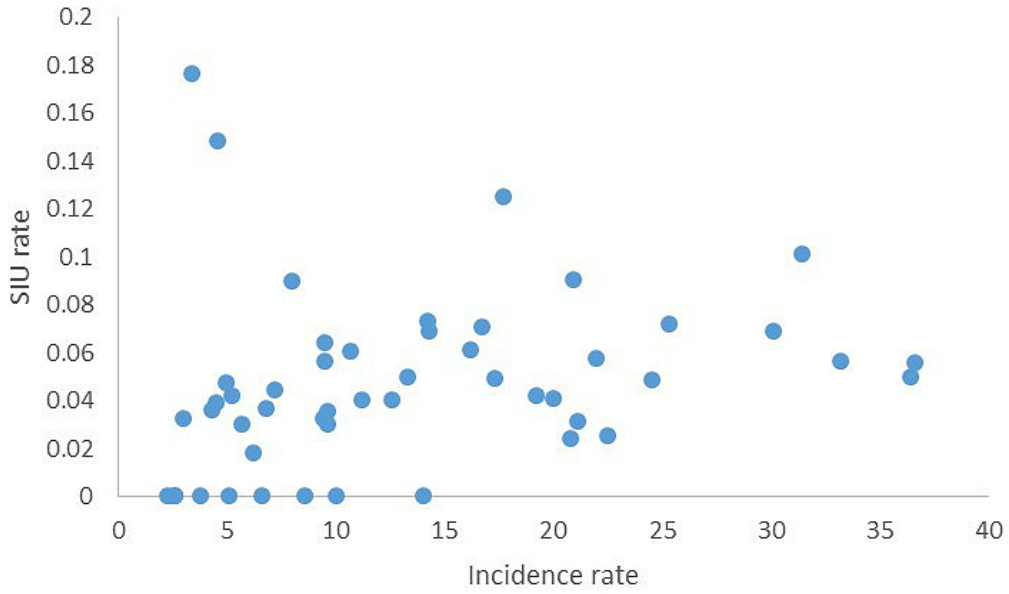
Similarly, we used the US state in which users resided to find the fraction of SIUs from the population of each state. This information was compared to the prevalence of HIV in each state (as reported by CDC [30]), as shown in Figure 4. The correlation of HIV incidence with SIU fraction is Spearman rho=.452 ($P=9*10^{-4}$).

Biological Gradient

For many risk factors, greater exposure leads to greater incidence of the effect. For example, exposure to more sexual partners increases the likelihood of contracting a sexually transmitted disease. To validate if such biological gradients exist in the precursors identified in our work (Table 5), we proceeded as follows. For each precursor and condition, we measured the fraction of users identified as having the condition of interest from all users who queried for the precursor, stratified by the number of times they searched for the precursor.

We then categorized these precursors according to whether there was a positive correlation (rho≥.5) between the fraction of users identified with the condition and the number of searches for the precursor, negative (rho<.5), or undetermined. Accordingly, 64% of precursors had a positive correlation and 22% a negative one. Thus, the majority of precursors show a biological gradient of an elevated likelihood for a medical condition associated with an increased interest in the precursors.

Figure 4. Self-identified user (SIU) rate for users reported having HIV, compared to the HIV incidence rate by state. The correlation between the two variables is Spearman rho=.452 (P=9*10-4).



Discussion

Principal Findings

The experimental results identified a number of known risks associated with specific health events, providing support for the proposed method. New potential risks factors were also identified that could form the basis for traditional epidemiological investigation and verification. Of course, the risk factors we identified are correlational and not necessarily causal. In fact, with very few exceptions, no online behavior will ever be directly causal of a health event.

Our approach minimizes the role of chance, bias, and confounding. The large numbers of search engine users reduces the role of chance. The SCCS approach, whereby people with the health event act as their own controls, largely eliminates selection bias (systematic differences in how cases and controls or exposed and unexposed individuals are selected for the study). Recall bias is minimized as people's Internet searches are recorded in real time and likely relate to their current concerns. It is also reassuring that demographic and geographic evidence correlated well with external data (supplementary materials). Similarly, the searches related to precursor behaviors may not reflect genuine behavior. A major advantage of the SCCS is that confounding by factors that do not vary significantly over the study period are implicitly controlled for. Nevertheless, some of the associations may be due to confounders that are temporally related to the identified search categories. The fact that the method identifies search categories preceding the health event helps to clarify the direction of association, but it is likely that the method may not always accurately identify the timing of the events/behaviors of interest. Most of the associations identified meet many of the Bradford Hill criteria [31] for

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assessing causality including temporality, strength of response, plausibility, and coherence and consistency with other research.

Conclusions

To conclude, while we recognize that the wider issues of data privacy and the societal acceptability of Web-based studies for health need to be considered, the method is an important scientific breakthrough to providing a faster and more economic means of automatically generating risk factors linking behaviors with the onset of major health conditions. The approach could be adapted to testing of pre-specified hypotheses, over short- and long-term studies. A better understanding of Web-based health-seeking behaviors could also help to direct disease prevention efforts to high risk in the physical or virtual world.

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Conflicts of Interest

None declared.

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Abbreviations

AIDS: acquired immune deficiency syndrome
AUC: area under the curve
FDR: false discovery rate
HIV: human immunodeficiency syndrome
ICD-10: International Classification of Diseases, Tenth Revision
ROC: receiver operating characteristic
SCCS: self-controlled case series
SIU: self-identified user
SLAPB: search log analysis for precursor behaviors
STI: sexually transmitted infection
SVM: support vector machine

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Original Paper

Health Information–Seeking Behavior of Seniors Who Use the Internet: A Survey

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Abstract

Background: The Internet is viewed as an important source for health information and a medium for patient empowerment. However, little is known about how seniors use the Internet in relation to other sources for health information.

Objective: The aim was to determine which information resources seniors who use the Internet use and trust for health information, which sources are preferred, and which sources are used by seniors for different information needs.

Methods: Questions from published surveys were selected based on their relevance to the study objectives. The Autonomy Preference Index was used to assess information needs and preferences for involvement in health decisions. Invitation to participate in this online survey was sent to the email list of a local senior organization (298 addresses) in the Netherlands.

Results: There were 118 respondents with a median age of 72 years (IQR 67-78 years). Health professionals, pharmacists, and the Internet were the most commonly used and trusted sources of health information. Leaflets, television, newspapers, and health magazines were also important sources. Respondents who reported higher use of the Internet also reported higher use of other sources (P<.001). Use of health professionals, pharmacists, leaflets, telephone, television, and radio were not significantly different; use of all other resources was significantly higher in frequent Internet users. When in need of health information, preferred sources were the Internet (46/105, 43.8%), other sources (eg, magazines 38/105, 36.2%), health professionals (18/105, 17.1%), and no information seeking (3/105, 2.8%). Of the 51/107 respondents who indicated that they had sought health information in the last 12 months, 43 sought it after an appointment, 23 were preparing for an appointment, and 20 were deciding if an appointment was needed. The source used varied by the type of information sought. The Internet was used most often for symptoms (27/42, 64%), prognosis (21/31, 68%), and treatment options (23/41, 62%), whereas health professionals were asked for additional information on medications (20/36, 56%), side effects (17/36, 47%), coping (17/31, 55%), practical care (12/14, 86%), and nutrition/exercise (18/30, 60%).

Conclusions: For these seniors who use the Internet, the Internet was a preferred source of health information. Seniors who report higher use of the Internet also report higher use of other information resources and were also the primary consumers of paper-based resources. Respondents most frequently searched for health information after an appointment rather than to prepare for an appointment. Resources used varied by health topic. Future research should seek to confirm these findings in a general elderly population, investigate how seniors seek and understand information on the Internet, and investigate how to reach seniors who prefer not to use the Internet for health information.

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KEYWORDS

aged; aged, 80 and over; information-seeking behavior; Internet; patient education; empowerment

Introduction

Patient empowerment is defined by the World Health Organization as "a process through which people gain greater control over decisions and actions affecting their health" [1]. Patient empowerment is viewed as both a practical and moral necessity: a means to change health-related behaviors, to control costs, improve the quality of care, ensure continuity of care, improve the patient experience, and enable shared decision making so that patients can participate more fully in decisions about their own health and health care [2]. An informed decision can be defined as one that is based on relevant, high-quality information and reflects the decision maker's values [3]. Thus, access to high-quality information is a prerequisite for shared decision making.

The Internet is an important resource for health information [4]. A recent survey of the general Dutch population showed that the Internet is widely used for health information [5]. Seniors are the fastest-growing group of Internet users in the Netherlands [6] and Europe [7]. In a national survey in the Netherlands in 2012, 81% of people aged 65-75 years used the Internet and 54% used the Internet for health information. However, this does not tell us whether the Internet is used frequently or infrequently, why and how the Internet was used for gathering health information, or whether seniors feel they can trust the information they find there. It also does not address how use of the Internet compares to other sources of health information and whether seniors would prefer to get health information from some other source. If we know more about why and how seniors seek health information, we can more efficiently and effectively empower seniors by using the right information resource at the right time. Thus, we sought to learn what resources seniors who use the Internet use and trust for health care information, their preferences regarding sources of information, and the resources used in relation to the timing and types of information sought.

Methods

Survey Development

Questions from the survey "e-Health and the Internet: How Seniors Use the Internet for Health Information" [8] were expanded with questions from other published surveys on health information seeking [4,9-15]. The questions were selected based on relevance to our study questions: which health information resources seniors use and trust, and whether they use different sources for different types of information. The questions were reviewed by 3 experts in medical informatics (AA, SE, and DS) and a geriatrician (SdR). To assess respondents' preferences for information, we used the questions from the Autonomy Preference Index (API) [16] reported to have good reliability in a German study population [17]. The API is a validated survey to assess the desire for information and preferences for involvement in medical decision making. It consists of two 100-point scales, Decision Making and Information Needs, where 0 represents the minimum possible score and 100 the maximum [17]. References to the source of each question are included with the annotated survey instrument in Multimedia Appendix 1. All survey questions were forward- and back-translated to Dutch (DS and SM). Before deployment, a geriatrician (SdR) and the head of the local senior organization filled in the resulting survey and were asked to give feedback on whether the questions were understandable for seniors, whether any questions seemed out of place, and the time required to fill in the survey. Their feedback was incorporated into the survey by 2 of the researchers (SM and SE).

Survey Deployment

Members of a local organization for seniors (Protestants Christelijke Ouderen Bond) affiliated with a national organization who had an email address listed with their organization were contacted via email. One reminder email was sent 2 weeks later. The emails contained a brief description of the survey and research project, and a link to fill in the survey online using a commercial survey site (Survey Gizmo). The survey was presented with 1 page per section, with an introduction on each page explaining the purpose of the questions. The introduction to the first section included the information that collection and analysis of survey data were anonymous.

The Medical Ethics Committee of the Academic Medical Center of the University of Amsterdam determined that this study was exempt from the need for approval under the Netherlands Medical Research Involving Human Subjects Act.

Analysis

Statistical Analyses

Differences between rating scales were calculated using the Wilcoxon rank sum test. All other associations between variables were assessed using linear regression, and the result reported as the standardized coefficient (β) with a confidence interval (CI). In the analyses of use of Internet related to use of other sources of health information, respondents who reported using the Internet for health information "a lot" or "a fair amount" were compared to the group that used the Internet "a little" or "not at all." The *P* value was adjusted with the false discovery rate (FDR) correction whenever >5 hypotheses were tested on the same dataset, using an overall significance level and accepted q-value of .05 (indicated by P_{adj}). All analyses were performed using R 3.1.0 [18].

Duplicate and Missing Responses

It was possible for the same respondent to fill in the survey multiple times. If 2 responses originated from the same Internet protocol address and had identical demographics, then responses were considered to have originated from the same person. In those cases, numeric responses were the mean of the 2

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responses; in nominal responses, the most recent answer was used. Respondents were allowed to skip questions; therefore, we analyzed each question with n equal to the number of responses to that question. When the respondent filled in a source that had been used when searching for health information, but failed to check "yes" indicating that they had searched for that information, we assigned a "yes" response by inference.

Socioeconomic Status

Socioeconomic status (SES) was derived from the 4-digit postcode based on data from The Netherlands Institute for Social Research [19]. The number represents a combination of average educational level, income, and market position of the neighborhood. Zero represents the national average and national scores per postcode range from -3.65 to 6.04.

Results

Survey Instrument

The final survey instrument (given in Multimedia Appendix 1) consisted of 6 sections: demographics, the API, use and trust of information sources, the timing and subjects of information sought in the last 12 months, perceived need for additional information, and the consequences of information seeking. The evaluation by the geriatrician and the head of the senior organization suggested minor changes to the presentation, indicated that the survey was understandable for older people, and indicated that the survey required 30 minutes to complete.

Survey Results

Overview

The invitation to participate was sent to all 298 email addresses available from the 670 members of the organization and responses were collected from October 25 to November 25, 2011. The site received 184 visits during this time, of which 130 resulted in at least 1 response. Of these, 11 were judged to be from an earlier respondent according to our matching criteria and were combined with 10 previous responses, resulting in a total of 118 responses and a maximum of 173 unique visitors (minimum of 68% participation rate), with a completeness rate of 103/118 (87.3%). A total of 913/9676 (9.44%) of responses were missing or 475/8446 (5.62%) of responses in completed surveys. An additional 65/9676 (0.67%) of responses were imputed. The number of respondents per section is given in the results for each section.

Demographics and the Autonomy Preference Index

The demographics of respondents are given in Table 1. The median age of respondents was 72 years, with a range of 49-94 years (IQR 67-78). Of these, 88.9% (105/118) were aged 65 years or older. The respondents were 56.0% women (65/116), primarily with a high school–equivalent education (61/117, 52.1%), of Dutch ethnicity (108/114, 94.7%), and in good health (69/117, 59.0%). In all, 18/116 (15.5%) were the caretaker for someone with a serious health condition and all but 1 (116/117, 99.1%) were community-dwelling. The quality of health services were rated highly: 106/116 (91.4%) felt they could get an appointment as quickly as they wanted and the overall health care received a median score of 8/10 (range 0-10, IQR 7-10). Four respondents reported that they had assistance in filling in the survey.

The median score on the API Involvement in Decision Making scale was 58 (IQR 42-67) and the median score on the API Information Needs scale was 71 (IQR 66-90). The Information Needs score was not significantly associated with age, gender, SES, education, health status, or caretaker status; however, a higher score on the Decision Making scale was associated with both lower age (β=–0.07, 95% CI –0.12 to –0.03, P=.002) and higher educational level (β=0.37, 95% CI 0.08-0.65, P=.01).

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Table 1. Demographics of respondents in the survey (N=118).

Item	Participants
Age (years), mean (IQR)	72 (67-78)
Gender (female; N=116), n (%)	65 (56.0)
Socioeconomic status[a] (N=116), median (IQR)	0.27 (0.16-0.27)
Educational level (N=117), n (%)	
Primary school	2 (1.7)
Some high school	14 (12.0)
Vocational/technical school	5 (4.2)
High school	61 (52.1)
Vocational school	10 (8.5)
University	25 (21.4)
Country of birth (N=114), n (%)	
Netherlands	108 (94.7)
Other	6 (5.1)
Is a primary caretaker (N=116), n (%)	18 (15.5)
Health status (N=117), n (%)	
Very good	7 (6.0)
Good	69 (59.0)
Fair	37 (31.6)
Poor	4 (3.4)
Very poor	0 (0.0)
Perceived access to care ("I can see my primary care practitioner as soon as I want" N=116), n (%)	
Strongly agree	28 (24.1)
Agree	78 (67.2)
Disagree	9 (7.8)
Strongly disagree	1 (0.9)
Rating of overall quality of care (0-10 scale, N=112), median (IQR)	8 (7-10)
Assistance filling in survey (N=94), n (%)	
Yes	4 (4)
No	90 (96)

[a] Based on postcode. National average=0.

Use and Trust of Sources of Health Information

Respondents' self-reported use and trust in various sources of health information are given in Table 2. Health professionals, pharmacists, and the Internet were the most commonly used, with respectively 61/115 (53.0%), 59/111 (53.1%), and 60/113 (53.1%) of respondents indicating that they used each source "a lot" or "a fair amount". Health professionals, pharmacists, and the Internet were also the 3 most-trusted sources of health information with respectively 75.5% (80/106), 72.9% (78/107), and 40.4% (42/104) of respondents indicating that they trust these sources "a lot" or "a fair amount".

Respondents were also asked how much they trust health information from each resource. Generally, trust closely tracked use, implying that the underlying construct is the same or highly correlated for most resources. However, trust in the resource was significantly higher than use of the resource for health professionals and pharmacists, and significantly lower for television and newspapers (Table 2).

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Table 2. Use and trust of health information sources and use of non-Internet health information sources by Internet use. Respondents were allowed to skip questions; therefore, the n/N is reported per question. *P* values are corrected for multiple testing.

Information resource	Use and trust of information sources: all respondents			Use of information sources a lot/a fair amount by Internet use		
	Use resource a lot/a fair amount (median 23%), n/N (%)	Trust resource a lot/a fair amount (median 25%), n/N (%)	Difference in use and trust, P_{adj}	Use Internet a lot/a fair amount (N=60; median 30%), n/N (%)	Use the Internet a little/not at all (N=53; median 9%), n/N (%)	Difference in use of other resources, P_{adj}
Face-to-face contact with a health professional	61/115 (53.0)	80/106 (75.5)	.002	28/59 (47)	27/53 (51)	.10
Pharmacists	59/111 (53.2)	78/107 (72.9)	.02	35/59 (59)	22/49 (45)	.16
Leaflets at the doctor's office	47/115 (40.9)	37/105 (35.2)	.43	26/59 (44)	20/53 (38)	.24
Telephone helpline	14/113 (12.4)	17/106 (16.0)	.23	11/58 (19)	3/53 (6)	.07
Television	35/115 (30.4)	14/105 (13.3)	.001	21/59 (36)	13/53 (24)	.06
Radio	14/115 (12.2)	11/106 (10.4)	.23	8/59 (14)	5/53 (9)	.13
Newspapers	40/114 (35.1)	21/105 (20.0)	<.001	27/59 (46)	12/53 (23)	.007
Health magazines	36/114 (31.6)	23/107 (21.5)	.29	26/59 (44)	9/52 (17)	.004
Other magazines	20/112 (17.9)	10/103 (9.7)	.12	15/56 (27)	4/53 (8)	.007
Family and friends	27/114 (23.7)	20/105 (19.0)	.29	19/58 (33)	6/53 (11)	.004
Church/religious group	2/112 (1.8)	1/101 (1.0)	.43	2/58 (3)	0/52 (0)	.05
Courses and lectures	11/111 (9.9)	16/105 (15.2)	.44	11/57 (19)	0/52 (0)	.07
Internet	60/113 (53.1)	42/104 (40.4)	.12	—	—	—
Self-help/support group	17/110 (15.5)	17/105 (16.2)	.43	14/57 (25)	2/52 (4)	.004
Books/encyclopedias	24/112 (21.4)	20/101 (19.8)	.65	19/58 (33)	4/52 (8)	.004
The library	14/111 (12.6)	11/103 (10.7)	.79	12/57 (21)	2/53 (4)	.02

Use of the Internet for health information decreased slightly with age (β=–0.02 per year, 95% CI –0.05 to –0.001, *P*=.03), but was not associated with gender, education, health status, or caretaker status. The association with age did not persist when the analysis was restricted to respondents aged 65 years and older (n=102). Use of other (non-Internet) information sources also was not associated with age, gender, education, health status, or caretaker status.

Overall use of information sources was not associated with either the Decision Making or Information Needs scales of the API (Decision Making: β=–0.01, 95% CI –0.06 to –0.04, *P*=.65; Information Needs: β=0.06, 95% CI –0.02 to 0.14, *P*=.13), nor was use of the Internet for health information (Decision Making: β=0.21, 95% CI –0.18 to 0.61, *P*=.29; Information Needs: β=0.39, 95% CI –0.22 to 1.0, *P*=.23). However, higher use of other (non-Internet) information sources was associated with higher use of the Internet (β=0.06, CI 0.04-0.08, *P*<.001). Use of health professionals, pharmacists, leaflets, telephone helplines, television, and radio were not significantly different; use of all other resources was significantly higher for Internet users (Table 2).

When asked which resources are preferred when they have a need for health information, 46/105 (43.8%) respondents indicated that they preferred the Internet. An additional 38/105 (36.2%) indicated that they prefer resources other than the Internet and 18/105 (17.1%) indicated that they prefer to only ask health professionals. The remaining 3/105 (2.9%) said that they have no need for additional health information. For the 92 respondents aged 65 years and older, responses were similar: 42 (46%) preferred Internet, 31 (34%) preferred other resources, 16 (15%) preferred health professionals, and 3 (3%) indicated that they had no need for additional information. In a post hoc sensitivity analysis, there was no significant difference between the proportions of respondents that preferred the Internet in the age categories of <65 years (4/13, 30%) and 65-75 years (22/54, 41%; *P*=.64), those aged 65-75 and >75 years (20/38, 53%; *P*=.53), or those <65 years and >75 years (*P*=.33).

Timing and Types of Information Sought

Of the 107 respondents completing the section on timing of information seeking, 51/107 (47.7%) indicated that they had sought health information in relation to an appointment with a health professional in the last 12 months (Table 3). Of these, 43/51 (84%) indicated that they sought information after an appointment. Far fewer had sought information to prepare for an appointment (23/51, 45%) or to decide if an appointment was needed (20/51, 39%). Reponses were similar for those aged 65 years and older (45/93 indicated they had sought health information in the last 12 months: 37/45, 82% after an appointment; 21/45, 46% to prepare for an appointment; and 19/45, 42% to decide if an appointment was needed). In all cases, the Internet was used more than other sources. Women were more likely than men to seek health information after an appointment (30 women and 13 men, β=–0.26, 95% CI –0.45 to –0.07, P_{adj}=.01); there were no other significant associations

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of the timing of information seeking with age or gender (see Multimedia Appendix 2).

Of the 107 respondents who completed the section on specific types of information sought, 70 (66%) indicated that they had sought health information on 1 or more of the listed subjects in the last 12 months (Table 4). The resources used varied widely by subject area. Respondents preferentially used the Internet when seeking additional information about symptoms (64%, 27/42), prognosis (68%, 21/31), and treatment options (62%, 23/37), but tended to ask health professionals for additional information about prescription medications (56%, 20/36) and side effects (47%, 17/36), practical care information (86%, 12/14), and nutrition/exercise advice (60%, 18/30). Advice from non–health professionals and paper-based resources were not commonly used, except for paper-based information about side effects (44%, 16/36). More women sought information in the last 12 months than men (women: 46/58; men: 24/49; β=–0.31, 95% CI –0.51 to –0.12, P_{adj}=.002). There were no gender differences in the types of information sought after correction for this and no association with age (see Multimedia Appendix 2).

Table 3. Timing and source of information seeking in relation to a doctor's appointment.

Timing of information seeking	Sought information within last 12 months, n/N (%)	Source of information, n/N (%)			
		Asked a health professional	Asked someone else (eg, family or friends)	Looked on Internet	Information on paper
After an appointment	43/104 (41)	5/37 (14)	11/37 (30)	29/37 (78)	3/37 (8)
To prepare for an appointment	23/103 (22)	3/16 (19)	7/16 (44)	10/16 (63)	0/16 (0)
To decide if an appointment is needed	20/106 (19)	5/18 (28)	7/18 (39)	8/18 (44)	0/18 (0)

Need for Additional Health Information

One-third of respondents (34/104) indicated that they had a need for additional health information but did not know where to find it. Most (98/106) indicated that they did not have difficulty finding information in their own language. Nearly all respondents (101/106) indicated that they expect their doctor to provide them with all necessary information.

A total of 74 respondents reported seeking information on 1 or more subjects in the past 12 months, of which 63 specified a source for that information. Respondents were allowed to choose multiple sources of information.

Table 4. Subjects of information seeking.

Subject	Sought information within last 12 months, n/N (%)	Sources for health information on specified subject,[a] n/N (%)			
		Asked a health professional	Asked someone else (eg, family or friends)	Looked on Internet	Information on paper
Look up symptoms to determine cause	46/105 (43.8)	18/42 (43)	7/42 (17)	27/42 (64)	4/42 (10)
Prognosis	34/104 (32.7)	16/31 (52)	6/31 (19)	21/31 (68)	3/31 (10)
Treatment options	41/102 (40.2)	20/37 (54)	2/37 (5)	23/37 (62)	5/37 (14)
Prescription medications	43/102 (42.2)	20/36 (56)	2/36 (6)	11/36 (31)	11/36 (31)
Side effects of treatment or medicines	45/100 (45.0)	17/36 (47)	2/36 (6)	8/36 (22)	16/36 (44)
Coping with an illness	33/101 (32.7)	17/31 (55)	6/31 (19)	17/31 (55)	4/31 (13)
Practical care information (eg, showering after a surgery)	18/102 (17.6)	12/14 (86)	1/14 (7)	2/14 (14)	2/14 (14)
Nutrition/exercise	40/103 (38.8)	18/30 (60)	5/30 (17)	13/30 (43)	6/30 (20)
Total (all topics)	74/106 (69.8)	151/430 (35.1)	56/430 (13.0)	169/430 (39.3)	54/430 (12.6)

[a] Number specifying at least 1 source.

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Discussion

Principal Results

Health professionals, pharmacists, and the Internet were the most used and the most trusted sources of health information in this group of seniors who use the Internet, although trust in pharmacists and other health professionals was higher than trust in the Internet. Responses on the API were not correlated with overall use of health information resources or with use of the Internet for health information. Use of the Internet was strongly correlated with use of other information resources. Respondents who reported using the Internet "a little" or "not at all" for health information reported using health professionals, pharmacists, leaflets, telephone information, TV, and radio approximately the same amount/extent as Internet users, but all other sources were used significantly more by Internet users. The Internet was also the most often preferred source for additional health information. Concerning the timing of seeking information, most respondents sought information after seeing a health professional, whereas only about half as many reported seeking information to prepare for a doctors' visit or to decide if they needed to see a doctor. Different resources were used for different health information subjects: the Internet was predominantly used when searching for information on symptoms, prognosis, and treatment options, whereas health professionals were predominantly used for information on prescriptions, side effects, practical care information, and nutritional advice. One-third of respondents reported a need for more information that they did not know how to find. Nearly all respondents reported that they expect their health professional to provide all necessary information.

Limitations

The main limitation of this study is the study sample. To avoid the confounding effect of the many possible barriers to Internet use in general, we chose to survey only people who already use the Internet and, thus, could potentially use it for health information. However, this limits the generalizability of our results because seniors who do not use the Internet were excluded. We anticipated a larger population of seniors who do not use the Internet for health information. For example, in a recent US study, younger adults were 3 times more likely to seek health information on the Internet than people older than age 65 [20]. However, only 18 seniors in our sample reported that they did not use the Internet for health information, limiting our analysis of the preferences of this population. Our survey found much higher use of the Internet for health information by seniors than the US survey from which the questions were drawn [8], which found only 21% of seniors had ever used the Internet for health information. However, only 31% of the seniors participating in the US survey had gone online or used email, implying that 68% of seniors in that study who used the Internet also used it for health information. A similar percentage of people aged 65-75 years used the Internet in the Netherlands in 2005 (35%) [6], the year of the US study, implying that the difference in this result between the original study and ours may be primarily because of increasing Internet use in both countries over time. More recent studies show higher rates of Internet use in older adults; for example, 53% in a recent US survey [21] and 45% of people aged 65-74 years in a 2007 Canadian survey (52% of which used it for health information) [22]. Our study is relatively small, with respondents from 1 senior organization, primarily from 1 geographic region of the Netherlands, who were fairly uniform in ethnic background. Thus, we were not able to investigate factors such as ethnicity or rural compared to urban residence, which may influence the use of the Internet for health information [23]. It is likely that some of our respondents knew one another and, although unlikely, it is possible they even filled in the survey together, which may further reduce heterogeneity and could create a social desirability bias. However, our study sample was similar to the general Dutch population aged ≥65 years [24] in terms of gender (66% female in both the general population and in our study sample) and age distribution (57% aged 65-75 years and 43% aged >75 years in the general population vs 56.2%, 59/105 and 43.8%, 46/105, respectively, in our study sample), indicating that our sample is at least broadly representative of seniors in the Netherlands.

Our sample could be affected by a participation bias: seniors who are willing to fill in an online survey may also be more willing to search for health information online compared to seniors who are capable of using the Internet but prefer not to fill in an online survey. Neither health information seeking nor use of the Internet as a health information resource were associated with health status in our study. However, people in poorer health may be less inclined to complete a survey and, thus, may be underrepresented in this study. All our respondents are connected to a senior organization, which may represent a more proactive group of seniors than the general population. Seniors who are more willing to participate in a survey may also be more willing to participate in their own health care decisions. We used the API to assess the respondents' general desire for health information and involvement in health decisions. Our respondents had a median Decision Making scale score of 58 and a median Information Needs scale score of 71. The authors of the original API study reported a similar mean Information Needs scale score (79.5) to that found in our study, but a considerably lower Decision Making scale score (33.2) [16]. The authors also reported that the scores in their study tended to decrease with age, implying that we should expect lower scores in our older study population. The fact that our respondents seem to have a rather high desire for involvement in decision making could explain why we did not see an association between the API and information-seeking behavior. Finally, neither the original surveys on which our questions are based nor this survey have been validated, with the exception of the API, and all questions needed to be translated to the Dutch language. We cannot be sure that our respondents interpreted the questions in the way we intended. However, we used forward-and-back translation to retain comparability to the original studies.

Comparison to Prior Work

The original US survey also reported a much higher use of paper-based resources (books and magazines) [8], whereas in our study we found that these resources were primarily used by people who also use the Internet for health information. This implies that offering both Internet-based and paper-based

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resources may reach the same audience twice rather than different audiences and, therefore, may miss an important segment of the population that uses neither. Use of health professionals, pharmacists, leaflets, telephone help lines, television, and radio were similar in groups with both high and low Internet use. In retrospect, these resources are more verbal (except leaflets) than the other resources, suggesting that differences in health literacy or preferred modes of communication may be in play. Apart from telephone help lines, they also require less active information-seeking behavior on the part of the patient, implying that ease of access could be a factor. Trust of information sources could also be a factor, although overall trust in both the Internet and in other sources of health information was higher for those who report higher use of the Internet ($P<.001$).We found that use and trust of information sources were correlated, but it is not clear if sources are not trusted because they are unfamiliar (not used) or if they are not used because they are not trusted. In conjunction with the finding that information seeking typically occurs after an appointment, the timing of information seeking may also play a role in the number and type of resources used. Because of prior experience with other health information resources, seniors may also be more inclined to use the Internet in conjunction with rather than instead of these other resources. Further research is needed to learn whether this finding persists in a larger sample including non-Internet users, and whether the aforementioned underlying factors can be correlated to the result or if the result can be explained by a theoretical model (eg, the Health Belief Model [25]). If this finding persists in a general population, it has important implications for theory and practitioners who may seek out better ways of helping seniors attain health information.

In the survey conducted in the general population in Germany, the rates of seeking information after an appointment (66.2%), to prepare for an appointment (53.8%), and in deciding whether to consult with a health professional (65%) were similar and in all cases higher than in our survey [4]. Notably, our respondents reported seeking information primarily after an appointment. Presumably, this is because patients hear new information during the appointment that, in turn, stimulates information-seeking behavior. Furthermore, patients who sought information after an appointment were more inclined to use the Internet for this search (29/37, 78% vs 10/16, 62% when preparing for an appointment and 8/18, 44% when deciding whether they should go to the doctor). Thus, there may be a relationship between the timing of information seeking and the choice of resource. This is a useful finding for those who hope to provide tools to help older patients prepare for a doctor's visit because it implies that most potential users are unlikely to find the tool on their own before an appointment, but will need to be contacted in some other way.

The source of information varied substantially by clinical subject. The Internet was used most often when seeking information about symptoms, prognosis, and treatment options, but health professionals were asked for additional information about prescription medications, side effects, practical care information, and nutrition/exercise advice. The only subject for which paper-based resources were commonly reported was information about side effects, although the respondents may have been referring to reading the paper inserts that come with prescription medications. The 2005 US study reported that the Internet was commonly used for information about medications and nutrition and exercise [8], and a 2007 survey of US cancer patients found that information on treatment options, prognosis, and side effects were sought more on the Internet than information on coping with the disease [13], but neither study compared the Internet to other resources. The use of different resources for different subjects could be because of the availability of information from the Internet or other sources, a need for personalized information, a sense that some types of information on the Internet are more reliable than others, or other factors. Additional study is needed to learn whether this difference in use is attributable to preference or simple practicality.

As we reported previously [26], respondents reported both positive and negative emotional responses to the health information they found. The effects were not different between those who did and did not use the Internet for health information after correction for increased seeking of health information in general. Also, nearly all respondents expected their doctor to provide all necessary health information. This is a positive finding in that our respondents clearly trust their health care professionals, but it also places tremendous and possibly unrealistic expectations of the capacity to convey information in a typical 10-minute appointment. This suggests that all health information sought online and elsewhere is viewed as ancillary information by our respondents. This finding casts some doubt on whether patients would rely on a computer-based tool, such as a self-management program, to be a necessary part of their care.

Future study of seniors who use the Internet for (additional) health information should further investigate why and how seniors search for information on the Internet (eg, a preference for search engines vs health portals or whether the device used affects the search strategy [27]), whether they feel they have found the information they need, and whether they are able to understand and correctly judge the quality and reliability of information they find. A recent study of seniors asked to interpret a set of symptoms using online tools found that many of the participants had difficulty navigating the online tools and that this difficulty was correlated with reaching an incorrect conclusion [28]. Further study is also needed of seniors who do not use the Internet for health information. There are 2 groups of interest here: those who do seek health information but from other sources and those who do not actively seek health information. The latter group likely consists of people with little need for health information (healthy seniors or seniors in a stable health state) and people who have a need for health information but are not aware of it or prefer not to think about it. This latter population likely includes disadvantaged groups who are at higher risk for many health problems. Learning how to efficiently apply resources to reach those who actively seek information also frees more resources for reaching those who do not.

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Conclusions

We surveyed 118 seniors who use the Internet to learn how they use the Internet compared with other sources in searching for health information. Respondents used the Internet for health information as much as they asked health care professionals and pharmacists. Seniors who use the Internet for health information also report higher use of other sources of health information, particularly paper-based resources. This may imply that supplying both Internet and paper information is redundant and other channels must be used to reach those who will not find the information on the Internet. Most respondents who had searched for health information in the last year did so after an appointment, whereas only approximately half as many said they searched for information to decide to go to the doctor or prepare to go to the doctor. This implies that additional effort may be needed to encourage accessing information intended to prepare patients for an appointment. The resources used varied by health topic, implying that different channels may be preferred for different kinds of information. Although the findings of this survey should be considered preliminary, seniors who seek health information seem likely to use the Internet and seniors who do not use the Internet for health information also tend to make less use of health information resources apart from health care professionals. Future research should investigate how seniors seek and understand information on the Internet, whether seniors who seek information from all sources tend to be Internet users, and how to reach seniors who prefer not to use the Internet for health information.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Survey instrument, with references given for the source of each item in the survey.

[PDF File (Adobe PDF File), 73KB - jmir_v17i1e10_app1.pdf]

Multimedia Appendix 2

Statistical results for association between age and gender and the timing and subject of information seeking. Estimates and confidence intervals for each analysis are reported.

[PDF File (Adobe PDF File), 39KB - jmir_v17i1e10_app2.pdf]

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Abbreviations

API: Autonomy Preference Index
FDR: false discovery rate
SES: socioeconomic status

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Original Paper

Patient Perspectives on Online Health Information and Communication With Doctors: A Qualitative Study of Patients 50 Years Old and Over

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Abstract

Background: As health care systems around the world shift toward models that emphasize self-care management, there is increasing pressure for patients to obtain health information online. It is critical that patients are able to identify potential problems with using the Internet to diagnose and treat a health issue and that they feel comfortable communicating with their doctor about the health information they acquire from the Internet.

Objective: Our aim was to examine patient-identified (1) problems with using the Internet to identify and treat a health issue, (2) barriers to communication with a doctor about online health information seeking, and (3) facilitators of communication with a doctor about patient searches for health information on the Internet.

Methods: For this qualitative exploratory study, semistructured interviews were conducted with a sample of 56 adults age 50 years old and over. General concerns regarding use of the Internet to diagnose and treat a health issue were examined separately for participants based on whether they had ever discussed health information obtained through the Internet with a doctor. Discussions about barriers to and facilitators of communication about patient searches for health information on the Internet with a doctor were analyzed using thematic analysis.

Results: Six higher-level general concerns emerged: (1) limitations in own ability, (2) credibility/limitations of online information, (3) anxiety, (4) time consumption, (5) conflict, and (6) non-physical harm. The most prevalent concern raised by participants who communicated with a doctor about their online health information seeking related to the credibility or limitations in online information. Participants who had never communicated with a doctor about their online health information seeking most commonly reported concerns about non-physical harm. Four barriers to communication emerged: (1) concerns about embarrassment, (2) concerns that the doctor doesn't want to hear about it, (3) belief that there is no need to bring it up, and (4) forgetting to bring it up. Facilitators of communication included: (1) having a family member present at doctor visits, (2) doctor-initiated inquiries, and (3) encountering an advertisement that suggested talking with a doctor.

Conclusions: Overall, participants displayed awareness of potential problems related to online health information seeking. Findings from this study point to a set of barriers as well as facilitators of communication about online health information seeking between patients and doctors. This study highlights the need for enhanced patient communication skills, eHealth literacy assessments that are accompanied by targeted resources pointing individuals to high-quality credible online health information, and the need to remind patients of the importance of consulting a medical professional when they use online health resources to diagnose and treat a health issue.

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KEYWORDS

health communication; Internet; online health information seeking; barriers to patient-doctor communication; adults 50 years old and over; qualitative research

Introduction

Background

Initiatives to promote health and independence through self-care management are being developed around the world as a means of empowering patients [1-8]. Scholars and health professionals have raised concerns about using the Internet to identify and treat health issues because patients can misinterpret or misuse information, particularly in the absence of communication with a doctor [9-12]. This can occur because patients may have inadequate health literacy [13-15], inadequate eHealth literacy [16-20], or otherwise lack the ability to sort through online health-related information [21,22]. It has also been suggested that Internet-sourced health information can be difficult for patients to decipher because it comes from a wide range of different sources [23], may feature highly technical language [24], and the quality, accuracy, and safety of some health information available on the Internet can be suspect [25-27]. Researchers have also raised concerns that online health information seeking can increase patient anxiety [28-30] and be time consuming for patients [31].

While academics and health professionals have identified problems associated with patients' use of the Internet to identify and treat health conditions, less is known about the extent to which these concerns resonate with patients. While eHealth literacy has been defined as the ability to find, comprehend, appraise, and access health information from electronic or online sources to address health-related concerns [17], an underdeveloped component involves patient awareness of the limitations of Internet-sourced health information. Awareness of the limitations associated with information sources is an important component of ensuring that patients can critically evaluate and effectively collaborate with health professionals in the context of making decisions that relate to their health [32,33]. Approximately 35% of adults in the United States report that they have used the Internet specifically to diagnose a health condition, and half follow up with a visit to a medical professional [34]. While we would like to assume that the half who follow up with a visit are those in need of medical attention and the other half safely resolve their health issues, less is known about the relationship between patient online health information seeking and communication with medical professionals.

Prior research suggests that when patients talk with a doctor about health information seeking behaviors, these conversations can be used to avoid costly repercussions that can result from delayed treatment or hazards that can occur in response to acting on inaccurate or misunderstood health information [35,36]. It is puzzling that patients who regularly use the Internet to identify and treat their own health conditions fail to engage in conversation with a health professional about their online health information seeking. Prior research points to cost as a potential barrier to communication because some patients cannot afford medical insurance or the financial expenses associated with medical consultations [37,38] and highlights reasons doctors may be averse to discussing patient-acquired online health information [27,30,36,39,40]. However, less is known about patient-perceived barriers to these conversations particularly among individuals with free access to medical care.

In support of earlier calls for research that enhances understandings of patients' perspectives regarding online health information seeking [30,41-44], this exploratory study examines perspectives from a sample of patients 50 years old and over about using the Internet to identify and treat a health issue and about patient-provider communication. While much has been written about the perspectives that adolescents and younger people have about Internet-sourced health-related information [45-49], less is known about the perspective of adult populations. Prevalence rates for multiple chronic conditions increase starting around 50 years old [50,51], thus this age has been associated with a greater potential need for health information [52,53]. Among individuals 50 year old and over, Internet usage rates and social media usage rates have nearly doubled in recent years [54,55]. However, health literacy levels tend to decline with age [56], and inadequate health literacy has been associated with patient non-adherence and adverse disease management [57,58]. Thus, while experts have expressed a range of concerns regarding patient use of the Internet to search for health information, further research is needed to identify concerns among patient 50 years old and over and to explore how these concerns might relate to patient-provider communication.

Objectives

This qualitative study examined patient-identified concerns about using the Internet to diagnose and treat a health issue among a sample of adults 50 years old and over. Concerns identified by participants who regularly communicated with a doctor about their online health information seeking were compared to participants who had never discussed their online health information seeking with a doctor. This study also explored barriers to and facilitators of patient-provider communication about patient searches for health information on the Internet.

Methods

Design and Procedures

In order to focus on potential barriers to communication beyond cost, participants were interviewed in Toronto, Canada, where all residents have access to a publicly funded health care system. Face-to-face interviews were conducted with individuals who were recruited through brochures posted in eight randomly selected neighborhoods. A consent form along with information about the study was distributed to each eligible participant. When written consent was given, interviews were conducted in public spaces that included community centers, cafes, and libraries. The process of advertising and interviewing

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participants who met the selection criteria was repeated until data saturation was achieved [59].

All participants completed a questionnaire designed for this study with a set of close-ended demographic and Internet use questions. The demographic portion included questions about participants' gender, age, marital status, country of birth, education, and income. Internet use questions asked about the number of computers available in the participants' home, whether the participant owned a touch screen device that had Internet access, the number of hours per week the participant spent using the Internet, how they first learned to use the Internet, whether the participant had ever used the Internet to search for information relating to the treatment of a disease or illness instead of going to the doctor, whether the participant had ever used the Internet to get information about a health issue and then felt more prepared or comfortable when speaking with a doctor, whether they had ever looked up information about a disease, illness, or injury after being diagnosed by a doctor, and whether they would feel comfortable recording their own health information online.

After completing the questionnaire, all participants participated in face-to-face interviews where they were asked a set of semistructured interview questions that explored their views on using the Internet to identify and treat a health condition and their experiences regarding communication about their online health information seeking. Participants who had never communicated with a doctor about their online health information seeking were also asked about potential barriers to communication. The interview guide is available in Multimedia Appendix 1. Ethical approval for this study was obtained from the University of Toronto, Office of Research Ethics.

Participants

Eligibility criteria for participants included (1) community dwelling, (2) 50 years old and over, (3) fluency in English, (4) primary residence in Toronto, (5) regular contact with a primary care physician, general practitioner, or family doctor, and (6) regular use of the Internet to identify and treat health issues. In total, there were 56 participants. A subset of 14 had never communicated with a doctor or health professional about their online health searches. The interviews lasted 52 minutes on average (range 40-77). The data sources generated for analyses were verbatim transcripts of the audio-recorded interviews and synthesis of debriefing notes made during the interviews with additional summary notes made after each interview.

Analysis

Transcripts and notes were read repeatedly before coding to focus on preserving as much detail as possible. Responses were managed and analyzed in NVivo 9 (QSR International). Participant demographic and Internet usage information were stored and aggregated using Stata 10. Using inductive content analysis [60] derived from a grounded theory approach [61], concerns regarding use of the Internet to identify and treat a health condition were initially coded as a set of statements that synthesized participants' concerns. These initial descriptions were derived through a process that involved reading the relevant portion of each transcript multiple times, in some cases referring back to the original audio file, looking for overlap between participants, and combining ideas to form a broad set of basic descriptive statements. The author and 2 research assistants independently followed these steps, met multiple times to compare and discuss the statements, and then developed the initial descriptions through consensus.

Higher-level themes where then developed into general concerns by the author and a research assistant based on analysis of the initial descriptions and reexamination of the context in which these statements were made through the original transcripts. Interrater agreement was .786 (SE .025) calculated using Cohen's kappa. Examples of how each of the general concern categories were operationalized is available in Multimedia Appendix 2.

After the initial descriptions and general concern categories were created, this information was quantitized [62,63] by counting the frequency of concerns expressed by participants based on whether they had ever communicated with a doctor about their online health information seeking. The proportion of total responses in each general concern category and the average number of comments per individual within each general concern category were calculated separately for participants who communicated with a doctor about online health information and those who did not. This information was included to observe whether one group was in fact more verbal or able to articulate more concerns. Then substantive differences between the two groups were analyzed.

Thematic analysis [64,65] was conducted to explore potential barriers to and facilitators of communication. Emergent themes regarding barriers to communication were initially developed through analysis of responses to the question, "Can you tell me about any concerns you might have about using the Internet to diagnose and treat a health issue?" for participants who had never communicated with a doctor about their online health information seeking. Then transcripts for these participants were examined in their entirety. Responses were initially examined separately for each participant, then similarities across participants were developed into communication barrier themes. In a similar manner, facilitators of communication between patients and doctors about online health information seeking initially emerged based on analysis of comments in response to the question, "Have you ever talked with your doctor about information you found on the Internet that relates to your health?"

Results

Overview

Semistructured interviews were conducted with 56 participants, 30 of whom were women (Table 1). Participants ranged in age from 50-87 years (mean 69 years). Just under half of the sample was married (46%, 26/56), and 57% (32/56) were born in Canada. In total, participants were born in 26 different countries. Many were well educated, and almost half of the sample had a household income over CAN $60,000. The majority of participants reported that they used a touch screen device (80%, 45/56), while less than half had at least one computer at home

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(39%, 22/56). On average, participants spent 13 hours per week using the Internet. Participants most commonly had learned how to use the Internet from a family member; 34% (19/56) of the total sample had first learned to use the Internet in a school setting. Overall, less than half of the total sample had ever used the Internet to search for health information instead of going to the doctor and then felt more comfortable talking with their doctor, and 46% (26/56) searched after being diagnosed with a health condition by their doctor. Just under half (48%, 27/56) of the sample reported that they would feel comfortable recording their own health information online.

Of the 14 participants who did not report any communication with a doctor about their use of the Internet to search for health information, nine were men. The average age of these participants was 73 years old, half were married, born in Canada, and many had a relatively high educational attainment and income. Further, 36% (5/14) of participants who had never communicated with a doctor had a home computer, 79% (11/14) owned a touch screen device, and they reported spending on average 12.8 hours using the Internet on a weekly basis. More than half of these participants had been taught to use the Internet by a family member; 43% (6/14) had ever looked up information about a disease, illness, or injury after being diagnosed by a doctor. Just under half had ever used the Internet to search for health information instead of going to the doctor or used it after being diagnosed with a health condition by their doctor. Half said they would feel comfortable recording their own health information online.

Concerns With Using the Internet to Diagnose and Treat a Health Issue

In total, participants raised 300 potential concerns about using the Internet to diagnose and treat a health issue. These concerns were aggregated into six different higher-level general concern categories. These general concerns as well as the initial descriptive categories and frequencies are reported in Table 2. Every participant contributed to at least two different initial descriptions and at least two different general concerns. Frequencies are distinguished based on whether participants had ever discussed their online health information seeking with a doctor.

The average number of initial descriptive statements regarding problems with using the Internet to identify and treat a health issue raised by participants who communicated with a doctor about their online health searches (5.64, range 3-12) was similar to those who had never communicated with a doctor about their online health information seeking (5.57, range 2-9). However, there were substantive differences in the types of concerns each group of participants raised. Of the responses from participants who regularly communicated with a doctor, 45% (19/42) reflected general concerns about the credibility or limitations of information available online and the next highest proportion of responses (21%, 9/42) dealt with concerns about limitations in their own ability to sort through or evaluate online health information (Table 3). Among participants who had never communicated with a doctor about their online health information seeking, the highest proportion of concerns were related to non-physical harm that could arise from searching online for health information (36%, 5/14) and the next highest proportion of responses from within this group dealt with concerns related to anxiety (29%, 4/14).

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Table 1. Participant demographic and Internet usage summary statistics.

Characteristics	Total sample (N=56), n (%)	Participants who never spoke with doctors about their online health information seeking (N=14), n (%)
Demographic summary statistics		
Women	30 (54)	5 (36)
Age (in years)	69	73
Marital status		
Married	26 (46)	7 (50)
Divorced/Separated	10 (18)	1 (7)
Single	8 (14)	2 (14)
Widowed	12 (21)	4 (29)
Born in Canada	32 (57)	10 (71)
Education		
<High school	7 (13)	3 (21)
Completed high school	11 (20)	4 (29)
College/University	14 (25)	4 (29)
Graduate school	24 (43)	3 (21)
Income over CAN $60,000	26 (46)	7 (50)
Internet use summary statistics		
Has at least one computer at home	22 (39)	5 (36)
Owns a touch screen device that has Internet access	45 (80)	11 (79)
Hours per week spend using the Internet, in hours	13.12	12.8
First learned to use the Internet		
Self-taught	7 (13)	2 (14)
Learned in a school setting	19 (34)	1 (7)
Learned at work	2 (4)	1 (7)
A friend taught me	6 (11)	2 (14)
A family member taught me	22 (39)	8 (57)
Ever used the Internet to search for information relating to the treatment of a disease or illness instead of going to the doctor	24 (43)	8 (57)
Ever used the Internet to get information about a health issue and then felt more prepared or comfortable when you spoke with your doctor	23 (41)	5 (36)
Ever looked up information about a disease, illness, or injury after being diagnosed by a doctor	26 (46)	6 (43)
Would feel comfortable recording your own health information online	27 (48)	7 (50)

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Table 2. Patient concerns about using the Internet to identify and treat a health issue.

General concerns	Initial descriptions	n[a]	n[b]
Limitations in own ability	I might think I am making things better when I am actually making them worse	15	2
	I might inadvertently do something that is dangerous	14	0
	I might misdiagnose the problem in the first place	10	3
	I'm afraid I won't be able to follow the advice properly	10	2
Credibility/Limits of online information	There is a lot of low quality information out there	18	1
	I might end up chatting with someone who is not who I think it is	6	1
	I don't believe anything that doesn't come from my doctor's clinic	5	0
	Don't know who the information is coming from	22	1
	It can't see me	5	0
	It can't save me if I've fallen or need to go to hospital	2	0
	You can't use it to get a prescription	3	1
	The information can be wrong	9	0
	It shouldn't be used to replace the doctor	12	2
	It might be ok for something simple but nothing complex	9	0
	I still need to consult my doctor	8	0
Anxiety	I can end up feeling worse after I go online to look up a health problem	3	6
	Health problems start to sound so scary on the Internet	5	3
	I start thinking I have all sort of health problems	5	2
	The information can be disorienting	2	2
	It is geared toward young people and I don't like what I find/it makes me uncomfortable	1	3
	I get overwhelmed/confused by the information	5	2
	People say unnecessarily negative things in online chat rooms, blogs, or comments sections	11	2
Time consuming	It is a waste of time	12	2
	I don't have enough time	6	1
	I end up spending a very long time on my question	2	1
Conflict	It could upset my doctor	9	6
	It stirs up conflict with family	3	6
Non-physical harm	I may end up buying something that I shouldn't	5	7
	My bank information may get stolen	2	4
	I could end up making a mistake, like making the wrong purchase	0	6
	I might fall into a scam and accidently send money	1	2
	I could end up getting my identity stolen	1	4
	I could get a computer virus or something that causes my computer to stop working	1	6
Total		222	78

[a]Frequencies for participants who talked with a doctor about their online health information seeking (n=42).

[b]Frequencies for participants who had never talked with a doctor about their online health information seeking (n=14).

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Table 3. Aggregated responses in each general concern category by participant communication status.

	Proportion of total responses in each general concern category[a]	
	Participants who talked a doctor about online health information seeking (n=42), %	Participants who did not talk with a doctor about online health information seeking (n=14), %
Limitations in own ability	22	9
Credibility/Limits of online information	45	8
Anxiety	14	26
Time consuming	9	5
Conflict	5	15
Non-physical harm	5	37

[a]The cells for each column were calculated by dividing the number of initial descriptions in each general concern category by the total number of initial descriptions for participants who communicated with a doctor about their online health information seeking and separately for participants who had never communicated with a doctor about their online health information seeking.

Barriers to Communication With a Doctor

Overview

A range of barriers to communication arose from the in-depth interviews. These concerns included fear of embarrassment, a feeling that the doctor does not want to hear about it, the feeling that there is no need to bring it up, and some participants could not seem to remember to bring it up.

What Would My Doc Think of Me?

Participants often expressed the concern that they did not understand the health-related information they found through their Internet searches and therefore did not mention these searches to a doctor. They expressed a sense of being unsure how to explain the information they found or how it related to their own condition. Participants also made sense of their decision not to discuss their online searches based on the notion that this would result in embarrassment. One participant said:

> *I probably don't talk to my doctor about things I find on the Internet because I would end up making a fool of myself. I waste so much time searching around about something. I just get something in my head and my doctor doesn't need to know about that. Most of the stuff I'm looking up is hogwash anyway, but I pretty much always end up getting confused because I'll start with one thing and end up fifteen kilometers away from that looking up something else. What would my doc think of me if I explained how I waste my time?* [85-year-old man]

Online health information seeking was described as something that could be endless. Some participants discussed the time they wasted trying to find answers that only led to more questions or confusion over what they had initially suspected to be their problem, as one man described: "It's just pointless how much information is out there. I try to get to the bottom of something and then I realize I don't even know where to begin" [68-year-old man].

A number of participants mentioned multiple search engines and a range of health websites, but few expressed confidence in a trusted website or reliable source of information. Confusion about information read online coupled with the fear of what a doctor might think were barriers to obtaining clarification about questions that arose for some participants as they searched for health information on the Internet. This was the case, even among participants who used the same health-related websites regularly and who had relevant questions for their doctor. For example, one participant discussed how a fear of embarrassment inhibited communication:

> *I am embarrassed to admit it but my favorite website is this health one that sells things…I'd really like to understand how certain foods affect my prescriptions. But if I started to talk with my doctors about this website, I think they would think I was out to lunch. Or obsessed with food. I'm not going to bring it up. I don't get most of it anyway.* [86-year-old woman]

This participant had a relevant question for her doctors, namely about the relationship between her prescription drugs and what she eats. However, the concern that she could not explain the information she came across, coupled with the idea that the doctors would think less of her kept her from having this conversation with her doctor.

My Doctor Doesn't Want to Hear About That

Many participants showed deference to their doctors and some even implied that telling their doctor about their online health searches would be insulting to the doctor. Several participants wondered why a doctor would want to hear about what was on the Internet and feared that bringing up their online health information seeking would be insulting to the doctor. They seemed to trust that their doctors know what to look for. One participant mentioned, "Doctors can look things up on the Internet and they don't need patients to tell them how to do that" [70-year-old man].

Another participant indicated that doctors do not want patients to tell them how to do their job:

> *The Internet can't write me a prescription or look in my ear, why would I tell my doctor what I read online? Like I know what my doctor should be doing? How would that help? My doctor doesn't want to hear*

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> *about that, he wants to take some tests and check on my prescriptions.* [69-year-old man]

Some participants who suggested that their doctor would not want to hear about their online searches pointed to someone who had advised against this behavior. More than one participant mentioned that a daughter had told them not to discuss online searches with the doctor. These participants often described a situation where they seemed to have a specific question or set of questions but they were discouraged from bringing the discussion to the doctor for fear that "The doctor will get annoyed and he doesn't want to hear about that" [64-year-old man].

One woman described her sense that discussing online searches with a doctor was simply not appropriate: "Oh, I love the Internet! I use it all the time…But I don't ask my doctor about things I find online. I have a lot of friends who do that. But I know not to do that. My daughter told me they don't like it when you do that" [84-year-old woman].

I Go to the Internet Instead of the Doctor

An underlying theme that emerged for some participants was that simply taking the advice they found online negated the need to discuss it. One participant mentioned a strong desire to avoid the doctor and hospital as much as possible. This participant went on to explain how easy it is to get sick in medical offices and expressed his preference for online information instead of seeing or talking with a doctor. Another participant expressed anger and frustration with his doctor. He thought that seeing his doctor was a waste of his time and implied that it would be pointless to discuss his health-related searches with his doctor:

> *I don't have a relationship between looking things up online and seeing my doctor. I go to the Internet instead of the doctor. I'm tired of wasting my time with my doctor who hasn't helped me anyway. I'm sick of waiting and I'm getting fed up quite frankly. Does it work for you?…But I do like to look things up on the Internet. I've been good at avoiding the clinic this way.* [62-year-old man]

It Didn't Come up Like That

There was clearly the sense that some participants might have brought up their online health searches only if the situation was right or they could remember to bring it up to their doctor. For many participants, the idea that a doctor would want to know about their Internet health searches was surprising. At the same time, there was no indication that some participants had any intention of trying to remember to bring it up. When asked about what she did to prepare for doctor's appointments, one participant told me that she prepared for appointments by looking up information online:

> *I get ready for our doctor's appointments by looking up what we want to talk about. Sometimes I've made the difference in figuring out the problem. So like, when my son was complaining that his stomach was hurting, I figured out it was a hernia and I think this would have taken a long time to figure out…I wouldn't have told them that I used the Internet research because I didn't think about it and it didn't come up like that.* [57-year-old woman]

This participant expressed a sense of self-satisfaction with the results of her online research skills. At the same time, she seemed disinclined to credit the Internet for providing the information. For other participants, the idea of bringing up information from their online searches seemed tedious. One participant said, "Oh that would be work and it is enough for me to take my meds and get to the appointments without having to make a presentation to my doctors" [70-year-old man]. This participant suggested that going to the doctor was a time when information was to be presented to him. He also made a distinction between his work, which required effort on his part, and his medical appointments, which was a time when his doctors were supposed to do the work. Another participant suggested that it simply did not occur to her to bring up the health information she had found online: "Now I hadn't thought of that. It doesn't come up so I just don't know about how that conversation would go. I do look things up but my doctors probably don't suspect and anyway I just let them tell me how to go on about things" [80-year-old man].

Facilitators of Communication With a Doctor

Overview

There were three facilitators of communication between participants and their doctor(s) that emerged: having a family member present at doctor visits, doctor-initiated inquiries, and encountering an advertisement that suggested talking with a doctor.

Family Presence at Doctor Visits

Participants who had experience talking with a doctor about their online health information seeking often mentioned the presence of a family member at the doctor's appointment. Family helped them remember what to ask and helped make the context for discussing their online health information seeking more comfortable. For example one man explained that "Looking at the Internet brings up a lot of questions…When my son is there, we talk with the doctor about the questions. I think this is the way people get information these days" [71-year-old man].

Family members also helped participants keep their records organized and keep track of concerns that came up between visits. Another participant suggested that her daughter keep a list of questions related to treatment options they found online for her cancer: "I talk to him and the three of us sort through things. The information is overwhelming so you need all the help you can get" [75-year-old woman].

Doctor-Initiated Inquiries

It was not uncommon for participants to explain that they initially started searching for health information online because their doctors had brought up the idea and that the doctors like having these discussions. For example, "I talked with my doctor about managing my diabetes and he told me about this app…When I find something, some new information I tell him. Sometimes I'll print it out and we discuss it…He appreciates it" [74-year-old woman].

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Several participants stated that they talked with their doctors about their online health information seeking when their doctor asked them directly whether they had looked online for information about their specific health condition. Another participant said, "My doctor welcomes this and we talk about things I find online at almost every visit" [56-year-old woman]. For these participants, discussions about their online health information seeking were facilitated by having doctors that inquired about patient-acquired information and who were responsive to the information patients brought them.

Encountering an Advertisement That Suggested Talking With a Doctor

It was also clear that advertisements encouraged some participants to initiate conversations with their doctors about their online health information seeking. For example, one participant described how she had been referred by a friend to look at a specific advertisement for a medication to treat a health condition she had:

> *I talked with my doctor after that probably because the ad said to. I found it online, well my friend did, and it seemed like the right fit so I brought it in with me and we ended up talking about how to look things up. My doctor even gave me a sheet.* [73-year-old woman]

Several participants who had brought Web-based advertisements that contained information they deemed relevant to their own health condition described how this prompted a conversation with their doctor and resulted in the transfer of information about how to look for quality Web-based resources from their doctor.

Discussion

Principal Findings

While prior research has warned of inherent dangers associated with having laypeople access health information online [66,67], this study contributes to existing research by describing patient-identified concerns from a sample of adults 50 years old and over. In spite of earlier conceptual work claiming that "digital immigrants", or people not born into the digital world, are less likely to be comfortable with and use the Internet relative to younger individuals [68], participants overall were aware of a broad range of concerns about using the Internet to diagnose and treat a health issue. Many of the concerns that participants raised were similar to those that have been articulated by scholars and health professionals. However, it should be noted that this sample was educated, of higher income, and computer literate.

Although the average number of concerns raised by participants who regularly communicated with a doctor about their online health information seeking was nearly the same as participants who had never discussed their online health information seeking with a doctor, there were qualitative distinctions in the types of concerns raised by each group. Had respondents who communicated with their doctors raised more concerns on average compared to those who had never communicated with a doctor about their online health information seeking, one could have argued that the communicating group was simply more verbal or somehow able to articulate more concerns. Instead, the highest proportion of participants who regularly communicated with a doctor about their online health information seeking raised concerns about the credibility of or limitations in health-related online information sources. In contrast, the highest proportion of participants who had never discussed their online health information seeking with a doctor mentioned non-physical harm as a concern.

This substantive distinction is disconcerting because non-physical harm is inherently a non-medical issue that could arise from any use of the Internet. This evidence highlights the need to foster awareness of the fact that not all online health resources are credible and that there are physical consequences associated with misuse of online health information. While there are many incentives to promoting patient use of online health resources, this study highlights the fact that some individuals fail to recognize distinctions in the quality and credibility of different online health information resources. Thus, it supports the need for continued research that assesses eHealth literacy [69,70] in a way that also points them to high-quality online health resources.

Thematic analysis generated a set of barriers to and facilitators of communication that point to ways of enhancing the exchange of information about online health information seeking between doctors and patients. In contrast to prior research with individuals suggesting that at around 50 years old adults are less trusting of the Internet as a source of health information [71] and more inclined to trust information provided by a doctor [72,73], evidence from this study points to some patients who "go to the Internet instead of the doctor". For these autonomous participants, prior frustrations seemed to be the overriding reason for failing to communicate and a potential barrier to future non-emergency medical visits. For these individuals and in light of potential breakdowns in patient-provider communication [74-77], it is all the more important that efforts to enhance eHealth literacy focus on potential physical dangers associated with delayed or self-treatment.

In sharp contrast were patients who were concerned that their doctor did not want to hear about their online health information seeking. Some seemed to hold their doctor in high regard and were afraid of saying the wrong thing to their doctor. This underscores prior research on the hierarchical relationship between doctors and patients [78,79]. It also provides evidence that some patients suppress communication with their doctors in the face of confusion, even if they have a practical question for their doctor. Prior work suggests that communication between doctors and patients can be facilitated when patients ask questions [80] and by communication skill interventions that focus on enhancing patient communication skills [81,82]. Findings from this study based on examination of the facilitators of communication between patients and doctors about patient use of the Internet for health information also demonstrate that doctors could be helpful in guiding patients to credible sources of online health-related information.

Consistent with prior research, a number of participants described how having family present at medical appointments

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facilitated conversations about their online health information seeking [83]. However, findings from this study suggest that family may serve as both an important conduit as well as a barrier to health information. Despite their ability to independently search for health information in order to identify and treat a health issue, several participants explained that their children had told them not to mention their online health information seeking to their doctor. This supports the need to further examine the role of family support in doctor-patient communication [84-88].

Other participants seemed to forget to bring up their online health information seeking with their doctor because it did not occur to them as something that they should be doing. Evidence from these participants may lend support for theories of uncertainty management, which suggest that failure to communicate can be due to intentional forgetting about acquired health information and other avoidance behaviors [66,89,90]. However, it is not clear whether these participants were forgetting because of lack of motivation, lack of an actual health threat, or some other reason. Yet regardless of the reasons for forgetting and even if participants were told by family not to bring up their online health information seeking, it is likely that they would respond to doctor-initiated conversations about their online health information seeking based on prior evidence of the hierarchical relationship between doctors and patients [78,79].

Overall findings support the need for patient skills interventions targeted at adults 50 and over and in some cases to the need for doctors to initiate conversations with patients about their online health information seeking. While it may be more difficult to reach individuals who are less inclined to consult their doctor than the Internet, evidence from this study based on examination of facilitators of communication suggests that support such as family presence or external prompts, such as advertisements, can encourage patient communication with their doctor about their online health information seeking. Findings from this study point to the need for doctors to be aware of their ability to direct patients to high-quality, credible online health resources and for policy makers to consider the fact that most patients do not have a medical education nor do they inherently know how to use online health information in a safe and effective way. It is not sufficient to create high-quality online health resources and tell patients that they ought to manage their own health issues. Instead, efforts must be made to guide patients, particularly those over 50 years old, to high-quality, credible resources and to remind them of the importance of consulting a medical professional when using online health resources to diagnose and treat a health issue.

Limitations and Suggestions for Future Research

Findings from this study are limited to the sample from which they were collected. The communication barriers and facilitators presented in this study are limited to being reflective of interactions with doctors, though other health professionals such as nurses play critical roles in the exchange of health information [91]. Findings from this study point to the need for continued research that incorporates awareness of limitations associated with using the Internet to diagnose and treat health issues into assessments of eHealth literacy. In addition, it highlights the need for future research that explores the relationship between family support and patient-provider communication regarding online health information seeking.

Conclusions

Exploration of patient concerns about using the Internet to diagnose and treat health issues is important in light of efforts to enhance independence and promote patient self-care management. Findings from this study point to a broad range of concerns about online health information seeking held by a sample of adults 50 years old and over, while highlighting distinctions based on whether or not patients had ever discussed information about their online health information seeking with a doctor. This study supports the need for patient skills interventions targeted at adults 50 and over, eHealth literacy assessments that are accompanied by targeted resources that point individuals to high-quality, credible online health information, and the need to remind patients of the importance of consulting a medical professional when they use online health resources to diagnose and treat a health issue.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Interview guide.

[PDF File (Adobe PDF File), 3KB - jmir_v17i1e19_app1.pdf]

Multimedia Appendix 2

Operationalization of the general concern categories.

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[PDF File (Adobe PDF File), 7KB - jmir_v17i1e19_app2.pdf]

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Original Paper

Characteristics and Help-Seeking Behaviors of Internet Gamblers Based on Most Problematic Mode of Gambling

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Abstract

Background: Previous studies of problem Internet gamblers have failed to distinguish whether their problem gambling relates to Internet or land-based gambling modes. Therefore, characteristics and help-seeking behaviors of people whose gambling problems relate specifically to Internet gambling are unknown, but could inform the optimal alignment of treatment and support services with the needs and preferences of problem gamblers.

Objective: This study aimed to compare (1) characteristics of problem Internet gamblers and problem land-based gamblers and (2) uptake of different types and modes of help between problem Internet gamblers and problem land-based gamblers. Hypothesis 1 was that problem Internet gamblers are less likely to seek help. Hypothesis 2 was that problem Internet gamblers are more likely to use online modes of help.

Methods: A sample of 620 respondents meeting criteria for problem gambling was drawn from an online survey of 4594 Australian gamblers. Respondents were recruited through advertisements on gambling and gambling help websites, Facebook, and Google. Measures consisted of gambling participation; proportion of gambling on the Internet; most problematic mode of gambling; help seeking from 11 different sources of formal help, informal help, and self-help for gambling problems; psychological distress (Kessler 6); problem gambling severity (Problem Gambling Severity Index, PGSI); and demographics.

Results: Problem Internet gamblers were significantly more likely than problem land-based gamblers to be male (χ^2_1=28.3, P<.001, ϕ=0.21), younger ($t_{616.33}$=4.62, P<.001, d=0.37), have lower psychological distress (χ^2_1=5.4, P=.02, ϕ=0.09), and experience problems with sports and race wagering (χ^2_4=228.5, P<.001, ϕ=0.61). Uptake of help was significantly lower among problem Internet compared to problem land-based gamblers (χ^2_1=6.9, P<.001, ϕ=0.11), including from face-to-face services, gambling helplines, online groups, self-exclusion from land-based venues, family or friends, and self-help strategies. Both problem Internet and problem land-based gamblers had similarly low use of online help. However, problem land-based gamblers (37.6%, 126/335) were significantly more likely to have sought land-based formal help compared to problem Internet gamblers (23.5%, 67/285; χ^2_1=14.3, P<.001, ϕ=0.15).

Conclusions: The findings suggest that more targeted and innovative efforts may be needed to increase use of gambling help by problem Internet gamblers. Alternatively, their lower PGSI and K6 scores suggest Internet problem gamblers may have less need for gambling-related help. This is the first known study to classify problem Internet gamblers as those whose problem gambling specifically relates to Internet gambling. Further research is needed to better understand why help-seeking rates are lower among Internet problem gamblers.

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KEYWORDS

gambling; Internet; pathological gambling; treatment

Introduction

Background

Problem gambling is characterized by difficulties in limiting time and/or money spent on gambling which leads to adverse consequences for the gambler, others, or the community [1]. Problem gamblers are typically distinguished by a pattern of excessive gambling, impaired control over gambling, and persistence with heavy gambling despite its significant negative consequences [2]. Prevalence studies in 202 jurisdictions indicate past-year problem gambling rates of 0.5%-7.6% of the adult population [3]. Severe negative financial, relationship, health, vocational, and legal consequences of problem gambling, along with low help-seeking rates, suggest that further research into the disorder and associated help seeking is warranted.

Although use of Internet gambling is increasing internationally and several studies have examined Internet gamblers, little is known about their preferences and likelihood of seeking help for gambling problems. This knowledge is lacking because most studies have classified problem Internet gamblers as Internet gamblers who meet criteria for problem gambling, regardless of whether their problem gambling is related to Internet or land-based gambling modes [4-11]. Therefore, this classification would identify a person as a problem Internet gambler who has significant problems with gambling on land-based table games, wagering, or electronic gaming machines (EGMs, also known as slot machines, poker machines, video slots, and fruit machines), but who occasionally purchases a lottery ticket online. Accordingly, this approach has been able to draw only limited conclusions about the role of Internet gambling in problem gambling and characteristics and help-seeking behaviors of people whose gambling problems relate specifically to online gambling modes.

The present study aimed to (1) compare the characteristics of problem Internet gamblers to problem land-based gamblers, differentiated according to their most problematic mode of gambling and (2) compare the uptake of different types and modes of help between problem Internet gamblers and problem land-based gamblers.

To our knowledge, this study is the first with a nonclinical sample to classify problem Internet gamblers as individuals whose problem gambling is specifically associated with Internet gambling. Understanding the comparative similarities and differences in characteristics and help-seeking behaviors of those nominating Internet (vs land-based) gambling modes can guide the optimal alignment of treatment and support services with the needs and preferences of problem Internet gamblers. This should improve rates of gambling help seeking from their currently low base rate. This is relevant given only 5%-10% of problem gamblers are in professional treatment at any 1 time and only small proportions access other supports such as self-exclusion (in which people voluntarily bar themselves from gambling venues or websites for a specified time period), peer support groups, informal assistance from family and friends, and self-help [12-20].

Characteristics and Help-Seeking Behavior of Problem Internet and Land-Based Gamblers

Research has not yet established whether the help-seeking behavior of problem Internet gamblers differs from that of problem land-based gamblers because the most problematic mode of gambling has not been considered previously. However, several reasons are discussed subsequently that support the 2 hypotheses tested in this study:

1. Hypothesis 1: Problem Internet gamblers are less likely to seek help for problem gambling compared to problem land-based gamblers.
2. Hypothesis 2: Problem Internet gamblers are more likely to seek online help for problem gambling compared to problem land-based gamblers.

Our first hypothesis was proposed based partly on the different sociodemographic and psychological profile of problem Internet gamblers compared to problem land-based gamblers. A large representative Australian telephone survey conducted in late 2011 (with different participants than this study) found that Internet moderate-risk/problem gamblers were more likely to be younger, male, married, and to have lower levels of psychological distress compared to moderate-risk/problem land-based gamblers [4]. Another large study conducted in 2006-2007 with Canadian and international samples [21] found that problem Internet gamblers were more likely to be single, of Asian ancestry, with lower household income, and have mental health problems and a history of other addictions. In a small sample of Spanish treatment-seeking problem gamblers recruited between 2005 and 2009, those who gambled only online (n=53) tended to have higher education and socioeconomic status than problem land-based gamblers [22]. Previous studies have found that help-seeking for problem gambling is less common among problem gamblers who are male, younger, unmarried, employed, and in ethnic minority groups [14,23-28], which largely aligns with the general profile of problem Internet gamblers, although this varies by jurisdiction. Thus, problem Internet gamblers in the current study were expected to be less likely to seek help than their land-based counterparts.

Differences in types of problematic gambling between Internet gamblers and land-based gamblers also lend support for our first hypothesis that problem Internet gamblers are less likely to seek help for problem gambling. An Australian telephone survey found that Internet problem gamblers were more likely to experience problems with sports and race wagering, and land-based problem gamblers were more likely to experience problems with EGMs [4]. Another study found Canadian Internet gamblers were significantly more likely to report poker as their most problematic gambling form compared to EGMs

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for non-Internet gamblers [11]. Although there is widespread agreement that most problem land-based gamblers attribute their problems to EGMs [13,17], problematic Internet gambling forms appear to be more diverse and far less commonly related to online EGM play. EGMs are played mostly in land-based venues where gambling help services are often widely advertised; in contrast, gambling on sports, races, and poker is more likely to occur through online websites where the advertising of help services is generally less apparent. Thus, problem Internet gamblers may be less likely to seek help because they are less exposed to gambling help service advertising compared to problem land-based gamblers.

Other features of Internet gambling may also impede help seeking for problem gambling. Use of electronic money, accounts, and credit may delay problem recognition and acknowledgment in contrast to land-based cash gambling where losses are immediately apparent [5,29]. Lack of scrutiny in the online environment may also facilitate problem denial, whereas staff and other patrons in land-based venues may heighten a gambler's attention to the extent of their gambling, either overtly or implicitly [29]. These distinctive features of Internet gambling can be expected to result in lower help-seeking rates.

Further, the negative consequences of gambling appear to differ between problem Internet and problem land-based gamblers. One study found that moderate-risk/problem land-based gamblers are more likely to experience more serious gambling consequences than their Internet gambler counterparts [30]. These consequences included major relationship breakdown, loss of contact with children, change or loss of employment, bankruptcy, and loss of savings. Given that help seeking is typically crisis-driven [13,31], less extensive, and severe, negative gambling consequences may lead to lower uptake of help by problem Internet gamblers compared to problem land-based gamblers.

In support of our second hypothesis that problem Internet gamblers are more likely to seek online help for problem gambling compared to problem land-based gamblers, preferred mode of help (face-to-face, telephone, online) may align with preferred mode of gambling. Studies suggest that Internet gamblers more frequently access Internet-based help and this may be a preference. Wood and Griffiths' [32] 2007 evaluation of a UK-based online help service for problem gamblers found that online gambling was the most popular gambling "location" among clients and more popular than among clients accessing a comparable UK gambling telephone helpline. The authors argued that online help is most likely the preferred mode for online gamblers because of their likely greater overall competence in, familiarity and comfort with, and access to the Internet. A 2009 study of 2 UK online forums for people affected by gambling problems also found they were most popular with online gamblers [33]. Of 2021 clients accessing real-time chat and email support through an Australian online gambling help service between 2009 and 2011, 16.6% preferred an online gambling mode [34], more than double the proportion of Internet gamblers in the Australian adult population [4]. Rodda and Lubman [34] speculated that the same reasons for preferring online gambling, such as convenience, ease, and comfort of their own home, may also make online help more attractive to this group. However, 1 large study found that both Internet and non-Internet problem/moderate-risk gamblers in its Canadian (n=8948) and international (n=12,521) samples expressed a preference for using a face-to-face service over an online or telephone service [11].

Methods

Overview

Approval for this study was obtained from 2 university human research ethics committees (Southern Cross University, The University of Sydney). An online survey was used to reach a large national sample, and for its anonymity and privacy which enhance response rates, response accuracy, and survey completeness, especially when focused on sensitive topics such as gambling [21,35]. Although the survey was only available to those with Internet access, 82.3% of Australians are Internet users [36].

Recruitment and Sampling

Advertisements were placed on 46 websites likely to be visited by Australians interested in gambling and obtaining help for gambling problems. These websites included those of 18 regulated gambling operators, 12 gambling-related sites (containing information and research), 7 government departments which regulate gambling, 6 gambling help organizations, and 3 sporting associations. Paid advertisements were also displayed on Facebook and Google. A sample of 4594 respondents was obtained between May and December 2012. Inclusion criteria were aged 18 years or older, gambling at least once in the previous 12 months, and English literacy. Most respondents (53.87%, 2475/4594) were alerted to the survey via advertisements on online wagering/lottery sites, Facebook (17.63%, 810/4594), and Google (6.27%, 288/4594).

Measures

Gambling Behavior

Gambling behavior was measured, including participation during the previous 12 months in 10 gambling forms: instant scratch tickets; lottery, lotto, or pools tickets; sports betting; betting on horse or dog races; bingo; keno; poker; casino table games not including poker; games of skill not including poker; and EGMs. For each type of gambling, respondents were also asked the percentage of their "purchases or play" during the previous 12 months that "was done over the Internet." Global measures to assess the proportion of all gambling money and time spent online were also included. Two questions were asked about use of alcohol and use of recreational drugs while gambling, with response options from "never" to "almost always."

Problem Gambling Severity

The Problem Gambling Severity Index (PGSI) [37] is widely used in Australia and elsewhere and is a recommended measure of problem gambling severity [38]. This 9-item scale is scored "never" (=0) to "almost always" (=3), with scores summed for a total between 0-27. Cut-off scores adhered to those used in the PGSI's original validation in which 0=nonproblem gambler, 1-2=low-risk gambler, 3-7=moderate-risk gambler, and 8-27=problem gambler. Cronbach alpha for this scale in this

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sample was .93. Only respondents scoring between 8 and 27 were included in the current study because those at lower risk, such as moderate-risk gamblers, tend not to seek help for a gambling problem [38].

Most Problematic Form of Gambling

Problem gamblers (based on PGSI scores) were asked which form of gambling had contributed most to any problems that they had experienced from gambling. Respondents could choose 1 of 10 forms listed previously, "other," or "I have not experienced problems from my gambling."

Most Problematic Mode of Gambling

Problem gamblers (based on PGSI scores) were asked "What type of gambling medium has contributed MOST to any problems you may have experienced from your gambling?" The following response options were provided: Internet via computers, Internet via mobile phone, Internet via portable/wireless device, Internet TV, land-based gambling, and betting via telephone. The first 4 options were recoded into "Internet gambling" to classify most problematic gambling mode.

Help Seeking for Gambling Problems

Problem gamblers were asked if they had ever sought help from 11 different sources encompassing the most common forms of formal help, informal help, and self-help [18]. Formal types of help were grouped for some analyses according to mode of help: (1) land-based forms (face-to-face from a specialist gambling counselor, face-to-face from a nongambling specialist professional, face-to-face support group, residential treatment program, self-exclusion from a land-based gambling venue), (2) online modes (online or email gambling counseling, online support group or discussion board, self-exclusion from a gambling website), and (3) telephone modes (gambling telephone helpline). In Australia, specialized gambling help services are provided free through government-funded services. These include appointment-based face-to-face counseling and immediate 24/7 information, support, counseling, and referral through telephone and online services. However, people may also access help through private practitioners (may incur a cost).

Psychological Distress

Psychological distress was assessed by the 6-item Kessler Psychological Distress Scale (K6) [39], which asked frequency of symptoms of psychological distress over the most recent 4 weeks with fixed responses ranging from "none of the time" (=0) to "all of the time" (=4). Total scores of 12-19 indicate mild to moderate mental health disorders and scores greater than 20 indicate clinically high levels of psychological distress [40,41]. The scale exhibited good reliability in this sample (Cronbach alpha=.93).

Demographics

Sex, age, place of residence, household type, highest educational qualification, work status, income, debt, and cultural background were self-reported.

Analyses

Problem Internet gamblers were defined as those meeting criteria for problem gambling as measured by the PGSI [37] and who nominated the Internet as their most problematic gambling mode. Problem land-based gamblers were defined as those meeting PGSI criteria for problem gambling and who nominated a land-based gambling mode as their most problematic. Most statistical analyses compared these 2 groups of respondents. These comparisons took the form of nonparametric tests (Mann-Whitney *U*), chi-square tests of independence (with post hoc pairwise comparisons using *z* tests for multiple degrees of freedom tests), or independent samples *t* tests. A binary logistic regression was also conducted and this is detailed in the results section. Finally, repeated measures nonparametric analyses were conducted for expenditure using the Wilcoxon signed rank test. Nonparametric tests were used for ordinal frequency data or for expenditure data where extreme values resulted in excessive variance. Alpha was set at .05 for all analyses unless stated otherwise.

Results

Sample Characteristics

Of the 4594 respondents to the survey, 70.51% (3239/4594) had gambled using the Internet at least once during the previous 12 months (designated as Internet gamblers), whereas 29.49% (1355/4594) had gambled only on land-based modes (designated as land-based gamblers). Among the 4594 respondents, 643 scored as problem gamblers on the PGSI, representing 14.20% (460/3239) of Internet gamblers and 13.51% (183/1355) of land-based gamblers in the sample. Problem land-based gamblers exhibited significantly higher PGSI scores (mean 14.4, SD 5.3, median 13.0) compared to problem Internet gamblers (mean 12.5, SD 4.6, median 11.0; U=37,845.5; z=4.47, P<.001).

Of the 643 problem gamblers surveyed, 9 respondents listed telephone betting as their most problematic medium and were excluded from further analysis, as were 14 people who did not answer the question. Of the remaining 620 problem gamblers, 285 (46.0%) nominated Internet modes as their most problematic either via computers, mobile phones, portable/wireless devices or interactive television (designated as problem Internet gamblers). The remaining 335 respondents (54.0%) nominated land-based modes as their most problematic (designated as problem land-based gamblers). Thus, problem Internet gamblers were past-year problem gamblers who nominated an Internet gambling medium as contributing most to their gambling problems. Problem land-based gamblers were past-year problem gamblers who nominated a land-based gambling medium as contributing most to their gambling problems.

The sample of problem gamblers (n=620) was predominantly male (79.8%, 495/620), with a mean age of 37.6 years (SD 13.1). The most common marital status was never married (44.4%, 275/620) followed by married (25.6%, 159/620) or de facto/living with partner (17.9%, 111/620). At least 70.0% (434/620) of the sample reported living with others and 62.6% (388/620) reported living in a major metropolitan city. Most (53.5%, 332/620) worked full-time and 52.7% (327/620) reported completing some form of tertiary study. Most (79.0%,

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490/620) were born in Australia and 81.0% (502/620) spoke English at home as their primary language. Median household income was AU$60,000-AU$69,999 per annum, with median household debt reported to be AU$20,000.

Characteristics of Problem Internet vs Land-Based Gamblers

Overview

Problem Internet gamblers were compared to problem land-based gamblers for demographic characteristics, mental health, gambling behavior, and most problematic gambling form.

Demographic Characteristics

Problem Internet gamblers were significantly more likely to be male (89.1%, 254/285) compared to problem land-based gamblers (71.9%, 241/335; χ^2_1=28.3 P<.001; ϕ=0.21) and significantly younger (mean 35.0, SD 11.3) compared to problem land-based gamblers (mean 39.7, SD 14.0; $t_{616.33}$=4.62, P<.001; d=0.37).

No significant differences were observed between problem Internet and problem land-based gamblers for any of the following demographic variables: marital status, household characteristics (ie, number of children or absence/presence of partners), location of residence (approximately 62% of both groups lived in major metropolitan cities), level of education, work status, household income or debt, country where the respondent was born, or language spoken at home.

Mental Health

Problem land-based gamblers were significantly more likely to be classified as having high psychological distress according to the K6 than were problem Internet gamblers (37.6%, 126/335 vs 28.8%, 82/285, respectively; χ^2_1=5.4, P=.02; ϕ=0.09).

Gambling Participation, Frequency, Expenditure, and Substance Use While Gambling

A significantly higher proportion of problem Internet gamblers participated in sports betting and horse and dog race betting, whereas a significantly higher proportion of problem land-based gamblers took part in EGMs, with no significant differences for lottery-type or other forms of gambling (Table 1). Furthermore, problem Internet gamblers who took part in sports or horse race betting did so more often (U=16,002, z=6.52, P<0.001 and U=16,461.5, z=5.50, P<.001, respectively) and spent more money (U=18,319.5, z=3.45, P<.001 and U=18,351, z=2.82, P<.001, respectively) on those forms than did problem land-based gamblers. In contrast, problem land-based gamblers gambled on EGMs significantly more frequently (U=17,685.5, z=7.20, P<.001) and spent significantly more money per month on them (U=14,248.5, z=8.46, P<.001) than did problem Internet gamblers. Repeated measures Wilcoxon signed rank tests were used to compare these 3 forms of betting for expenditure (reported here as z tests). Problem Internet gamblers spent more money on horse or dog race betting than sports betting (z=2.32, P=.02) or on EGMs (z=4.58, P<.001), but there was no significant difference between sports betting and EGMs (z=1.15, P=.25). Problem land-based gamblers reported spending significantly more money on EGMs than on horse or dog racing (z=5.35, P<.001) or sports betting (z=7.21, P<.001), and more on horse or dog race betting than on sports betting (z=3.55, P<.001). No significant differences were found between the 2 groups for alcohol or drug consumption while gambling.

Table 1. Number and percentage of respondents who participated in each gambling form in the past 12 months by most problematic gambling mode (N=620).

Form	Problem Internet gamblers (n=285)		Problem land-based gamblers (n=335)		χ^2_1	P	ϕ
	n (%)[a]	% Online[b]	n (%)[a]	% Online[b]			
Sports betting	248 (87.0)	72.6	198 (59.1)	35.8	59.4	<.001	0.31
Horse and dog race betting	223 (78.2)	70.1	210 (62.7)	28.8	17.7	<.001	0.17
EGMs	186 (65.3)	10.0	307 (91.6)	4.4	65.8	<.001	0.33
Lottery-type gambling[c]	258 (90.5)	NA	308 (91.9)	NA	0.4	.53	0.03
Other[d]	166 (58.2)	NA	186 (55.5)	NA	0.5	.50	0.03

[a]The percentages refer to the percentage of respondents in each group who reported engaging in that form of gambling during the past 12 months. Multiple responses allowed. The statistics are based on these values.

[b] The percentages refer to the mean percentage of that activity reported by respondents in each group as being conducted via an Internet mode (vs a land-based mode). These cannot be calculated for the lottery-type or other forms because they are combinations of numerous forms (NA: not applicable).

[c] Lottery-type gambling includes instant scratch tickets, lotteries/lotto/pools tickets, bingo, and keno.

[d] Other forms include poker, casino table games, games of skill, and any other forms. Multiple answers possible.

Most Problematic Gambling Form

When asked about the form of gambling that had most contributed to their gambling problems, problem Internet gamblers were significantly more likely to nominate sports betting and horse or dog race betting compared to problem land-based gamblers, who were significantly more likely to nominate EGMs (χ^2_4=228.5 P<.001; ϕ=0.61) (Table 2).

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Table 2. Number and percentage of respondents who attributed their gambling problems to each form by most problematic gambling mode (N=620).

Form	Problem Internet gamblers (n=285), n (%)	Problem land-based gamblers (n=335), n (%)
Sports betting	82 (28.8)	8 (2.4)
Horse and dog race betting	107 (37.5)	34 (10.1)
EGMs	51 (17.9)	248 (74.0)
Lottery-type gambling[a]	17 (6.0)	10 (3.0)
Other[b]	28 (9.8)	35 (10.4)

[a]Lottery-type gambling includes instant scratch tickets, lotteries/lotto/pools tickets, bingo, and keno.

[b]Other forms include poker, casino table games, games of skill, and any other forms.

Uptake of Different Types and Modes of Help by Problem Internet vs Problem Land-Based Gamblers

Overview

Among the 620 problem gamblers, 342 (55.2%) reported having sought at least 1 type of help for their gambling. Among the problem Internet gamblers, 141 of 285 (49.5%) had sought at least 1 type of help compared to 201 of 335 (60.0%) problem land-based gamblers. This difference was statistically significant (χ^2_1=6.9, P<.001; ϕ=0.11) and supported our first hypothesis that problem Internet gamblers are less likely to seek help for problem gambling.

Uptake of Different Types of Help

Table 3 compares uptake of the 11 different types of help between problem Internet and problem land-based gamblers. Problem land-based gamblers were significantly more likely than problem Internet gamblers to seek help from the following sources: face-to-face from a specialist gambling counselor, face-to-face from a nongambling specialist professional, gambling telephone helpline, an online support group or discussion board, through self-exclusion from a land-based gambling venue, from family or friends, and through self-help strategies. Problem land-based gamblers were also significantly more likely to have sought any type of help compared to problem Internet gamblers, providing further support for our first hypothesis that problem Internet gamblers are less likely to seek help for problem gambling.

Table 3. Number and percentage of respondents who sought each form of help by most problematic gambling mode (N=620).[a]

Form	Problem Internet gamblers (n=285), n (%)	Problem land-based gamblers (n=335), n (%)	χ^2_1	P	ϕ
Formal help					
Face-to-face from a specialist gambling counselor	37 (13.0)	77 (23.0)	10.3	.001	0.13
Face-to-face from a nongambling specialist professional	23 (8.1)	44 (13.4)	4.1	.04	0.08
Gambling telephone helpline	35 (12.3)	66 (19.7)	6.2	.01	0.10
Online or email gambling counseling	27 (9.5)	31 (9.3)	<0.1	.93	<0.01
Residential treatment program	7 (2.5)	6 (1.8)	0.3	.57	0.02
Face-to-face support group	16 (5.6)	31 (9.3)	2.9	.09	0.07
Online support group or discussion board	3 (1.1)	12 (3.6)	4.2	.04	0.08
Self-exclusion from land-based gambling venue	8 (2.8)	54 (16.1)	30.3	<.001	0.22
Self-exclusion from gambling website	21 (7.4)	19 (5.7)	0.7	.39	0.03
Informal help					
From family or friends	32 (11.2)	73 (21.8)	12.2	<.001	0.14
Self-help					
Through self-help strategies	33 (11.6)	89 (26.6)	21.9	<.001	0.19
Never sought gambling help	144 (50.5)	134 (40.0)	6.9	<.001	0.11

[a]Multiple responses were accepted.

Uptake of Different Modes of Help

Formal sources of help were categorized into land-based modes, online modes, and telephone modes to test our second hypothesis. A total 193 of 620 problem gamblers (31.1%) had sought formal land-based help, 103 of 620 (16.6%) had sought formal online help, and 101 of 620 (16.3%) had sought formal telephone help. There was some overlap between land-based,

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online, and telephone help seeking (Table 4). All comparisons between those who did and did not seek each form of help were treated independently. To account for any overlap, alpha was set at .01 for the following results.

Table 4. Combinations of modes of formal help seeking.

Form(s)	n (%)
No formal help	335 (54.0)
Land-based help only	110 (17.7)
Online help only	49 (7.9)
Telephone help only	35 (5.6)
Land-based and online help	25 (4.0)
Land-based and telephone help	37 (6.0)
Online and telephone help	8 (1.3)
All 3 forms	21 (3.4)

Mode of Formal Help by Participant Characteristics

Those who sought land-based help were significantly older (mean 40.1, SD 13.1 years) compared to those who had not sought land-based help (mean 36.4, SD 12.9 years; t_{618}=3.25, P=.001; d=0.26), but there was no difference in age between those who had and had not sought online help or telephone help.

No significant differences were observed between those who had and had not sought any of the 3 modes of help by the following demographic variables: gender, marital status, household characteristics, location of residence, level of education, work status, household income or debt, country where the respondent was born, or language spoken at home.

Mode of Formal Help Sought by Most Problematic Gambling Mode

Problem land-based gamblers (37.6%, 126/335) were significantly more likely to have sought land-based formal help compared to problem Internet gamblers (23.5%, 67/285; χ^2_1=14.3, P<.001; ϕ=0.15). However, no significant differences between the groups were observed for use of online help (16.8%, 48/285 of problem Internet gamblers vs 16.4%, 55/335 of problem land-based gamblers) or for use of telephone help (12.3%, 35/285 for problem Internet and 19.7%, 66/335 for problem land-based gamblers). Therefore, our second hypothesis that problem Internet gamblers are more likely to seek online help for problem gambling compared to problem land-based gamblers was not supported.

Multivariate Analysis of Types of Help by Most Problematic Gambling Mode

The preceding analyses are univariate analyses. Thus, a multivariate analysis was employed to account for overlap among the results. The dependent variable in this analysis was whether the respondent was a problem Internet gambler (coded as 1) or problem land-based gambler (coded as 2). The predictors were the 11 help-seeking variables (coded as 0="have not sought this form of help" and 1="have sought this form of help at least once," excluding the "never sought gambling help" variable), gender (reference group=female), and age in years (treated as a continuous predictor). The analysis was run as a binary logistic regression with all predictors entered in 1 step. Before conducting the logistic regression, a linear regression was run to check for tolerance issues. The lowest tolerance value obtained was 0.72, indicating little overlap between predictors. Alpha was set to .05 for all predictors.

The overall logistic regression model was significant (χ^2_{13}=99.5, P<.001) and successfully predicted 63.9% (182/285) of problem Internet and 64.8% (217/335) of problem land-based gamblers. Results for the predictors are shown in Table 5. Problem land-based gamblers were significantly more likely to have sought help from family or friends, to have attempted self-help strategies, or to have self-excluded from a land-based gambling venue. Problem Internet gamblers were significantly more likely to be male, to be younger, and to have self-excluded from gambling websites. No other variables were statistically significant. Thus, although the tolerance statistics indicate relatively little crossover between the variables, there was enough crossover for these other variables to not be statistically significant in a multivariate procedure.

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Table 5. Predictors in the logistic regression predicting Internet or land-based problem gambling status by key demographics and forms of help seeking.

Predictor	B (SE)	Wald	*P*	OR (95% CI)
Age (in years)	0.021 (0.007)	8.705	.003	1.021 (1.007, 1.036)
Gender (ref: female)	–0.955 (0.247)	14.981	<.001	0.385 (0.237, 0.624)
Help-seeking forms (ref: no)				
Face-to-face from a specialist gambling counselor	0.379 (0.257)	2.173	.14	1.461 (0.883, 2.418)
Face-to-face from a nongambling specialist professional	–0.089 (0.332)	0.072	.79	0.915 (0.478, 1.753)
Gambling telephone helpline	0.312 (0.268)	1.354	.25	1.366 (0.808, 2.308)
Online or email gambling counseling	–0.514 (0.324)	2.521	.11	0.598 (0.317, 1.128)
Residential treatment program	–1.310 (0.742)	3.115	.08	0.270 (0.063, 1.156)
Face-to-face support group	–0.313 (0.421)	0.553	.46	0.731 (0.320, 1.668)
Online support group or discussion board	0.846 (0.750)	1.273	.26	2.331 (0.536, 10.142)
From family or friends	0.725 (0.271)	7.132	.008	2.064 (1.213, 3.513)
Self-exclusion from land-based gambling venue	1.773 (0.443)	16.060	<.001	5.891 (2.475, 14.023)
Self-exclusion from gambling website	–1.036 (0.410)	6.393	.01	0.355 (0.159, 0.792)
Through self-help strategies	0.583 (0.269)	4.719	.03	1.792 (1.059, 3.033)

Discussion

Principal Results and Comparisons With Prior Work

To our knowledge, this study is the first to identify the characteristics of problem Internet gamblers classified according to most problematic mode of gambling. Consistent with earlier reports, the current study found that problem Internet gamblers were significantly more likely to be male and younger compared to their land-based counterparts [11,42,43]. However, age and gender were found to significantly distinguish problem Internet and problem land-based gamblers in contrast to previous studies in which marital status, ethnicity, socioeconomic status, and education were also implicated [4,21,22]. Our results identified higher rates of psychological distress among problem land-based gamblers compared to problem Internet gamblers, which is the reverse of previous findings [21]. These inconsistencies are likely due to the different method used to classify problem Internet gamblers in this study. In contrast to this study, previous studies have included Internet gamblers experiencing problems with a land-based mode of gambling as problem Internet gamblers [4,5,21].

Our results lend support to previous findings that Internet gamblers are more involved and diverse gamblers compared to non-Internet gamblers [4,11,42,44], at least in their use of different gambling modes. Problem Internet gamblers spent one-fifth of their gambling expenditure and time on land-based gambling modes, whereas problem land-based gamblers spent minimal expenditure and time on Internet gambling modes. As expected from prior research [13,34], EGMs were the most problematic form for land-based gamblers, whereas sports and race wagering were most problematic for problem Internet gamblers.

This study has revealed new information about help seeking among problem Internet gamblers. In support of our first hypothesis, it found that problem Internet gamblers were significantly less likely to access help than their land-based equivalents. This was reflected in their significantly lower uptake of professional face-to-face help and through a gambling helpline, self-exclusion from a land-based venue, from family or friends, and through self-help strategies. Problem Internet gamblers also had lower usage of online support groups or discussion boards compared to problem land-based gamblers. The results provide some indication that problem Internet gamblers were more likely to have self-excluded from a gambling website, but this was the only type of help used more than problem land-based gamblers. This greater use is unsurprising given that online gambling sites created the greatest problems for this cohort. It is possible that website self-exclusion is an adequate intervention for some Internet gamblers to maintain control over their gambling. Nevertheless, less than 1 in 10 problem Internet gamblers had used this intervention.

The most popular types of help among the problem Internet gamblers were face-to-face gambling counseling, followed by a gambling helpline and use of self-help and support from family and friends. Uptake of diverse forms of help may indicate that provision of a wide range of help options best caters for the varying preferences of problem Internet gamblers. However, slightly more than half had never sought any type of help for their gambling. These findings may reflect the greater promotion of help services advertised in land-based venues compared to online gambling websites. As suggested in prior studies, further publicity of formal help services, self-help tools and resources, and encouragement to use family and social support may be needed by online gambling sites to improve help-seeking rates among Internet gamblers [30,34,45-48].

Additional explanations are possible for the lower uptake of help among problem Internet gamblers. Lower uptake may reflect greater reticence to use gambling help among males and younger people [13,48], which are 2 distinguishing characteristics of problem Internet gamblers. Innovative targeted advertising strategies, including through social media, may be

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needed to better promote help services to target young male online gamblers experiencing problems with non-EGM forms of gambling [30,46]. A further explanation is that problem Internet gamblers may value their privacy more than problem land-based gamblers, as reflected through their choice of main gambling mode and an apparent reticence to disclose their problem gambling to those who can provide help. The privacy and lack of scrutiny afforded by the online gambling environment [49-54] may also facilitate problem denial. The relative isolation of Internet gambling means that Internet gamblers typically receive no cues from venue staff or other patrons that their gambling may be problematic [29].

However, problem Internet gamblers in this study were found to have lower levels of both gambling problems and psychological distress, and thus fewer reasons to seek help. Therefore, they may have less severe negative consequences from their gambling and may also be less likely to gamble for escape and dissociation, which are well-known motivations for EGM gambling among problem land-based gamblers [13,17]. In comparison, sports and race wagering are engaged in more often for recreational and entertainment reasons, as a hobby and a challenge. For example, a study of regular horse and EGM gamblers found that horse gamblers were motivated by positively reinforced outcomes, such as excitement and reward; in contrast, EGM players were generally responding to negatively reinforced outcomes, such as escape from emotional distress [55]. Gambling for escape and mood regulation has been endorsed in previous research as increasing risks for gambling problems [56-58]. Additionally, the predominantly young male problem Internet gamblers may have fewer financial responsibilities and be better able to sustain gambling losses without experiencing severe adverse consequences compared to problem land-based gamblers.

This study also compared use of formal online, telephone, and face-to-face help by most problematic gambling mode. Researchers have suggested that problem Internet gamblers are more likely to use online than land-based help [32-34] and this was proposed by our second hypothesis. However, an aversion to help seeking through the same medium associated with problem gambling has also been suggested, although this proposition has not been tested [11]. The current study found that use of online formal help did not differ by most problematic gambling mode. Despite the availability of diverse types of online help, including counselor-assisted therapy through live chat and email, peer support groups, and self-help tools, resources, and apps [34,59,60], online options did not appear to be more attractive to problem Internet gamblers than to problem land-based gamblers. Therefore, our second hypothesis that problem Internet gamblers are more likely to seek online help for problem gambling compared to problem land-based gamblers was not supported. In contrast, problem land-based gamblers in the current study were more likely to use land-based or telephone-based formal help compared to problem Internet gamblers. This finding may reflect their lower comfort levels with using the Internet to seek help, as reflected through their preferred gambling mode, but also greater promotion of land-based and telephone help services than online help options in the land-based venues they frequent. It may also reflect that the availability of online help options may not be well advertised or promoted to either Internet or land-based problem gamblers.

Further research is needed to explain why help-seeking rates appear to be lower among problem Internet gamblers compared to problem land-based gamblers. It may be that they have less need to seek help or that some find self-exclusion from gambling websites adequate to maintain control over gambling. Alternatively, barriers to help seeking may be different for problem Internet gamblers than those found among problem land-based gamblers, such as stigma, shame, problem denial, a belief that one can handle the problem alone, and false hope in the ability to win back losses or regain control [19,61-65]. Research with representative samples is also needed to verify results obtained.

Limitations

Low numbers of Internet gamblers in the population necessitated a targeted approach to recruitment. Thus, although the study sample was large, it was not necessarily representative of the general population of problem Internet gamblers or of problem land-based gamblers among whom use of the Internet may be low. This convenience sampling may explain the high rates of help seeking found in this study compared to previous estimates that approximately 10% of problem gamblers in Australia seek professional help for their gambling problem [13]. Recruitment of respondents through advertisements on gambling help sites, possibly greater participation in the survey by those with higher gambling involvement, and inclusion of specific questions on each types of help (eg, gambling telephone helpline, self-exclusion, self-help), may also explain the comparatively high help-seeking rates found in the current study. A further limitation is that the help-seeking questions did not specifically ask whether the help was sought in relation to Internet or land-based gambling; this limitation could be avoided in future research. Similarly, most problematic mode of gambling and most problematic form of gambling were self-assessed rather than being ascertained through screening. Additionally, the cross-sectional nature of the study did not allow causal inferences to be drawn.

Conclusions

Classifying problem Internet and problem land-based gamblers based on most problematic gambling mode appears an advantageous approach to analyzing their characteristics and behaviors because it removes the confounding issue that some Internet gamblers experience most problems with a land-based mode of gambling. By using this approach, this study was able to identify distinguishing characteristics of problem Internet gamblers as being more likely to be male, younger, with lower levels of psychological distress than their land-based counterparts, and to most likely have problems with sports and race wagering. Further, this approach identified lower uptake of help by problem Internet gamblers compared to problem land-based gamblers and a similarly low use of online help among the 2 groups.

Findings suggest that targeted, more innovative, and widespread efforts may be needed to increase use of gambling help by problem Internet gamblers, including through their promotion

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on Internet gambling websites. Internet gambling operators could also ensure that harm minimization measures, such as deposit limits, credit limits, and self-exclusion, are available and prominently advertised. Further, promotion of gambling help could be tailored to the predominantly young male profile of problem Internet gamblers and focus on risks associated with online sports and race wagering in addition to the current focus of most public health initiatives on EGM gambling. Online self-help resources should also be further developed to cater to Internet gamblers and be promoted to both Internet and land-based gamblers. However, additional research is needed to further understand why help-seeking rates appear to be lower among problem Internet compared to problem land-based gamblers. Whether this group of problem gamblers has the same need for gambling help as their land-based counterparts is not currently known.

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Conflicts of Interest

Hing, Russell, Gainsbury and Blaszczynski have received funding support and provided consultancies to organisations directly and indirectly benefitting from gambling, including government and industry sources.

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Abbreviations

EGM: electronic gaming machine
PGSI: Problem Gambling Severity Index

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Original Paper

The Effectiveness of Health Animations in Audiences With Different Health Literacy Levels: An Experimental Study

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Abstract

Background: Processing Web-based health information can be difficult, especially for people with low health literacy. Presenting health information in an audiovisual format, such as animation, is expected to improve understanding among low health literate audiences.

Objective: The aim of this paper is to investigate what features of spoken health animations improve information recall and attitudes and whether there are differences between health literacy groups.

Methods: We conducted an online experiment among 231 participants aged 55 years or older with either low or high health literacy. A 2 (spoken vs written text) x 2 (illustration vs animation) design was used. Participants were randomly exposed to one of the four experimental messages, all providing the same information on colorectal cancer screening.

Results: The results showed that, among people with low health literacy, spoken messages about colorectal cancer screening improved recall (P=.03) and attitudes (P=.02) compared to written messages. Animations alone did not improve recall, but when combined with spoken text, they significantly improved recall in this group (P=.02). When exposed to spoken animations, people with low health literacy recalled the same amount of information as their high health literate counterparts (P=.12), whereas in all other conditions people with high health literacy recalled more information compared to low health literate individuals. For people with low health literacy, positive attitudes mediated the relationship between spoken text and the intention to have a colorectal cancer screening (b=.12; 95% CI 0.02-0.25).

Conclusions: We conclude that spoken animation is the best way to communicate complex health information to people with low health literacy. This format can even bridge the information processing gap between audiences with low and high health literacy as the recall differences between the two groups are eliminated. As animations do not negatively influence high health literate audiences, it is concluded that information adapted to audiences with low health literacy suits people with high health literacy as well.

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KEYWORDS

health literacy; animation; medical illustration; reading; audiovisual media; cancer screening; colorectal cancer; prevention; memory; attitudes

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Introduction

Background

Web-based information about health and disease prevention is widely available. In 2013, the majority of the people living in the United States and The Netherlands used the Internet to find health-related information [1,2] and many people consider the Internet a valuable tool for finding health information [3]. However, a significant portion of the potential audience fails to understand Web-based health materials due to low health literacy [4]. This is problematic because health information could be valuable for this group. People with low health literacy are, for example, more often chronically ill and less likely to use preventive health services, such as cancer screening, compared to people with high health literacy [5]. To reduce health disparities in society, there is a need for health information that is easily understood and appreciated by people with low health literacy and that is not rejected by people with higher health literacy levels.

The rise of online communication has offered many new possibilities to make health communication more attractive, especially for people with low health literacy. On the Internet, information can be presented in various delivery modes such as videos or animations. A study on tailored feedback, delivered by text or video, showed that video computer tailoring was more effective than text computer tailoring in realizing smoking cessation [6]. A recent literature review, however, concluded that print and audiovisual information often perform equally well [7]. The authors argue that audiovisual messages are promising but that there is a need for well-designed experiments comparing different formats while keeping the content the same. The different message features make it difficult to compare both formats and to draw conclusions about the effective elements. For example, a video presents both visual and auditory information, which is assumed to improve information processing [8], but people with low health literacy can also suffer from paying too much attention to irrelevant details [9]. Therefore, animations consisting of simple line drawings could be preferred over realistic videos that often capture many details.

The aim of our study is to investigate how text modality (written vs spoken) and visual format (illustrations vs animations) influence health information recall and attitudes and whether this differs between people with different health literacy. We will focus on health animations in which the textual information is clearly depicted. An animation is defined as “a simulated motion picture depicting movement of drawn (or simulated) objects” (p 88) [8].

This study adds to the literature in the following ways. First, we move beyond the comparison of different media formats and try to identify the specific message features that affect processing by using an experiment. Most of the studies conducted in relation to health literacy are cross-sectional and do not test possible mechanisms [10]. Furthermore, our study responds to the need for effective population-level health literacy interventions. Intervention studies conducted in non-clinical settings, particularly with regard to communicable diseases, are scarce in Europe [11]. The topic addressed in this study is colorectal cancer screening. People with low health literacy participate less in cancer screening [12], which highlights the relevance of studying the effectiveness of cancer screening messages in this group. Colorectal cancer screening is particularly relevant to older people, as all people between 55 and 75 years are invited to have this screening in the Netherlands [13].

Text Modality: Visual (Written) Versus Auditory (Spoken)

Animations and written information fundamentally differ by text modality, or the way in which text is presented. Textual information in animations is often spoken, whereas leaflets or websites consist of written text. The cognitive theory of multimedia learning describes how people learn from words and pictures [14]. This theory is based on a dual-channel assumption, suggesting that people have separate channels to process visual and auditory information [14,15]. Both channels are expected to have their own limited processing capacity. This means that information presented in both modes (visual and auditory) is stored in memory better than information presented in a single mode. In written messages, both text and pictures are visual and processed by the eyes. Animations, in contrast, consist of auditory text and visual pictures. By using two modes, animations are expected to decrease the likelihood that the receiver experiences cognitive overload. Cognitive overload hinders information processing. According to the limited capacity model of motivated, mediated message processing [16], a message will be better processed, stored in memory, and retrieved at a later moment when people have sufficient cognitive capacity available. The final processing stage, information retrieval, is indicated by information recall. Based on this, it is hypothesized that: Health messages with spoken text (vs written text) improve information recall (H1).

Information recall is not the only important outcome in health communication. Next to optimal knowledge, positive attitudes are also required for informed participation in cancer screening [17]. Text modality could be expected to influence people’s attitudes toward a message by means of processing ease. Information addressing both eyes and ears (ie, audiovisual) could be easier to process than information addressing a single mode (eg, written). Literature on processing fluency subsequently states that the ease with which people process stimuli affects people’s preference for those stimuli [18]. Thus, people could be expected to have more positive attitudes toward messages that are easily processed compared to messages that are difficult to process. This idea has been confirmed in a study on websites, which showed that websites that include both visual and auditory information were associated with more positive and enduring attitudes toward the website compared to websites that included only visual information [19]. It could be expected that messages based on visual and auditory information positively influence people’s attitudes toward the message. This leads to our second hypothesis stating: Health messages with spoken text (vs written text) result in positive attitudes to the message (H2).

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Health Literacy

Health literacy refers to "the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions" (p 16) [20]. It is a broad concept that is still evolving [20]. Health literacy is closely related to functional literacy [21], which means that people with low health literacy often have reading problems as well. For this reason, spoken messages could be particularly effective for audiences with low health literacy because no reading is required [22]. Additionally, groups with low health literacy often lack the health-related background knowledge that is required to understand information [23]. Low health literates are, therefore, easily at risk of cognitive overload when presented with health-related information [24]. Reduction of cognitive load by using message features that enable processing could, therefore, be especially salient for people with low health literacy. For this reason, our third hypothesis states: The positive effect of spoken text (vs written text) on recall and attitude to the message only exists among people with low health literacy (H3).

Visual Format: Illustration Versus Animation

The other feature that distinguishes animations from written texts is moving visuals. A meta-analysis on the effectiveness of animations versus illustrations showed that animations generally result in better learning outcomes [25]. The authors state that an animation can provide an external model for a mental representation. As learning and understanding encompasses the creation of an adequate mental representation [14,26], animations will be better able to support this process compared to illustrations. This will apply particularly to audience groups that have limited knowledge available to build such mental representations themselves, such as people with low health literacy.

Based on the above reasoning, it could be expected that animated visual content improves information processing compared to illustrations. However, this will not always be the case. Movement in animations requires more visual attention from the viewer compared to still illustrations. It is suggested that, compared to illustrations, animations require a higher level of awareness from the receiver due to the ongoing changes in the visual information [27]. This may increase the cognitive capacity that people need to properly process the information. Receivers are expected to handle this increased cognitive load better when they are able to listen to the text rather than reading it. Thus, to reduce cognitive load, the textual information in animations has to be spoken and not written, particularly for people with low health literacy, as they are more likely to experience cognitive overload. Therefore, it is expected that animations (vs illustrations) positively affect recall, but only if the text is spoken (H4a). This interaction effect will only exist among people with low health literacy (H4b).

Next, other than improving recall, moving visuals can also positively affect attitudes toward the messages. Most likely, it is vividness that makes an animated advertisement more appealing to the audience compared to an illustration [28]. Due to the movement of animations, people will perceive them as more emotionally interesting and imagery provoking. A study of online advertising revealed that people had more positive attitudes toward animated advertisements compared to motionless ones [28]. However, the positive influence of moving images on attitudes is only expected in the case of spoken text messages. As animated visuals and written text are both processed by the eyes, people have to divide their visual attention between the text and the pictures. Moving objects automatically capture the visual attention of the viewer [29]. Thus, a combination of animation and written text increases cognitive load, resulting in less fluent processing. This could negatively affect attitudes toward the message. Based on this evidence, it is expected that animations (vs illustrations) positively influence attitudes to the message, but only if the text is spoken (H5).

Sequential Message Effects

In addition to knowledge improvement, information about cancer screening often aims to convince people about the screening's benefits. Ideally, screening participation should be based on informed decisions. This means that people need to be properly informed about the screening's benefits and disadvantages and they also need to hold attitudes toward the behavior that are congruent with the actual behavior [17]. From a communication perspective, however, it can be expected that people's evaluation of the message affects their attitudes toward the behavior. If the features of a message about colorectal cancer enhance information processing, experienced fluency will induce a positive attitude toward the message [18]. For example, positive attitudes toward the message can be transferred to behavioral attitudes, which is called the spill-over effect. Spill-over effects have been found in other fields of communication where positive attitudes toward an advertisement or game positively affect brand attitudes [30]. Thus, a positive attitude toward a cancer screening message could improve attitudes toward the screening itself.

According to the theory of planned behavior [31], attitudes toward the behavior affect behavioral intention. This relationship has often been confirmed in health research [32,33], suggesting that someone with a positive attitude toward cancer screening is likely to intend to screen as well. In concurrence with the preceding hypotheses, it is expected that this sequence of message effects induced by message format primarily exists in people with low health literacy. Therefore, our sixth hypothesis refers only to this group. It is expected that among people with low health literacy, spoken text (vs written text) improves the intention to screen for cancer. This relationship is mediated by both the attitude toward the message and the attitude toward the behavior (H6).

Methods

Design and Participants

A 2 (text format: written vs spoken) by 2 (visual format: illustration vs. animation) between-subjects design was used. Ethical approval of this study was provided by the Amsterdam School of Communication Research (2013-CW-5). Participants aged 55 years or older were randomly selected from a large respondent pool by the ISO-certified market research company PanelClix. A minimum age of 55 years was required due to the

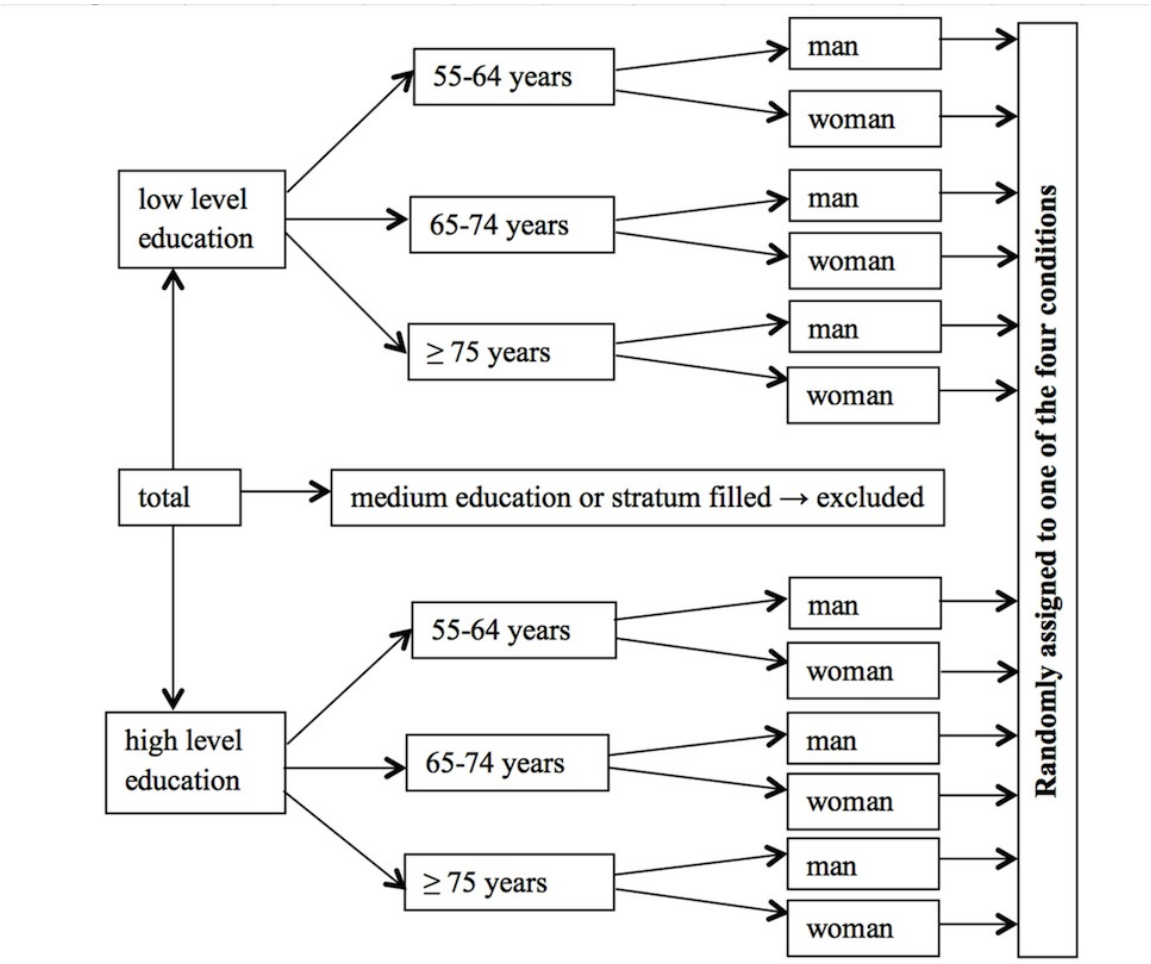
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topic of the experimental messages: colorectal cancer screening. At the time of data collection, a national screening program on colorectal cancer was planned in the Netherlands, but the public had not been informed yet. Therefore, limited prior knowledge was expected. We nevertheless measured prior knowledge to control for its potential influence. An invitation was sent by email to 1295 individuals in November 2013, of which 397 unique participants started the survey (participation rate 30.66%). Uniqueness of participants was determined by the "pid-code" (this is an anonymous individual code assigned to participants by the research company). Two participants filled out the survey twice, indicated by identical pid-codes in the dataset. In both cases, the second entry was excluded from the analysis.

A stratified sample was created in which gender, different age groups (55-64 years, 65-74 years, ≥75 years), and high versus low education levels were equally represented. Low education level ranged from no education to the lower levels of secondary school ("VMBO"), whereas a high education level represented higher education or a university degree. We excluded the middle education group because PanelClix was not able to stratify the sample on health literacy, but it was possible to sample participants based on education level. As health literacy and education level are related, we decided to include only people with low or high education to make sure that enough low and high health literates were included in the sample. Most strata were properly filled (at least 20 participants), with the exception of highly educated participants over the age of 75 years. This could be because a higher education level is quite rare among people of this age, especially among women.

Of the 397 people who viewed the first page of the survey, 353 (88.9%) continued after the informed consent page. After stratification, 250 participants (70.8%) were eligible to participate and 103 individuals (29.2%) were excluded because either their education level did not meet our inclusion criteria or the stratum to which they belonged was already full. Of the eligible participants, 16 people (6.4%) quit during the experiment, and three (1.2%) were excluded because they had not been exposed to any stimulus due to a technical issue. The mean age of the 231 participants who reliably completed the entire questionnaire was 68.22 years (SD 8.67, range 55-99) and 121 (52.4%) were male). The flow chart in Figure 1 provides an overview of the stratification procedure. Due to the stratification, participant's gender, age, and education level were equally distributed over the four experimental conditions. Before the survey was sent to the participants, it was pre-tested several times among people of the target population who were not in the final sample. During these pretests, the duration and usability of the questionnaire was tested.

Figure 1. Flow chart of the stratification procedure.



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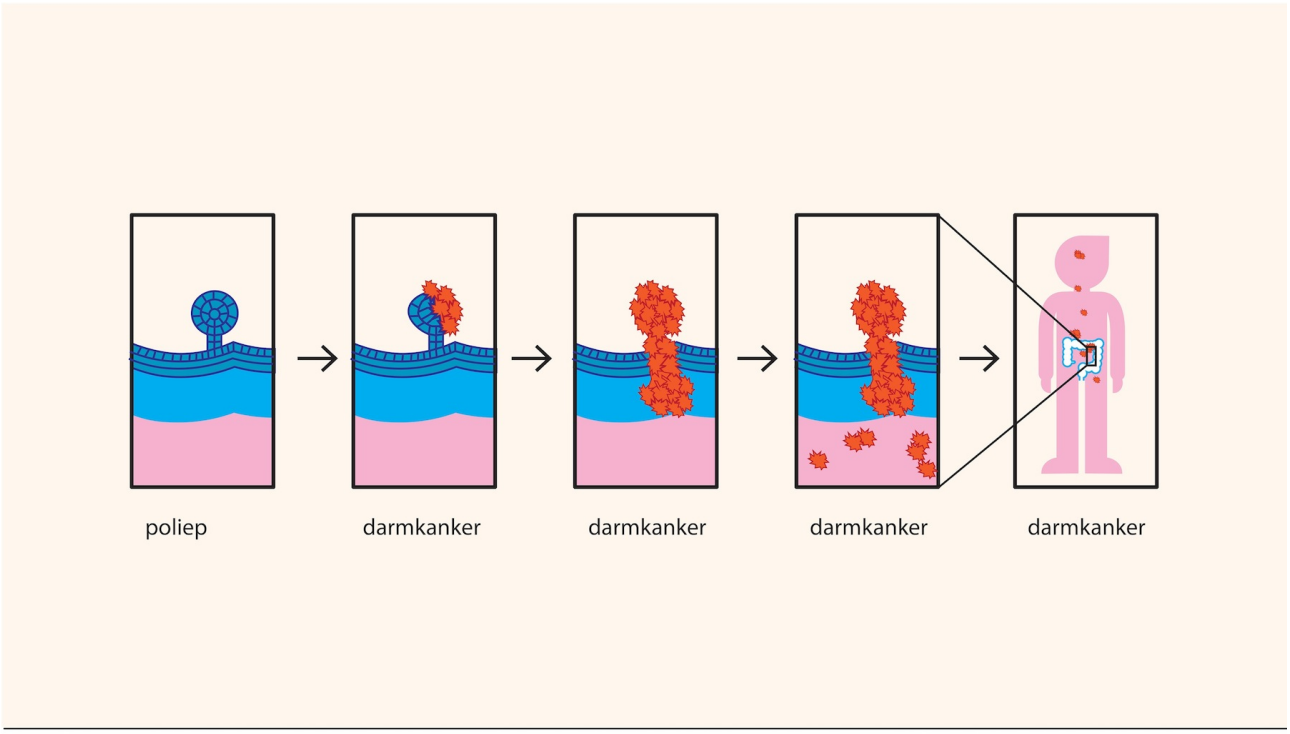
Procedure

At the beginning of the questionnaire, participants were informed about the topic of the study, their anonymity and right to withdraw their data within 24 hours, the survey length, and contact details of the researchers. Subsequently, participants gave informed consent and answered the stratification questions about gender, age, and education level. If the participant fit in one of the strata, the questionnaire continued by asking for the participant's professional medical background, knowledge about medicine in general, colorectal cancer, and colorectal cancer screening. Then, within each stratum, people were randomly assigned to one of the four experimental messages. All of the messages were self-paced and consisted of 15 separate webpages. Participants clicked a button to continue to the next page; returning to the previous page was not possible. The audio text and the animation started automatically and all parts could be replayed. We purposely provided the participants with the opportunity to replay the message as this enabled us to rule out pacing differences that would otherwise exist between the written and spoken/animated conditions. In the audio conditions, participants were clearly instructed to switch on their speakers or use headphones. They were also exposed to a test question, the sound of a ringing telephone, which was played to see if participants could identify the sound. After the experimental messages, attitude toward the message, information recall, attitude toward the behavior (screening), behavioral intention (intention to screen), and health literacy were measured. Participants were rewarded by receiving credit points from the research company. People could not miss any of the questions due to forced response settings and all responses were automatically stored into a database.

Experimental Stimuli

The experimental messages were about colorectal cancer screening, in which the following topics were discussed: the risks of colorectal cancer, the development of the disease, why early detection is beneficial, the procedure of the test (fecal occult blood test), and the possible test outcomes. Four experimental messages were created (450 words) based on information that was provided by the screening organization. These messages were complex (ie, written at C1 level in the Common European Framework of Reference for Languages). An extensive description of the development of the messages is provided elsewhere [34]. In the two audio conditions, the text was narrated by a professional Dutch radio news presenter. The simple, non-detailed illustrations were created for the purpose of this study and supported the text. Research has shown that simple drawings are comprehended better than more naturalistic drawings or photographs [9]. In the animated conditions, the illustrations were replaced by animations. Figure 2 shows an example of the illustration and written text. First, a healthy bowel polyp is depicted, followed by a polyp that has malign cells. The animated version shows a healthy polyp turning malignant (see Multimedia Appendix 1).

Figure 2. Example of the static picture and written text.



In darmpoliepen schuilt het risico dat deze zich ontwikkelen tot maligne darmtumoren. Het gevaar van darmkanker is voornamelijk dat de ziekte kan metastaseren. Uitgezaaide darmkanker bemoeilijkt de behandeling.

The text in the message states the following (translated): "There is a risk of bowel polyps becoming malignant tumors. Bowel cancer is dangerous because of its ability to metastasize. Once cancer has been metastasized, it is difficult to treat."

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Measures

Health Literacy

Health literacy was measured using the Short Assessment of Health Literacy in Dutch (SAHL-D) [35], which consists of 33 words related to health and health care, such as obesity, ventricle, and palliative. We used only the comprehension test of the SAHL-D and not the word recognition test because the first one is more relevant in the context of our study. When exposed to mediated health information, people should not necessarily be able to correctly read this aloud. It is more important to examine whether people understand the information. For each word, people were prompted to select the correct meaning out of three multiple choice options. Each correct answer received 1 point. If the incorrect meaning was selected, or people indicated that they did not know the meaning of the word, no points were awarded. Consequently, health literacy scores ranged from 0 to 33 (mean 23.20, SD 7.45).

Recall of Information

Information recall was measured with an adapted version of the Netherlands Patient Information Recall Questionnaire [36]. Participants answered 14 open-ended recall questions about the content of the messages by typing the responses into a text box. Based on a predefined codebook, the responses were scored, and each answer was marked 0 (false), 1 (partly good), or 2 (good). Consequently, total recall scores could range between 0 and 28 (mean 12.81, SD 5.90). Intercoder reliability was calculated for 19.0% (44/231) of the responses, coded by the first author and then a second coder who was not one of the authors, and appeared to be good: Cohen's kappa=.90 (range 0.51-1.00).

Attitudes Toward the Message

Nine items on a 7-point semantic differential were used to measure attitudes toward the message. The items were based on a measure for attitudes toward the information [37] and a Website Satisfaction Scale [38]. The items were presented in a randomized order to the participants. Participants evaluated the message using the following anchor points: provided bad feelings/good feelings, unpleasant/pleasant, not interesting/interesting, not informative/informative, not reassuring/reassuring, bad/good, not creative/creative, not appealing/appealing, and ugly/beautiful. The scale was reliable (α=.94, mean 5.95, SD 0.98).

Attitudes Toward the Behavior

Seven items, presented in a randomized order, were used to measure attitudes toward the behavior [39]. Participants evaluated colorectal cancer screening on a 7-point semantic differential scale, ranging from 1 (negative) to 7 (positive). The following anchor points we used: negative/positive, bad/good, undesirable/desirable, useless/useful, unimportant/important, unpleasant/pleasant, and not reassuring/reassuring (α=.93, mean 6.11, SD 0.97).

Behavioral Intention

Intention to participate in colorectal cancer screenings was measured with one item on a 7-point scale. People responded to the following statement: "If I am invited to participate in colorectal cancer screening, I will…" Answer options ranged from 1=definitely not participate to 7= definitely participate (mean 6.12, SD 0.97).

Control Variables

Participants' knowledge was measured as a control variable using three items on a 7-point Likert scale (1=no knowledge, 7=much knowledge). The items referred to general medical knowledge, colorectal cancer knowledge, and knowledge of colorectal cancer screening (see Table 1 for means and standard deviations). People also indicated whether they had a professional medical background or not (ie, medical, nursing, or paramedical). Analysis of variance showed no differences between conditions in participants' knowledge of medicine in general ($F_{3,227}$=1.36, P=.26), knowledge of colorectal cancer ($F_{3,227}$=1.78, P=.15), and knowledge of colorectal cancer screening ($F_{3,227}$=0.99, P=.40). The groups were also found to be similar with respect to the participant's professional background in medicine (χ^2_3=4.08, P=.25).

Statistical Analysis

To investigate the influence of text modality, visual format, and health literacy on information recall, attitudes, and intention, a multivariate analysis of variance (MANOVA) was conducted using SPSS 20. Health literacy scores of 24 and below were labeled as "low health literacy" and scores of 25 or higher were labeled as "high health literacy". To reduce false positives (ie, people incorrectly categorized as low health literate), we used a cut-off point that is slightly lower than the optimal cut-off scores based on the full SAHL-D [35]. The cut-off point corresponds to the sample median (25).

PROCESS (model 6, 10,000 bootstrapped samples) was used to test the indirect effect of text modality on the intention to screen through both the attitudes toward the message and the attitudes toward the screening. PROCESS is a macro for SPSS [40] that uses bootstrapping to estimate 95% bias corrected bootstrap confidence intervals for total and specific indirect effects. Due to intention to screen being negatively skewed (skewness=−1.86, SE 0.16), this measure was first reversed to create a positive skew [41]. The square root values were subsequently re-reversed and used in the analysis. The mediation hypothesis concerned people with low health literacy. Therefore, only people who belonged to this group (n=108) were included in this analysis.

Results

Study Population

Table 1 provides an overview of participant characteristics.

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Table 1. Overview of participant background characteristics (n=231).

Characteristic		n (%)	mean (SD)
Gender			
	Male	121 (52.4)	
	Female	110 (47.6)	
Age, years[a]			68.22 (8.63)
Education level			
	Low	123 (53.2)	
	High	108 (46.8)	
Medical background			
	Medical	1 (0.4)	
	Paramedical	9 (3.9)	
	Nursing	17 (7.4)	
	None	204 (88.3)	
Prior knowledge [b]			
	Medical knowledge in general		2.92 (1.44)
	Knowledge of colorectal cancer		2.31 (1.38)
	Knowledge of colorectal cancer screening		2.53 (1.61)
Health literacy [c]			
	Low (SAHL-D[d]score ≤24)	108 (46.8)	
	High (SAHL-D score ≥25)	123 (53.2)	

[a]Age ranges from 55 to 99 years.

[b]Prior knowledge scores range from 1 to 7, with higher scores indicating more knowledge.

[c]Health literacy ranges between 0 and 33.

[d]SAHL-D: Short Assessment of Health Literacy in Dutch.

Effects of Text Modality and Visual Format in Different Health Literacy Groups

A main effect was found for text modality on information recall ($F_{1,223}$=5.43, P=.02, η_p^2=.02). The means presented in Table 2 show that spoken messages were recalled better than written messages. Spoken messages also resulted in more positive attitudes toward the message ($F_{1,223}$=7.90, P=.01, η_p^2=.03), supporting H1 and H2. Simple effect analysis revealed that the superiority of the spoken text modality on recall and attitudes to the message existed only in the low health literacy group and was not found in people with high health literacy. This finding supports H3.

The fourth hypothesis predicted a positive effect of animations (vs illustrations) on information recall. An interaction was expected because this positive effect was predicted only in spoken messages (vs written messages). No interaction was observed between Text Modality and Visual Format on information recall ($F_{1,223}$=1.49, P=.22, η_p^2=.01), rejecting H4a. However, as predicted by H4b, a three-way interaction was found for Text Modality, Visual Format, and Health Literacy on information recall ($F_{1,223}$=4.22, P=.04, η_p^2=.02). As shown in Table 3, this interaction suggests that, in the case of spoken texts, animations result in higher recall scores among people with low health literacy compared to illustrations. This effect was not found in people with high health literacy, confirming H4b.

Our fifth hypothesis concerned the influence of animated visuals on attitudes toward the message, in the case of spoken messages. No interaction was found between Text Modality and Visual Format on attitudes toward the message ($F_{1,223}$=0.14, P=.71, η_p^2=.001). This was not expected and H5 was, therefore, rejected.

Mediation analysis showed a significant indirect effect of spoken text (controlling for visual format) on the intention to screen (b=.12, 95% CI 0.02-0.25) in people with low health literacy. Compared to written texts, spoken messages positively affected people's attitudes toward the message. This, in turn, influenced attitudes toward the screening, which improved screening intention. Figure 3 shows the mediation model with the direct effects (unstandardized coefficients).

The indirect effects of the serial mediation model are presented in Table 4. The results show that spoken text positively affected the intention to screen, but only through attitudes toward the message and attitudes toward the behavior. The indirect effects of the single mediator models are not significant on a 95%

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confidence level, indicating that both mediators contribute to the effect. With this finding, the sixth hypothesis is supported.

Table 2. Main effects of text modality on information recall and attitudes toward the message in people with low and high health literacy.[a]

Group	n	Information recall Scale range: 0-28		Attitudes toward the message Scale range: 1-7	
		mean (SE)	95% CI	mean (SE)	95% CI
All participants					
Written text	126	11.97[b](0.46)	11.06-12.89	5.79[c](0.09)	5.62-5.96
Spoken text	105	13.60 (0.52)	12.58-14.61	6.15 (0.10)	5.97-6.35
Low health literacy					
Written text	64	9.12[d](0.66)	7.83-10.41	5.75[e](0.12)	5.51-5.99
Spoken text	44	11.42 (0.79)	9.87-12.98	6.20 (0.15)	5.91-6.49
High health literacy					
Written text	62	14.83 (0.66)	13.51-16.14	5.83 (0.12)	5.59-6.07
Spoken text	61	15.77 (0.67)	14.45-17.09	6.11 (0.13)	5.86-6.35

[a]Higher scores indicate more recall and positive attitudes.
[b]Differs significantly from spoken text in all participants (*P*=.02).
[c]Differs significantly from spoken text in all participants (*P*=.01).
[d]Differs significantly from spoken text in low health literacy group (*P*=.03).
[e]Differs significantly from spoken text in low health literacy group (*P*=.02).

Table 3. Interaction effects of text modality and visual animation in people with low or high health literacy.[a]

Group	n	Information recall Scale range: 0-28		Attitudes toward the message Scale range: 1-7	
		mean (SE)	95% CI	mean (SE)	95% CI
Low - written - illustration	29	9.59 (0.97)	7.67-11.50	5.78 (0.18)	5.42-6.13
Low - written - animation	35	8.66 (0.88)	6.92-10.40	5.71 (0.17)	5.39-6.04
Low - spoken - illustration	23	9.61[b](1.08)	7.47-11.75	6.22 (0.20)	5.82-6.62
Low - spoken - animation	21	13.24 (1.14)	11.00-15.48	6.19 (0.21)	5.77-6.60
High - written - illustration	33	14.52 (0.91)	12.73-16.30	5.87 (0.17)	5.53-6.20
High - written - animation	29	15.14 (0.97)	13.23-17.05	5.80 (0.18)	5.44-6.15
High - spoken - illustration	29	16.03 (0.97)	14.13-17.94	6.03 (0.18)	5.67-6.39
High - spoken - animation	32	15.50 (0.92)	13.68-17.32	6.18 (0.17)	5.84-6.52

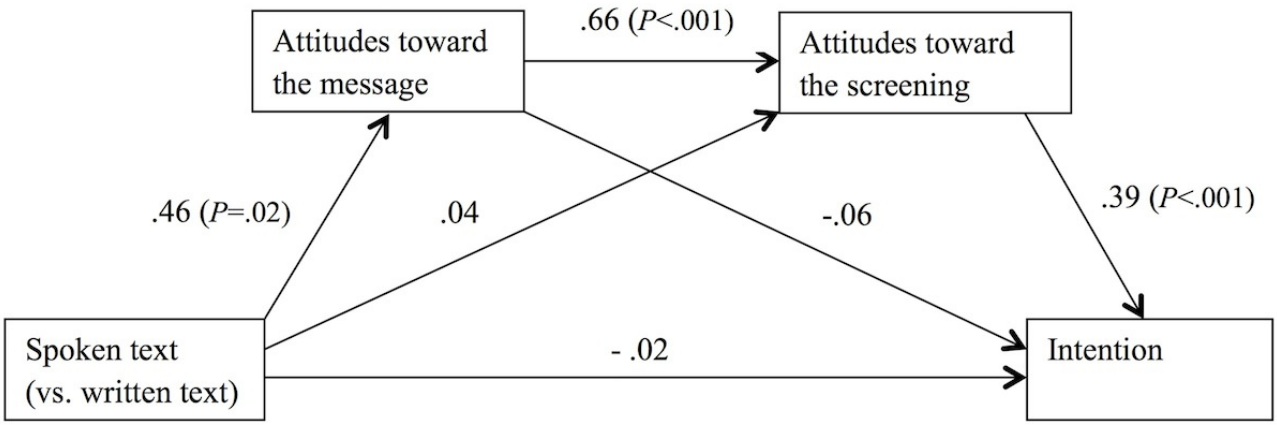
[a]Higher scores indicate more information recalled and positive attitudes.
[b]Mean differs significantly when comparing low health literates in the spoken animation condition to those in the spoken illustration condition (*P*=.02).

Table 4. Total and indirect effects for text modality on intention mediated by attitudes toward the message and attitudes toward the screening (n=108).

Indirect effect	Estimate (SE)	Bootstrap 95% CI
Total	0.11 (0.07)	−0.03 to 0.25
modality → attitude to message → intention	−0.03 (0.03)	−0.10 to 0.01
modality → attitude to message → attitude to screening → intention	0.12 (0.06)	0.02 to 0.25
modality → attitude to screening → intention	0.01 (0.06)	−0.10 to 0.13

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Figure 3. Influence of text modality on intention to screen, mediated by attitudes toward the message and attitudes toward the screening (n=108). Unstandardized regression coefficients are presented.



Discussion

Principal Findings

This study investigated the effectiveness of animated features among people with either low or high health literacy. Six hypotheses were tested, with four being confirmed and one being partly confirmed. The results showed that spoken messages are better recalled and induce more positive attitudes compared to written texts (H1 and H2). Animated messages with spoken text result in more recall and positive attitudes compared to illustrations. Both effects applied only to low health literates (H3 and H4b). In the low health literate group, message format indirectly influenced intention to get cancer screening through both attitudes toward the message and attitudes toward the screening (H6). Animations did not significantly improve people's attitudes toward the message, rejecting H5. Textbox 1 provides an overview of the hypotheses and findings.

Textbox 1. Overview of the hypotheses and findings of the study.

- H1: Health messages with spoken text (vs written text) improve information recall.
  - Supported. Spoken messages were significantly better recalled than written messages, indicated by a main effect for text modality on information recall.
- H2: Health messages with spoken text (vs written text) result in positive attitudes to the message.
  - Supported. Spoken messages resulted in significantly more positive attitudes toward the message compared to written messages, indicated by a main effect for text modality on attitudes toward the message.
- H3: The positive effect of spoken text (vs written text) on recall and attitude to the message exists only among people with low health literacy.
  - Supported. Simple effect analysis showed that spoken text (compared to written text) only improved recall and attitudes to the message in the low health literacy group, not for people with high health literacy.
- H4a: Animations (vs illustrations) positively affect recall, but only if the text is spoken.
  - Not supported. Overall, no interaction was found between text modality and type of visualization on information recall.
- H4b: This interaction effect will only exist among people with low health literacy.
  - Supported. A significant three-way interaction was found showing that in the case of spoken messages, animations (compared to illustrations) result in higher recall scores among people with low health literacy. This effect was not found in people with high health literacy.
- H5: Animations (vs illustrations) positively influence attitudes to the message, but only if the text is spoken.
  - Not supported. No interaction was found between text modality and type of visualization on attitudes toward the message.
- H6: Among people with low health literacy, spoken text (vs written text) improves the intention to screen for cancer. This relationship is mediated by both the attitude toward the message and the attitude toward the behavior.
  - Supported. Spoken text indirectly improved intention to have screening in people with low health literacy. Compared to written texts, spoken messages positively affected people's attitudes toward the message, which influenced screening attitude and subsequently screening intention.

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The results of our study support the modality effect that is part of the cognitive theory of multimedia learning [14]. In addition to the students who often participate in modality experiments, this study shows that vulnerable groups in society—those having low health literacy—learn better from multimodal information as well. Although people with low health literacy especially seem to benefit from animated health messages, our study also showed that animated messages do not induce negative effects among people with high health literacy. This is in line with a study on tailored health information, which showed that audiovisual messages on smoking cessation are effective, regardless of education level [6]. This study adds to the literature by focusing on the specific features of animations that influence information processing in different health literacy groups. By doing this, the effective components of either audiovisual messages or written text messages could be identified, providing better insight into the usefulness of animations in reducing disparities in health information processing.

The effectiveness of animations in health communication likely depends on the type of content that is presented. Our messages described the development of colorectal cancer, how bowel polyps are removed, and the testing procedure, which can be easily shown in an animation. Other types of content are most likely less easily visualized. It is possible that the positive effect of animations therefore does not apply to informed consent information, for example, which would explain the negative result in one of the studies [42]. The studies that found positive results for audiovisual messages focused on sleep apnea and the functionality of positive airway pressure [43], or inhaler use in asthma [44]. It can therefore be expected that animations are effective when the images truly represent the content of the message and contribute to its understanding. If this is not the case, the movement of animations could potentially distract from the content. In that case, people exposed to animations could primarily remember the fact that they saw an animation instead of its content [28]. In our study, the animation clearly represented the text without adding additional and possibly distracting content, which could explain our findings.

Different explanations apply to the finding that spoken information is better recalled by people with low health literacy. It is possible that information through multiple modes improves information processing, as predicted by the cognitive theory of multimedia learning. Another explanation relates to the fact that health literacy and functional literacy are associated [21]. Possibly, participants with low health literacy were less skilled readers, which might have caused the superiority of the spoken messages where no reading was required. Although we controlled for the influence of education level in this study by stratifying our sample, we did not test actual reading ability. Future research should, therefore, disentangle the mechanism underlying this finding.

Limitations

A limitation of this study relates to the experimental messages of this study. We divided the messages into 15 short segments that could be replayed. We intentionally provided participants with the opportunity to replay the messages to avoid pacing differences between the spoken and written conditions [22]. However, tracking data of the participants' clicking behavior revealed that only a few participants actually made use of this opportunity. A disadvantage of the split-up into shorter segments is that the animation was not as natural as possible. In a natural setting, animations can be viewed entirely and not as separate pieces. Future research should, therefore, address modality differences and animations in longer messages. However, it could be expected that complete animations are even better processed because the exposure is more fluent and not disturbed by unnatural stops. Moreover, a recent meta-analysis on the modality effect has shown that the superiority of spoken messages over written messages has mainly been found in system-paced messages [27]. The fact that our study showed a modality difference in self-paced messages adds to the expectation that for longer, system-paced messages, modality differences will be even larger.

In our study, we aimed to identify the specific message features that impact the way in which people with different health literacy levels process information. We used the SAHL-D as an indicator of health literacy as it objectively measures comprehension of health-related information. However, to successfully make use of the information that is available online, people need multiple skills. For example, finding relevant information online and judging the information for its credibility goes beyond our health literacy measure. These skills are better captured by an eHealth literacy scale such as the eHEALS [45]. Including eHealth literacy in future research on information on colorectal cancer screening might be relevant, as eHealth literacy has shown to be related to colorectal cancer knowledge and screening participation [46]. A disadvantage of the eHEALS measure is, however, that it does not always adequately reflect people's actual performance on online tasks [47]. As our study addressed the influence of health literacy on quality of information processing, we considered SAHL-D to be the best health literacy measure for this purpose, also in an online setting.

Conclusions

To conclude, the findings of this study show that animated visual information combined with spoken text is the best way to communicate complex health messages to people with low health literacy. This format can even bridge the gap between audiences with low and high health literacy as the recall differences between the two groups are eliminated. Spoken information generates more positive attitudes toward the message, as well as the screening, and improves the intention to screen in people with low health literacy. It must be noted that the animations and narrated text were both of professional quality. The animations were made by a professional animator and the text was narrated by a professional radio news presenter. This could also have induced positive attitudes toward the message. There are free or inexpensive programs available to make animations. However, the limited options of these programs might not be sufficient to make a good, credible, and professional-looking animation. Future research should investigate whether the design quality of animations actually influences message effects. For now, we recommend the use of professional software packages when designing health animations. In this study, spoken animations improved information processing among people with low health literacy,

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whereas no negative format effects were observed in people with high health literacy. This conclusion indicates that, in public health messages, information adapted to audiences with low health literacy suits people with high health literacy as well.

Authors' Contributions

The study was designed by CM, JvW, and ES. All authors participated in the development of the materials, which were created by CH. CM did the statistical analyses; CM, JvW, and ES interpreted the data. CM drafted the manuscript; JvW and ES contributed to the final write-up of the manuscript. All authors approved the final article.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The entire animated message combined with spoken text.

[MP4 File (MP4 Video), 45MB - jmir_v17i1e11_app1.mp4]

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Abbreviations

eHEALS: eHealth Literacy Scale
SAHL-D: Short Assessment of Health Literacy in Dutch

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Original Paper

Validity of Electronic Diet Recording Nutrient Estimates Compared to Dietitian Analysis of Diet Records: Randomized Controlled Trial

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Abstract

Background: Dietary intake assessment with diet records (DR) is a standard research and practice tool in nutrition. Manual entry and analysis of DR is time-consuming and expensive. New electronic tools for diet entry by clients and research participants may reduce the cost and effort of nutrient intake estimation.

Objective: To determine the validity of electronic diet recording, we compared responses to 3-day DR kept by Tap & Track software for the Apple iPod Touch and records kept on the Nutrihand website to DR coded and analyzed by a research dietitian into a customized US Department of Agriculture (USDA) nutrient analysis program, entitled GRAND (Grand Forks Research Analysis of Nutrient Data).

Methods: Adult participants (n=19) enrolled in a crossover-designed clinical trial. During each of two washout periods, participants kept a written 3-day DR. In addition, they were randomly assigned to enter their DR in a Web-based dietary analysis program (Nutrihand) or a handheld electronic device (Tap & Track). They completed an additional 3-day DR and the alternate electronic diet recording methods during the second washout. Entries resulted in 228 daily diet records or 12 for each of 19 participants. Means of nutrient intake were calculated for each method. Concordance of the intake estimates were determined by Bland-Altman plots. Coefficients of determination (R^2) were calculated for each comparison to assess the strength of the linear relationship between methods.

Results: No significant differences were observed between the mean nutrient values for energy, carbohydrate, protein, fat, saturated fatty acids, total fiber, or sodium between the recorded DR analyzed in GRAND and either Nutrihand or Tap & Track, or for total sugars comparing GRAND and Tap & Track. Reported values for total sugars were significantly reduced (P<.05) comparing Nutrihand to GRAND. Coefficients of determination (R^2) for Nutrihand and Tap & Track compared to DR entries into GRAND, respectively, were energy .56, .01; carbohydrate .58, .08; total fiber .65, .37; sugar .78, .41; protein .44, .03; fat .36, .03; saturated fatty acids .23, .03; sodium .20, .00; and for Nutrihand only for cholesterol .88; vitamin A .02; vitamin C .37; calcium .05; and iron .77. Bland-Altman analysis demonstrates high variability in individual responses for both electronic capture programs with higher 95% limits of agreement for dietary intake recorded on Tap & Track.

Conclusions: In comparison to dietitian-entered 3-day DR, electronic methods resulted in no significant difference in mean nutrient estimates but exhibited larger variability, particularly the Tap & Track program. However, electronic DR provided mean estimates of energy, macronutrients, and some micronutrients, which approximated those of the dietitian-analyzed DR and may be appropriate for dietary monitoring of groups. Electronic diet assessment methods have the potential to reduce the cost and burden of DR analysis for nutrition research and clinical practice.

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Trial Registration: Clinicaltrials.gov NCT01183520; http://clinicaltrials.gov/ct2/show/NCT01183520 (Archived by WebCite at http://www.webcitation.org/6VSdYznKX).

(J Med Internet Res 2015;17(1):e21) doi:10.2196/jmir.3744

KEYWORDS

diet records; nutrition assessment; electronic data

Introduction

Assessment of food intake to determine nutrient consumption in free living conditions is an integral part of dietetics practice and nutrition research. These data are essential for evaluating intake and making client-specific nutritional recommendations in clinical practice [1]. Additionally, intake assessment is an integral part of nutrition research as nutrient intake is often the primary or secondary endpoint in human trials [2]. The collection and analysis of dietary records (DR) is a standard tool for the evaluation of nutrient intake in both the clinical and research settings and is used extensively by dietitians and nutritionists. Furthermore, dietary record keeping is an important tool for patients/clients to self-monitor their progress with weight loss or their management of diet-related diseases such as diabetes. The availability of diet assessment methods with low respondent burden coupled with reliable food composition data in nutrient analysis programs is essential for monitoring nutrient intake of groups and individuals, to evaluate nutritional advice compliance and to conduct nutrition research [3].

Typically patients, clients, or study participants are taught to record their intake for a specified number of consecutive days, with record length of ≥3 days deemed as appropriate for usual diet representation [4]. Absent biomarkers, the DR is often considered the “gold standard” for determination of actual food intake and is generally utilized as the evaluation tool for determining the validity of other dietary assessment methods [5,6].

Manual entry of hand-recorded DR into a nutrient analysis program must be performed to generate the desired nutrient value output. Qualified personnel (typically dietitians, nutritionists, or technical staff under their supervision) perform DR entry. The collection of records, coding, and entry into nutrient analysis programs, and generation of desired data is costly in terms of personnel time and effort [7]. Valid, reliable, and inexpensive diet assessment tools with low time investment for both clients and dietitians are required to reduce the labor and financial costs to clinicians and researchers [8-10].

Depending on the purpose of the nutrient data collection, more automated methods of diet recording may prove useful. Many applications are available for use on the Web, for personal computing, and for handheld devices such as mobile phones [11]. In clinical nutrition practice, DRs are used to evaluate nutritional adequacy and to monitor dietary change after counseling. Nutrient intake data obtained in research projects may serve as the primary or secondary endpoints assessing intake or determining compliance and/or diet change. Therefore, careful evaluation of electronic diet recording methods is required to evaluate the validity of their use in clinical practice and research.

DR may be more efficiently entered by clients or research participants with electronic methods rather than hand-recorded. Electronic tools that are currently available for DR have the potential to reduce effort spent in diet entry by the dietitian. The utility of commercial methods of electronic diet capture has not been widely studied; the validity of such methods must be ascertained to demonstrate their suitability for clinical and/or research data collection. Herein, we report a study performed to assess the validity of two electronic DR methods compared with dietitian-coded, handwritten DR in a sample of 19 healthy volunteers. We compared nutrient analysis data of 3-day DR kept by Tap & Track (software [12] for the Apple iPod Touch), records entered into the Nutrihand website [13], and those coded and entered by a dietitian into a customized US Department of Agriculture (USDA) nutrient analysis program.

Methods

Study Design

A total of 19 participants (11 women, 8 men), enrolled in a crossover-designed clinical trial evaluating intake of farmed Atlantic salmon, are included in this experiment [14]. All participants were recruited from the Greater Grand Forks Area, Grand Forks, ND. The mean age of the group was 51.6 (SE 1.5) years and the mean body mass index was 29.2 (SE 0.6) kg/m^2.

All participants completed three dietary treatments of 4 weeks, each separated by a 4-week washout period. During each of the washout periods, participants maintained 3-day DR by handwritten record and by electronic capture with random assignment to one of the two electronic tools under evaluation. During the second washout period, both the alternate electronic DR and an additional 3-day DR were obtained. These entries resulted in 228 daily DR for statistical analysis.

The study was approved by the Institutional Review Board of the University of North Dakota. Informed consent was obtained from all study participants prior to initiation of the study. The trial was registered at clinicaltrials.gov as NCT01183520.

Dietary Measurement Tools

All participants were provided in-depth, individual instruction from a research dietitian on how to maintain a DR, how to access Nutrihand, the Web-based program, and how to use the iPod-based Tap & Track program. DR instruction was provided by a research dietitian at the USDA, Agricultural Research Service (ARS), Grand Forks Human Nutrition Research Center (GFHNRC). Standard forms were provided for recording purposes, which included entry of food items, descriptions, and

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amounts consumed. Participants were advised to record food consumption at each eating occasion. The need for detailed descriptions of foods and beverages consumed was emphasized and the dietitian instructed participants to estimate portions consumed using household measures (eg, measuring cups or spoons), serving size weight from a Nutrition Facts Label, number, consumed actual weight of item from a food scale, or Food Intake and Analysis System (FIAS) 2-dimensional food models [5].

Diet records were obtained from November, 2010 to May, 2011. Participants submitted their written DR to the dietitian and were interviewed to assure completeness of the records. Participants were queried about the portion sizes, exact food items, and additions of condiments to foods consumed. The dietitian coded and entered the records obtained at each washout period into the GFHNRC customized in-house nutrient analysis program. In addition, during each washout period, participants were randomly assigned to record their diet concurrently in one of the electronic apps: Tap & Track software (Nanobit Software, version 4.9.8), which is an app for the Apple iPod Touch, or on the Web using Nutrihand.

Client-recorded DR were reviewed and coded by the study dietitian (AS) and entered into the nutrient analysis program entitled GRAND (Grand Forks Research Analysis of Nutrient Data). GRAND is the customized nutrient analysis program of the GFHNRC using the USDA National Nutrient Database for Standard Reference, Release 22 (SR22) for nutrient values [15].

Tap & Track was selected for use due to its ability to collect data without connection to the Internet. This app is specifically marketed for use by individuals to monitor their intake and was one of the highest consumer-rated diet assessment apps in the iTunes App Store at the time this study was planned. Study participants were trained to use this app on an Apple iPod Touch provided to them for study purposes. Current versions of this app are available for iPhone use. Participants were asked to search the database for reported foods and beverages. Completed logs listing foods consumed and their nutrient values were downloaded from the instrument into a spreadsheet.

Nutrihand was selected for use due to the ability of a dietitian to assign clients and view client-entered DR. The program is marketed to the dietitian and other health professionals as a monitoring tool for use with clients. A HIPAA-compliant sign-on allows the dietitian to both monitor entries and communicate with clients. In addition to the food intake monitoring, additional functions such as physical activity monitoring and medical data recording are part of the program. For the purposes of this trial, only the dietary record-keeping function was utilized. Participants were trained to use this website on a personal computer with Internet access. They were asked to search the database for reported foods and beverages. Nutrihand records were analyzed with their database, which used the USDA National Nutrient Database for Standard Reference (Release 21 as of 9/2013), along with recipes, branded foods, restaurant information, and items entered by users from nutrition fact labels or as recipes. Reports from completed DR were generated and downloaded from the website as a text file for study comparison.

Statistical Analysis

All statistical analyses were performed in SAS (version 9.3, SAS Institute Inc., Cary, NC). Means and standard deviations for macro- and micronutrients were calculated from the DR entered into the GRAND, Tap & Track, and Nutrihand programs. Mixed model analysis of variance was used to test for differences between methods and whether observed differences were dependent upon the order in which the recording methods (Nutrihand or Tap & Track) were used. Method and time were fixed effects and subjects were random effects. Concordance of results obtained from dietitian entry of DR into GRAND and each electronic diet recording method were evaluated using Bland-Altman plots [16,17] to determine agreement between the two measures. In these plots, the difference between values obtained from two methods (electronic method vs GRAND) is plotted against the average of the values. The limits of agreement between the two methods are calculated as the mean of the differences±1.96*(standard deviation of the differences) for each nutrient by each method of comparison (electronic methods vs GRAND). To assess the strength of the linear relationship between methods, correlations were computed between the macro- and micronutrient estimates obtained from Tap & Track and Nutrihand to those obtained from GRAND. Coefficients of determination, R^2, are reported for each comparison. Linear regression lines are shown in the figures to assist in visualizing the relationships between the methods.

Results

All participants completed the hand-recorded DR and the electronic dietary records to which they were assigned during each washout period of the feeding trial. Participants reported 114 matched days of DR, Nutrihand, and Tap & Track (n=228 recalls) from records obtained on 3 consecutive days including 2 weekdays and 1 weekend day (either Thursday, Friday, and Saturday or Sunday, Monday, and Tuesday).

Table 1 includes the nutrient values obtained by each DR assessment method. The nutrient data available were more limited in the electronic capture methods than the GRAND program. No significant differences were observed between the mean nutrient values obtained for energy, carbohydrate, protein, fat, saturated fatty acids, total fiber, or sodium between GRAND and either Nutrihand or Tap & Track, and for total sugars comparing GRAND and Tap & Track. Reported values for total sugars were all significantly reduced ($P<.05$) comparing Nutrihand to GRAND.

Figures 1 and 2 illustrate the percentage of values obtained electronically compared to dietitian entry of DR into GRAND. Values were as follows (mean %, SE; Nutrihand and Tap & Track, respectively): energy 104.2 (SE 4.7), 100.1 (SE 8.6); carbohydrate 107.6 (SE 4.3), 104.6 (SE 7.7); sugar 85.0 (SE 5.9), 102.8 (SE 8.2); total fiber 92.8 (SE 5.2), 88.7 (SE 8.3); protein 106.2 (SE 8.3), 92.1 (SE 8.0); fat 102.6 (SE 8.3), 97.6 (SE 12.0); saturated fatty acids 102.1 (SE 14.0), 89.3 (SE 12.0); sodium 104.7 (SE 8.1), 105.7 (SE 10.8). Additional nutrients not available in the Tap & Track program were analyzed for Nutrihand compared to GRAND: cholesterol 99.8 (SE 9.2);

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vitamin A 75.3 (SE 15.7); vitamin C 119.1 (SE 17.0); calcium 126.2 (SE 30.0); and iron 97.3 (SE 5.5).

The 95% limits of agreement of the electronic capture methods of diet recording compared to the dietitian-entered records are shown in Table 2. A statistically significant difference in mean reported intake was observed for sugars when comparing Nutrihand to GRAND. The Bland-Altman plots for nutrient estimates between the electronic diet capture and GRAND are illustrated in Figure 3 and Multimedia Appendices 1 and 2. The Bland-Altman plots display the variability of responses for each individual, for each nutrient evaluated for the two electronic diet methods under evaluation. On each plot, the mean difference from the GRAND estimates is illustrated as well as variance in individual responses.

Correlation of the electronic diet assessment methods to the records coded and analyzed by the dietitian in GRAND are illustrated in Figures 4 and 5. Coefficients of determination, (R^2), for Nutrihand and Tap & Track compared to GRAND, respectively, were energy .56, .01; carbohydrate .58, .08; total fiber .65, .37; sugar .78, .41; protein .44, .03; fat .36, .03; saturated fatty acids .23, .03; and sodium .20, .00. Additional nutrients not available in the Tap & Track program were analyzed for Nutrihand compared to GRAND: cholesterol .88; vitamin A .02; vitamin C .37; calcium .05; and iron .77.

Table 1. Reported nutrient intake for GRAND and Nutrihand, and GRAND and Tap & Track.

Nutrient	GRAND mean (SD)	Nutrihand mean (SD)	GRAND mean (SD)	Tap & Track mean (SD)
Energy (kcal)	1876.1 (501.1)	1961.4 (715.7)	1873.6 (499.4)	1772.9 (619.6)
Carbohydrate (g)	209. 1 (58.5)	224.6 (75.5)	224.8 (70.5)	222.3 (78.6)
Sugars, total (g)	85.1 (33.5)	74.7 (40.3[a])	78.3 (39.3)	74.8 (34.8)
Protein (g)	79 (24.3)	82.1 (30.9)	74.6 (19.8)	65.5 (26.2)
Fat (g)	77.4 (23.9)	79.9 (41.3)	71.9 (26.4)	62.4 (30.1)
Saturated fatty acids (g)	27.1 (8.7)	28.3 (23.5)	25.4 (8.3)	18.7 (10.3)
Monounsaturated fatty acids (g)	26.7 (9.3)	24.3 (13.4)		
Polyunsaturated fatty acids (g)	15.3 (4.8)	11.3 (5.7)		
Cholesterol (mg)	298 (221.7)	298.5 (258.7)		
Total Fiber (g)	16.4 (5)	15.4 (6.6)	17.9 (4.7)	16.1 (9.7)
Calcium (mg)	930.1 (359.7)	1146.2 (1297.1)		
Iron (mg)	14.9 (7.5)	14.5 (7.2)		
Sodium (mg)	3107 (997)	3150 (1250)	2894 816	2859 (1239)
Vitamin A (mcg)	635.6 (248.9)	450.2 (482.9)		
Vitamin C (mg)	71.8 (37)	83.4 (76.5)		

[a]$P<.05$ compared to GRAND by mixed model analysis of variance.

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Table 2. Mean difference and limits of agreement[a] between electronic diet recording (Nutrihand and Tap & Track) and dietitian-entered handwritten records (GRAND).

Comparison		Mean difference	95% Limits of Agreement	
			Lower limit	Upper limit
Nutrihand to GRAND				
	Energy (kcal)	85.3	−851.5	1022.1
	Carbohydrate (g)	15.4	−80.6	111.4
	Sugars (g)	−10.5[b]	−47.5	26.6
	Fiber (g)	-1.0	−8.7	6.7
	Protein (g)	3.1	−42.8	49.0
	Fat (g)	2.6	−62.4	67.5
	Saturated fatty acids (g)	1.3	−39.6	42.1
	Sodium (mg)	43.3	−2319.9	2406.4
	Cholesterol (mg)	0.6	−182.1	183.3
	Vitamin A (mcg)	−185.4	−1192.1	821.3
	Vitamin C (mg)	11.6	−109.1	132.3
	Calcium (mg)	216.0	−2265.5	2697.5
	Iron (mg)	−0.4	−7.6	6.8
Tap & Track to GRAND				
	Energy (kcal)	−100.6	−1748.7	1547.5
	Carbohydrate (g)	−2.5	−178.8	173.8
	Sugars (g)	−3.5	−65.8	58.8
	Fiber (g)	−1.8	−17.1	13.5
	Protein (g)	−9.1	−67.5	49.3
	Fat (g)	−9.6	−94.5	75.3
	Saturated fatty acids (g)	−4.7	−32.7	23.3
	Sodium (mg)	−35.1	−2959.1	2889.0

[a]The upper and lower limits of agreement define the range within which most differences between the methods are expected to occur.

[b]$P<.05$ by mixed model analysis of variance.

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Figure 1. Percentage agreement between electronic methods of diet recording and dietitian-entered 3-day diet record (DR) comparing Nutrihand and Tap & Track to values obtained from Grand Forks Research Analysis of Nutrient Data (GRAND).

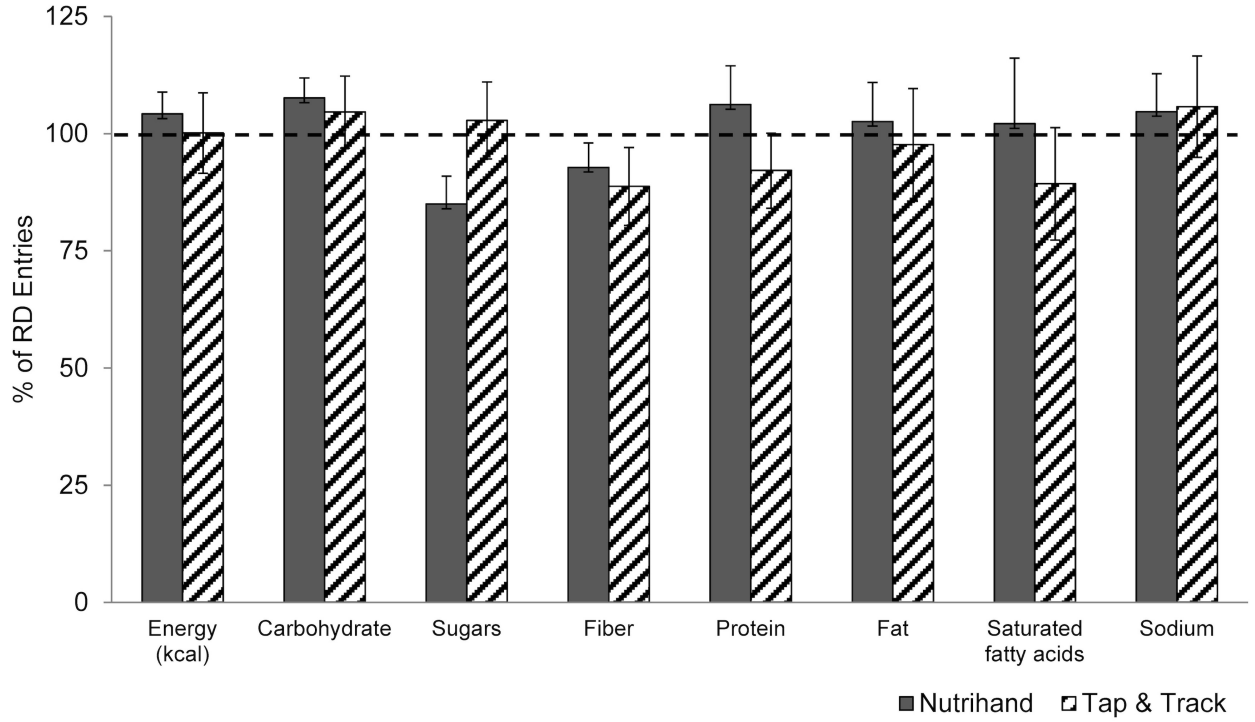
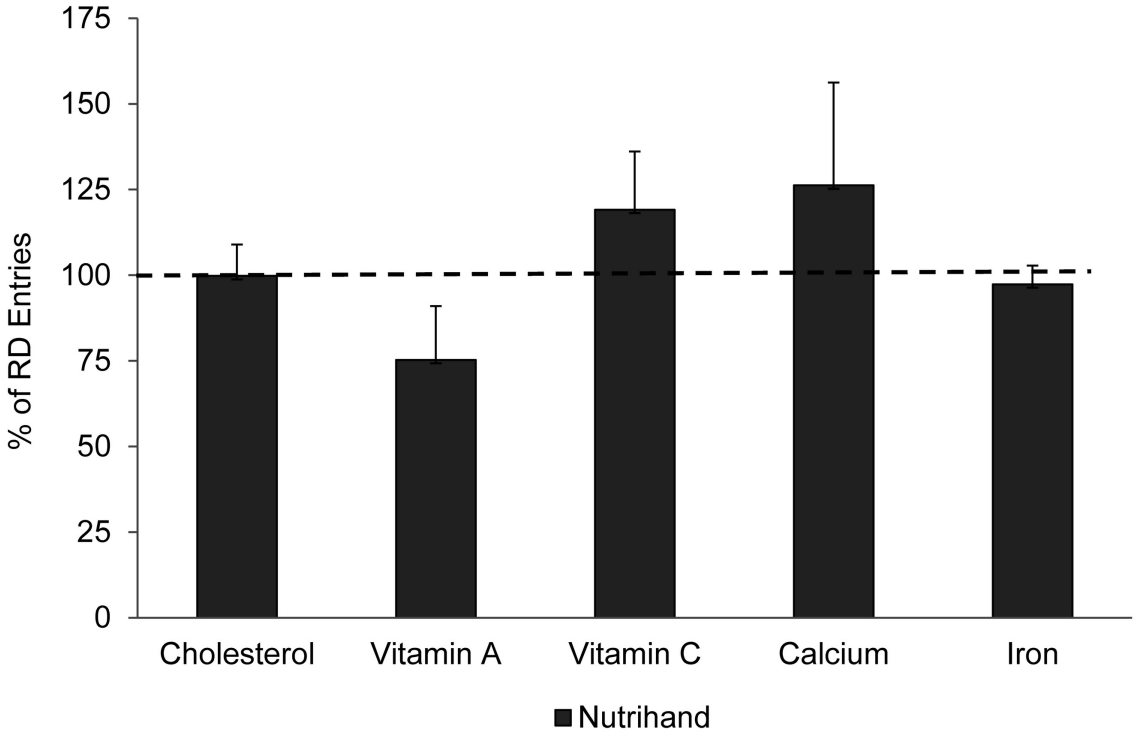
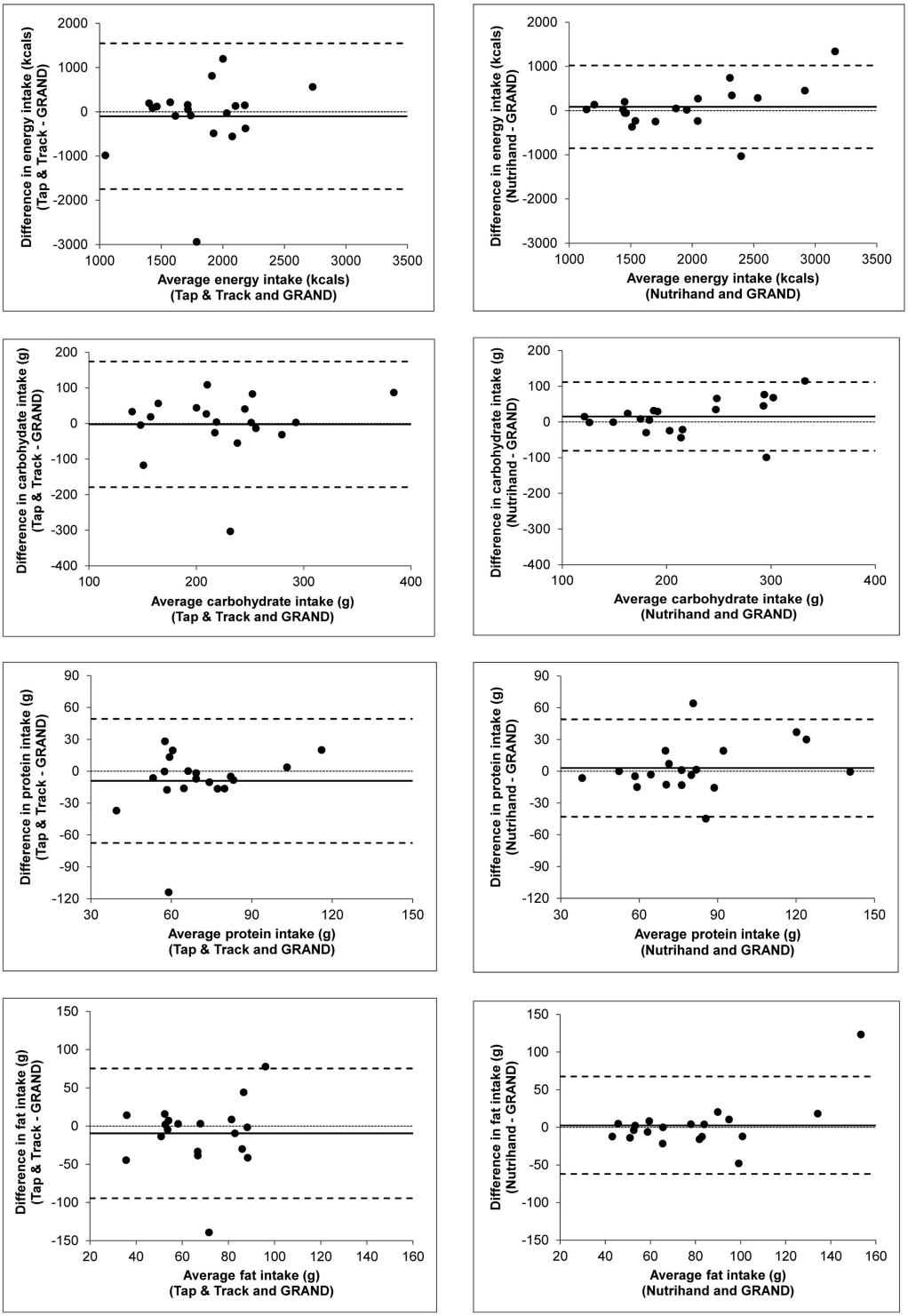


Figure 2. Percentage agreement between electronic methods of diet recording and dietitian-entered 3-day diet record (DR) comparing Nutrihand to values obtained from Grand Forks Research Analysis of Nutrient Data (GRAND).



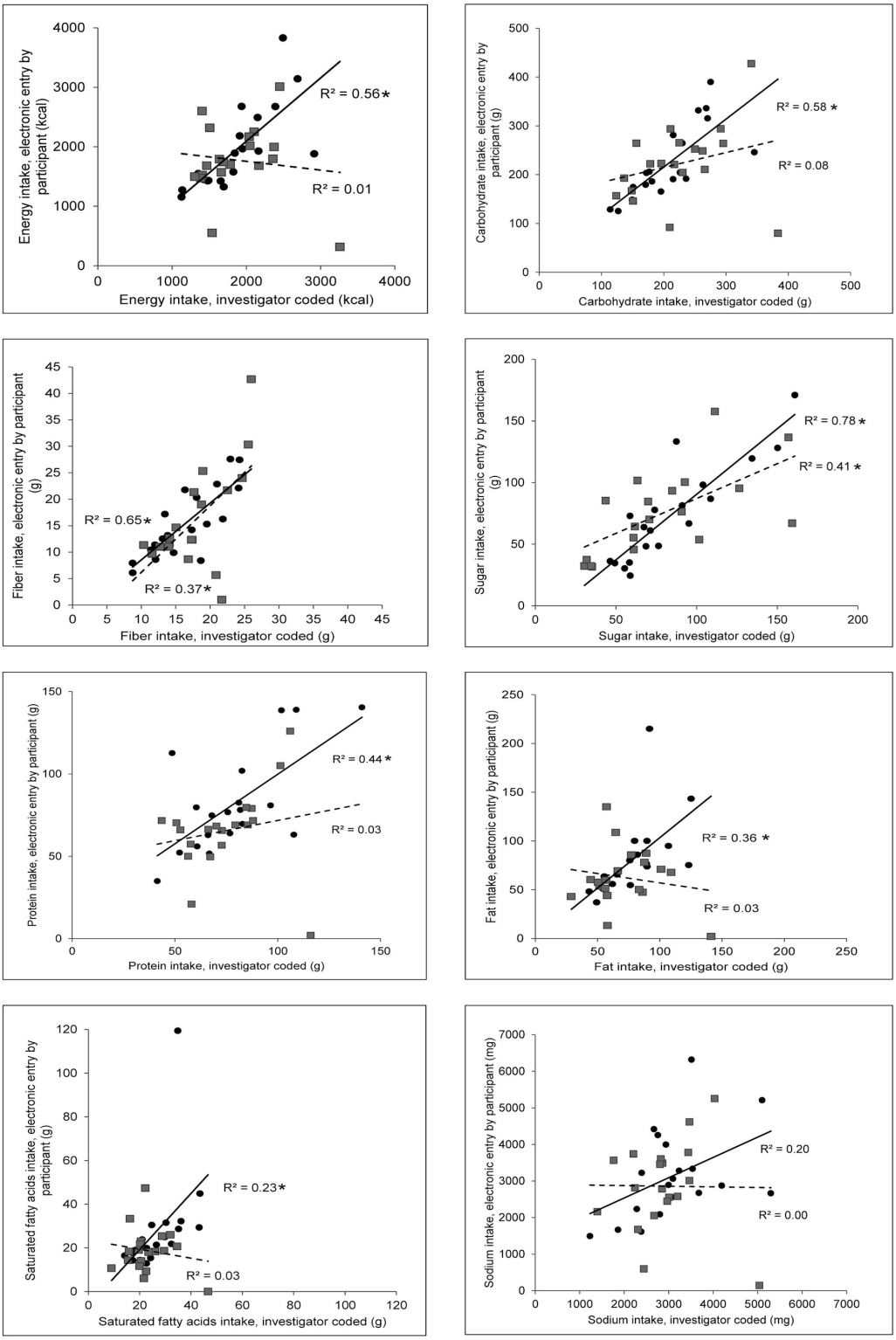
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Figure 3. Bland-Altman plots comparing electronic diet entry by participants to dietitian entry of 3-day diet record (DR) into Grand Forks Research Analysis of Nutrient Data (GRAND). Plots for energy and macronutrients comparing Nutrihand and Tap & Track to GRAND. Solid horizontal line indicates mean of differences between Nutrihand or Tap & Track and GRAND. Upper and lower limits of agreement (dashed lines) define range within which most differences between methods are expected to occur. Dotted line at y=0 is given for reference.



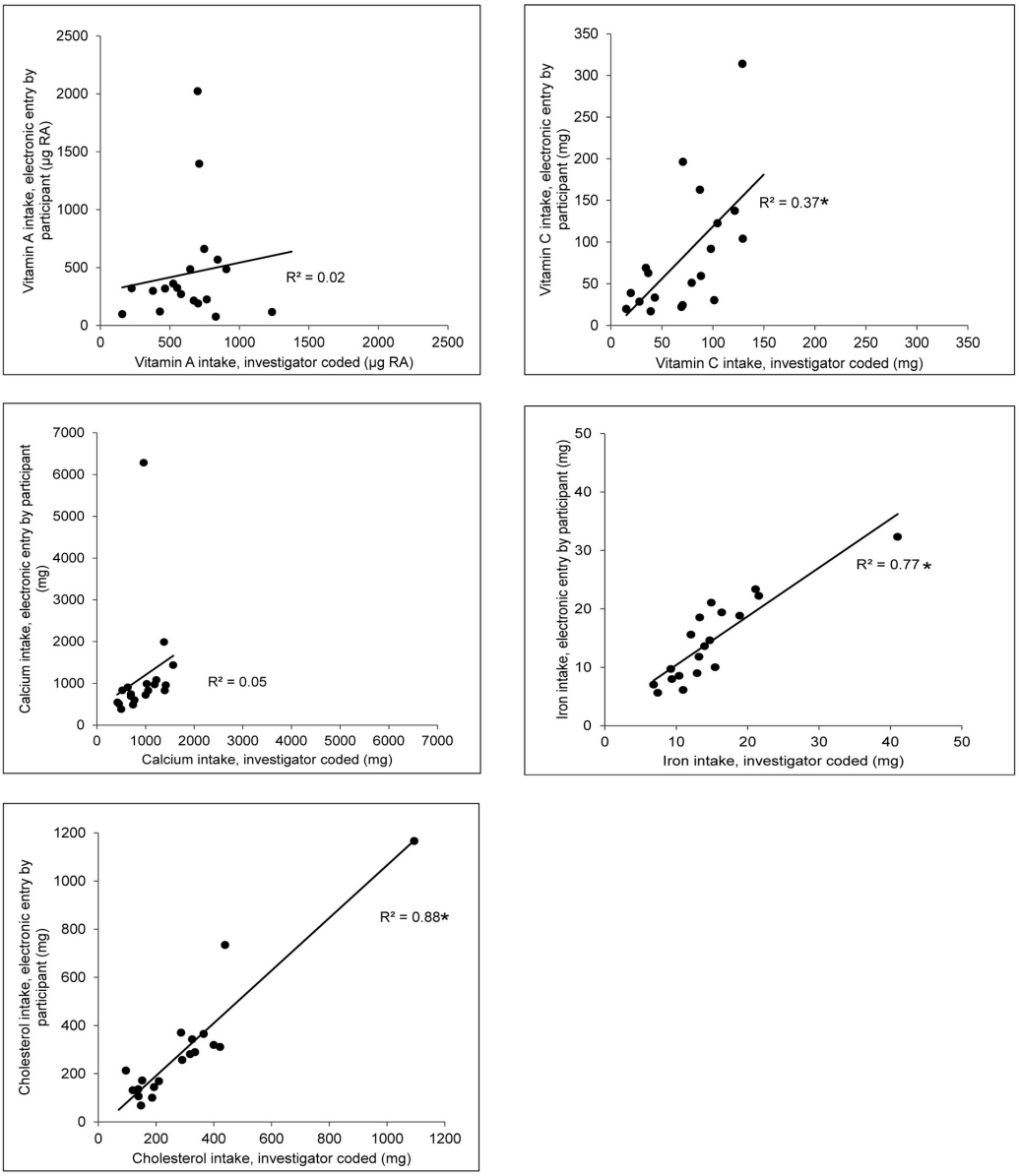
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Figure 4. Plots comparing nutrient intakes estimated from 3-day diet records coded by investigator to same 3-day diet records entered electronically: Comparing Nutrihand (black circle) or Tap & Track (grey square) to Grand Forks Research Analysis of Nutrient Data (GRAND). Each point represents mean of food records for 3 days for each individual (n=19). Regressions comparing intake estimates from Nutrihand (solid line) and Tap & Track (dashed line) to estimates obtained from investigator-coded records were performed and R2 values are reported. *Statistical significance at P<.05.



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Figure 5. Plots comparing nutrient intakes estimated from 3-day diet records coded by investigator to the same 3-day diet records entered electronically: Comparing Nutrihand (black circle) to Grand Forks Research Analysis of Nutrient Data (GRAND). Each point represents mean of food records for 3 days for each individual (n=19). Regressions comparing intake estimates from Nutrihand (solid line) and Tap & Track (dashed line) to estimates obtained from investigator-coded records were performed and R2 values are reported. *Statistical significance at P<.05.



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Discussion

Principal Findings

Classically, the methods for assessing nutrient intake include the hand recording of intake on multi-day DR by participants, interviewer-assisted recalls, and diet histories or completion of paper questionnaires for food frequency assessment [5]. Use of computerized methods for dietary analysis by the dietitian/nutritionist came into common use in the early 1980s as personal computing became common in clinical dietetics practice [18,19]. Although these methods saved considerable time over hand computation, the time demands on the interviewer and analytic staff are still considerable. Recently, there has been an increase in the study of new technologies to reduce the cost of gathering dietary intake data [20,21]. Moreover, innovative technological methodologies are being investigated to improve the quality and completeness of dietary data gathered by electronic capture [8,10]. Computers and cell phones are commonly used by all age and sex categories and there is widespread availability and popularity of apps to track dietary intake [22].

A number of electronic methods of DR capture have been evaluated, although, to our knowledge, this is the first assessment of Web-based DR tools or apps available commercially for the public. Comparisons have been made between the accuracy of diet recording on paper or on computer and personal digital assistant (PDA) based software programs. Beasley et al compared diet records kept by a PDA software program, and hand-recorded records to a 24-hour dietary recall and concluded that the PDA-based program did not appear to be more valid than the hand-recorded records [23]. PDA-based software for dietary self-monitoring over 7 days was not found to improve energy intake estimates [24] or to provide comparable estimates [25] in reference to handwritten records. In a long-term study, Burke et al demonstrated that diet record keeping over 6 months was improved by PDA-based entry of records versus hand entry in a group of participants in a weight loss trial, but no assessment was made of program validity [26].

In comparison to dietitian-entered 3-day DR, the electronic methods evaluated herein resulted in no significant difference in mean estimates of macronutrients, but significantly lower estimates of most micronutrients. There was high concordance of mean values for reported nutrient intakes from the electronic capture compared to the dietitian entry of records, with the exception of sugars comparing Nutrihand to GRAND. However, when correlating individual values, the electronic methods resulted in point estimates with much larger variability, particularly with the use of Tap & Track. The Bland-Altman plots illustrate that, in general, the responses obtained from Tap & Track displayed more variability than those from Nutrihand indicating reduced agreement. When a dietitian reviews diet records with participants and clarifies issues of food items, portion size, and added condiments prior to entry into a nutrient analysis program, the intake estimates are improved. The greater variability of nutrient estimates we observed with the electronic capture methods may be due to factors associated with diet record-keeping accuracy, including food options in the database, and the ability of participants to pick appropriate food items, to estimate portion sizes, and to accurately account for all foods consumed [22].

Reported energy intake in this study was less than that found in the What We Eat in America, National Health and Nutritional Examination Survey (WWEIA, NHANES 2009-2010) for men of this age (2482, SD 55.3 kcal), but similar to that found in women (1759, SD 38.4 kcal) [27]. This is in contrast to recent research comparing interviewer-coded DR to the Web-based, participant-coded Automated Self-Administered 24-hour recall (ASA24), which found much lower energy estimates [6]. This may be a reflection of the design differences in the investigation. Typically, diet recording is done concurrently or close to the time of food consumption, which may reduce the error seen in a diet recall performed the day after intake.

Although lower mean intake values for many micronutrients were reported with Nutrihand compared to GRAND, dietary fiber, calcium, potassium, and sodium, and other evaluated nutrients were concordant. A major methodological difference is that the hand-recorded DR method is open-ended; any food may be recorded, with detail. When using the electronic methods of DR entry, the foods are limited to those in the database. Recording errors such as implausible amounts of food consumed or foods lacking detail enough to code can be resolved during the dietitian review. During the coding process, the dietitian is better-suited to make informed decisions about coding combination foods or foods without brand names than the client [23]. It appears that dietitian-entered DR are most appropriate when the data collected is a primary research outcome and when micronutrient intake are required. However, if the goal of the DR is to collect macronutrient data as a secondary outcome variable or to allow clients/study participants to monitor their own nutrient intake, then electronic capture of DR with Nutrihand or Tap & Track may be appropriate.

The paper-based, handheld iPod and Web-based methods may be recorded at different times relative to eating. While the DR and Tap & Track can be entered immediately after eating or drinking, a client must wait until they have computer and Internet access to record with Nutrihand. As DR are the fastest way to record what is eaten, it is probable that the DR was used as a guide when entering Nutrihand, which may explain some of the smaller variability compared to Tap & Track. Despite these cognitive differences, the three methods were remarkably similar.

Strengths and Limitations

One of the strengths of our project was the fact that we randomly assigned participants to the order of the electronic DR capture during the two washout periods of the clinical trial. Another is that all participants were provided detailed instruction by the dietitian in how to maintain a complete and accurate diet record. Due to the similarity of energy intake of the DR analyzed in GRAND compared to the nationally representative WWEIA, NHANES data, it appears that participants were able to provide estimates of usual intake. These results are therefore appropriate for use as the standard with which to compare the electronic dietary recording methods. An additional strength of the study

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is our use of a highly rated app (Tap & Track) for the handheld record, indicating that the app is popular and easy to use.

We were limited by the small sample size of the study; however, the large number of DR allowed us to statistically test differences between methods. In retrospect, it may have been appropriate for us to include a non-correlated dietary intake method in our study design as between-method agreement is enhanced when the source of measurement error is correlated. There are limitations in the use of the Bland-Altman analysis for the comparison of these methods of diet assessment. These analyses are based on the assumption that measures are performed on the same samples. However, it is possible that those individual foods entered by participants into the electronic diet-recording device and those entered by the dietitian into GRAND may have been different. Nevertheless, this assessment allows us to estimate the amount and direction of variability in responses. All self-reported diet assessment is subject to error and bias. A participant may choose to over-report foods perceived as healthy or not report foods perceived as unhealthy. If it is not convenient, a participant may not record food items immediately and may forget eating them. Portion size is difficult to determine and may be under- or over-reported. Even the act of recording foods consumed can change a person's eating habits, either purposefully or not. A potential limitation of this study is that the errors in the different methods may be correlated, which would increase observed correlations.

There is a need for further development of valid digital methods of dietary assessment. These must be simple for participants to use and not overly burdensome for dietitians and researchers to interpret. Disposable cameras have been used to capture meal images before and after consumption, but are inconvenient for use and did not provide enough information for interpretation. Much research has focused on digital camera images. Digital cameras are more convenient for participants, but still suffer from lack of information for use without having participants provide additional information. Both also need to be coded by a dietitian. Currently, Web-based and mobile phone diet entry may be considered to be, on balance, useful tools that minimize both participant and researcher time [20-22].

Conclusions

This study demonstrated that two readily available self-administered electronic DR capture methods (Nutrihand and Tap & Track for the iPod) showed high concordance of mean nutrient values with a traditional dietitian-coded and analyzed DR. These data indicate that electronic diet recording may be suitable for group intake estimates and their use may reduce time spent on dietary assessment. Compared to the dietitian-coded and analyzed DR, Nutrihand in particular performed well, especially for energy and macronutrients, both critical in self-monitoring of dietary intake. Our results suggest that electronic DR capture may be appropriate for diet monitoring and useful in reducing the workload of DR coding and entry. The validity of nutrient intake estimates by electronic capture for an individual needs further assessment. Additional research is required to evaluate other electronic DR capture methods as is work to improve the precision with which clients are able to enter their dietary intake.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Bland-Altman plots comparing electronic diet entry by participants to dietitian entry of 3-day diet record (DR) into Grand Forks Research Analysis of Nutrient Data (GRAND). Plots for sugars, fiber, SFA, and sodium comparing Nutrihand and Tap & Track to GRAND. Solid horizontal line indicates mean of differences between Nutrihand or Tap & Track and Grand. Upper and lower limits of agreement (dashed lines) define the range within which most differences between methods are expected to occur. Dotted line at y=0 is given for reference.

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Multimedia Appendix 2

Bland-Altman plots comparing electronic diet entry by participants to dietitian entry of 3-day diet record (DR) into Grand Forks Research Analysis of Nutrient Data (GRAND). Plots for cholesterol, vitamin A, vitamin C, calcium, and iron comparing Nutrihand to Grand. Solid horizontal line indicates mean of differences between Nutrihand or Tap & Track and Grand. Upper and lower limits of agreement (dashed lines) define range within which most differences between methods are expected to occur. Dotted line at y=0 is given for reference.

[JPG File, 3MB - jmir_v17i1e21_app2.jpg]

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Abbreviations

ARS: Agricultural Research Service
DR: diet records
FIAS: Food Intake and Analysis System
GFHNRC: Grand Forks Human Nutrition Research Center
GRAND: Grand Forks Research Analysis of Nutrient Data
SR22: National Nutrient Database for Standard Reference, Release 22
USDA: United States Department of Agriculture

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Original Paper

Development and Assessment of an E-Learning Course on Breast Imaging for Radiographers: A Stratified Randomized Controlled Trial

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Abstract

Background: Mammography is considered the best imaging technique for breast cancer screening, and the radiographer plays an important role in its performance. Therefore, continuing education is critical to improving the performance of these professionals and thus providing better health care services.

Objective: Our goal was to develop an e-learning course on breast imaging for radiographers, assessing its efficacy, effectiveness, and user satisfaction.

Methods: A stratified randomized controlled trial was performed with radiographers and radiology students who already had mammography training, using pre- and post-knowledge tests, and satisfaction questionnaires. The primary outcome was the improvement in test results (percentage of correct answers), using intention-to-treat and per-protocol analysis.

Results: A total of 54 participants were assigned to the intervention (20 students plus 34 radiographers) with 53 controls (19+34). The intervention was completed by 40 participants (11+29), with 4 (2+2) discontinued interventions, and 10 (7+3) lost to follow-up. Differences in the primary outcome were found between intervention and control: 21 versus 4 percentage points (pp), $P<.001$. Stratified analysis showed effect in radiographers (23 pp vs 4 pp; $P=.004$) but was unclear in students (18 pp vs 5 pp; $P=.098$). Nonetheless, differences in students' posttest results were found (88% vs 63%; $P=.003$), which were absent in pretest (63% vs 63%; $P=.106$). The per-protocol analysis showed a higher effect (26 pp vs 2 pp; $P<.001$), both in students (25 pp vs 3 pp; $P=.004$) and radiographers (27 pp vs 2 pp; $P<.001$). Overall, 85% were satisfied with the course, and 88% considered it successful.

Conclusions: This e-learning course is effective, especially for radiographers, which highlights the need for continuing education.

(J Med Internet Res 2015;17(1):e3) doi:10.2196/jmir.3344

KEYWORDS

breast neoplasms; continuing education; distance learning; evaluation studies; mammography

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Introduction

Overview

In Europe, breast cancer is responsible for one in every six deaths from cancer in women [1]. In Portugal, breast cancer-related mortality incidence reaches 1500 women every year [2]. Thus, early detection and diagnosis of breast cancer is essential to decrease its associated mortality rate, and mass screening is recommended by the medical community [3].

Mammography

Mammography is currently considered the best imaging technique for breast cancer screening [3] and the most effective tool for the early detection of this disease, helping reduce mortality and increasing treatment options [4,5]. Due to its importance, not only for screening but also for diagnosis, intervention, and follow-up [6], mammography has undergone constant improvements to enhance its diagnostic quality, namely in image acquisition, equipment design and components, and technical parameters [7]. Also, other diagnostic technologies are being developed such as breast tomosynthesis, which aims to reduce or eliminate the tissue overlapping effect thus detecting lesions with higher sensitivity [8].

Radiographer Role

Radiographers play an important role in the performance of mammographic examinations; their knowledge requirements go beyond radiation exposure, positioning techniques, and other characteristics of the equipment used [9-11].

Radiographers are part of a multidisciplinary team, both during screening or diagnosis and intervention, allowing them to be aware of the clinical information as well as previous breast exams of the patient [10,11]. Therefore, it is important that the radiographer establishes direct contact with the radiologist in order to contribute to a proper diagnosis. Together with the radiologist, the radiographer is responsible for image quality assurance; the availability, accessibility, and interpretation of mammographic images; and for the performance of additional imaging, preoperative localization, and biopsy techniques [9,10].

Beyond these technical issues, radiographers are usually the first professionals to have face-to-face contact with women in primary health care, during breast cancer screening. Therefore, they should be able to provide the patient with sound answers regarding the examination and the implications of the results [11]. According to the European Society of Breast Cancer Statistics (EUSOMA) recommendations [9,10], the correct understanding of senology concepts such as breast cancer statistics and family history, and knowledge of breast disease symptoms and treatment options are critical. Further, radiographers require a fair degree of sensitivity since mammography causes considerable anxiety in most women [11].

This extended role could contribute to decreasing the mortality rate of breast cancer and thus reducing health care needs [5,11].

In this context, the knowledge of senology concepts is essential to the health professional, highly considered in some countries (such as in England, Denmark, Australia, and United States) [11-14]. Unlike the aforementioned countries, breast cancer screening in Portugal is not fully organized by the government but by a private institution [2]. This may be one of the reasons why there are no existing specific training programs and the role of the radiographer is not as differentiated and valued as elsewhere. Hence, the need for continuing education for Portuguese radiographers in this area is critical.

E-Learning in Health Care

Continuing education is known to improve the performance of professionals, providing better health care services [15]. For example, the National Health Service University identified e-learning as a central strategic delivery mechanism for all its professionals [16]. Several studies [12,17,18] have shown that radiographers are receptive to new technologies and training and are able to upgrade their skills and extend their role.

The asynchronous ability, cost-savings, personalized learning, increased accessibility, ease of distribution, and updated content are some examples of e-learning advantages [19,20]. However, time constraints and the difficulty of “ease of use” are commonly pointed out as drawbacks [16].

With the development of new information technology, there is a surplus of software that can be used to implement e-learning systems, ranging from websites and email to blogs, wikis, and discussion forums [19]. Dedicated Learning Management Systems (LMS) support the planning, organization, and access control of specific learning processes. In radiology, there are some LMS technologies that improve collaboration, interactivity, simulation, and self-testing [20]. E-learning is therefore a useful tool helping not only students but also professionals move towards a vision of lifelong and continuous education [19,20].

E-Learning Evaluation

The potential of e-learning may not always translate into significant improvements in educational outcomes [21]. For this reason, e-learning needs to be justified by its effectiveness and relevance [22]. One important method for evaluating a learning system is the framework developed by Kirkpatrick [23], which consists of four categories: learner perception, knowledge, behavior, and impact on organization.

Most of the studies on the evaluation of e-learning processes rely on users’ satisfaction and knowledge [22-25]. Although some authors believe that there is no evidence that learners learn more from e-learning than traditional learning, it is acknowledged that they can learn more effectively [21,22]. E-learning combined with traditional learning—that is, blended learning, or b-learning—is considered the best way to obtain higher knowledge gain [21-23]. Using pre- and post-knowledge tests within an experimental study, if the experimental group performs better than the control group, the e-learning system can be identified as the cause of the improvement [23]. According to certain authors [22,26], there is a lack of randomized controlled trials (RCTs) in research on e-learning, despite RCTs being considered the best way to assess e-learning efficacy and effectiveness. Therefore, RCTs are recommended for evaluating e-learning systems [21,22,26].

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One of the most cited questionnaires for user satisfaction with e-learning [27] considers four dimensions of the e-learner satisfaction measurement: content, learner interface, personalization, and learning community. From these dimensions, the tool specifies 26 items using a 7-point Likert scale (ranging from "strongly disagree" to "strongly agree"), although the last two questions actually reflect global measures related to overall satisfaction and overall success of the e-learning system. Globally, the questionnaire has presented reliability (Cronbach alpha) of .95 [27].

The work presented in the following sections aims to provide a new easy-to-use e-learning course, thus contributing to senology teaching, while emphasizing continuing education and professional development.

Objectives

In this context, our research question is whether an e-learning system improves the senology knowledge of radiographers and radiology students. The objectives of this work include knowledge promotion and understanding of all aspects of breast illness and patient care required by radiographers. To achieve this, we proposed to (1) develop an easy-to-use course in e-learning environment, (2) assess its efficacy and effectiveness, and (3) assess the satisfaction of users.

Methods

Overview

An asynchronous e-learning course on breast imaging for radiographers was developed and evaluated for its efficacy, effectiveness, and satisfaction.

Target Population and Sample Strategy

The target population in this study was all radiographers working at public health institutions in Porto's metropolitan area, in Portugal, with ability to perform mammographic exams, and all radiography students attending the 3rd and 4th years of the radiology course at the School of Allied Health Science, Porto Polytechnic Institute who already had mammography training. Hence the sample was stratified by professional status into two groups: students and radiographers, who were invited by email to participate in the study, after an individual request.

Randomization

All radiographers and students included in the study were asked to perform the pre-knowledge test. Randomization was performed with the population elements in each stratum who accepted and effectively took the pretest. Therefore, 50% of the elements of each stratum were randomly allocated to the intervention group and contacted to participate in the course, after being properly informed of the randomization process. The remaining sample was allocated to the control group and afterward contacted to participate in a second test.

Implementation

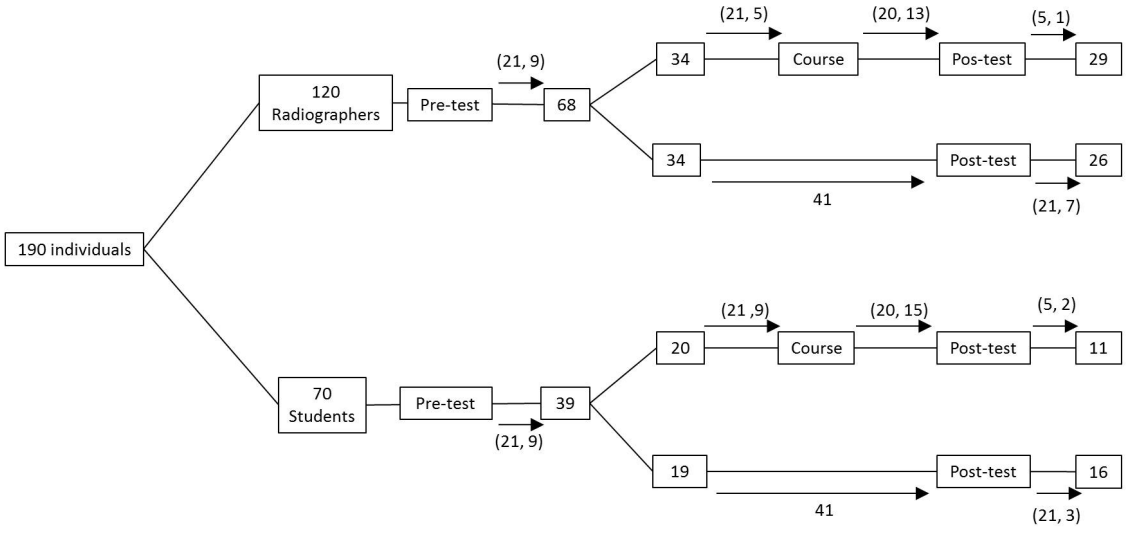
The communication with all participants was performed mainly by email (maximum three attempts) as described in Figure 1.

The intervention group was contacted in order to perform the e-learning course, and a similar process to the pretest enrollment occurred. Private asynchronous access was given during a 20-day period to those who agreed to do the course. Then, a final assessment test was delivered, to be answered within 5 days. Those who discontinued the intervention were requested nonetheless to perform the posttest, to allow an intention-to-treat analysis.

The control group was contacted 41 days after randomization to perform another test. During this period, neither radiographers nor students allocated to the control group had any formal educational activity concerning senology lectures given by our research team and were asked to answer tests in an honest manner, without consulting external sources, which could in the future evolve into a clear accreditation process [28].

The course was created and revised between October 2011 and January 2012. Contact with the participants occurred between February 1 and March 7, 2012, and the trial was conducted between March 7 and May 31, 2012.

Figure 1. Study design and post-implementation duration: numbers in boxes represent number of participants; numbers in arrows correspond to the elapsed time in days (maximum, average) at each phase.



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The E-Learning Course Description

The course was written in Portuguese and developed in Netbeans version 8.0, using simple and wide-spread technologies such as Hypertext Preprocessor (PHP), HyperText Markup Language (HTML), JavaScript, Cascading Style Sheets (CSS), and Extensible Markup Language (XML), and was hosted on the server at the Faculty of Medicine of the University of Porto. Website security was guaranteed through an authentication mechanism with username and password, and no collaborative activities [29] were available, setting the focus on self-learning.

The course instructions were available on the website, along with a glossary, and it was structured into four modules (Table 1). The contents were based on guidelines proposed by EUSOMA [9].

Table 1. Description of the main contents included in the intervention e-learning course.

Module	Contents
1. Breast anatomy and physiology of breast	Breast localization and superficial anatomy
	Breast tissues constitution
	Radiological anatomy
	Breast tissues patterns
	Breast lesions localization
2. Breast cancer: multidisciplinary approach	Breast cancer statistics
	Breast cancer screening: Mammography
	Breast cancer signs and symptoms
	BI-RADS classification
	Additional imaging techniques
	Breast cancer management and treatment options
3. Breast pathology	Pathology of benign and malignant lesions
	Male breast cancer
4. Mammography: technical approach	Mammography history
	Technical aspects of the equipment and new technologies
	Image quality control
	Positioning techniques and indications for standard and additional mammographic views
	Localization and biopsy techniques for non-palpable lesions
	Radiographer role

The content was presented using text, images, videos, and Prezi presentations. Diagnostic images were collected directly from the Breast Unit of S João, Hospital Center, with proper legal authorization. All content was reviewed by specialists from the same institution. Screenshots are presented in Figures 2-5.

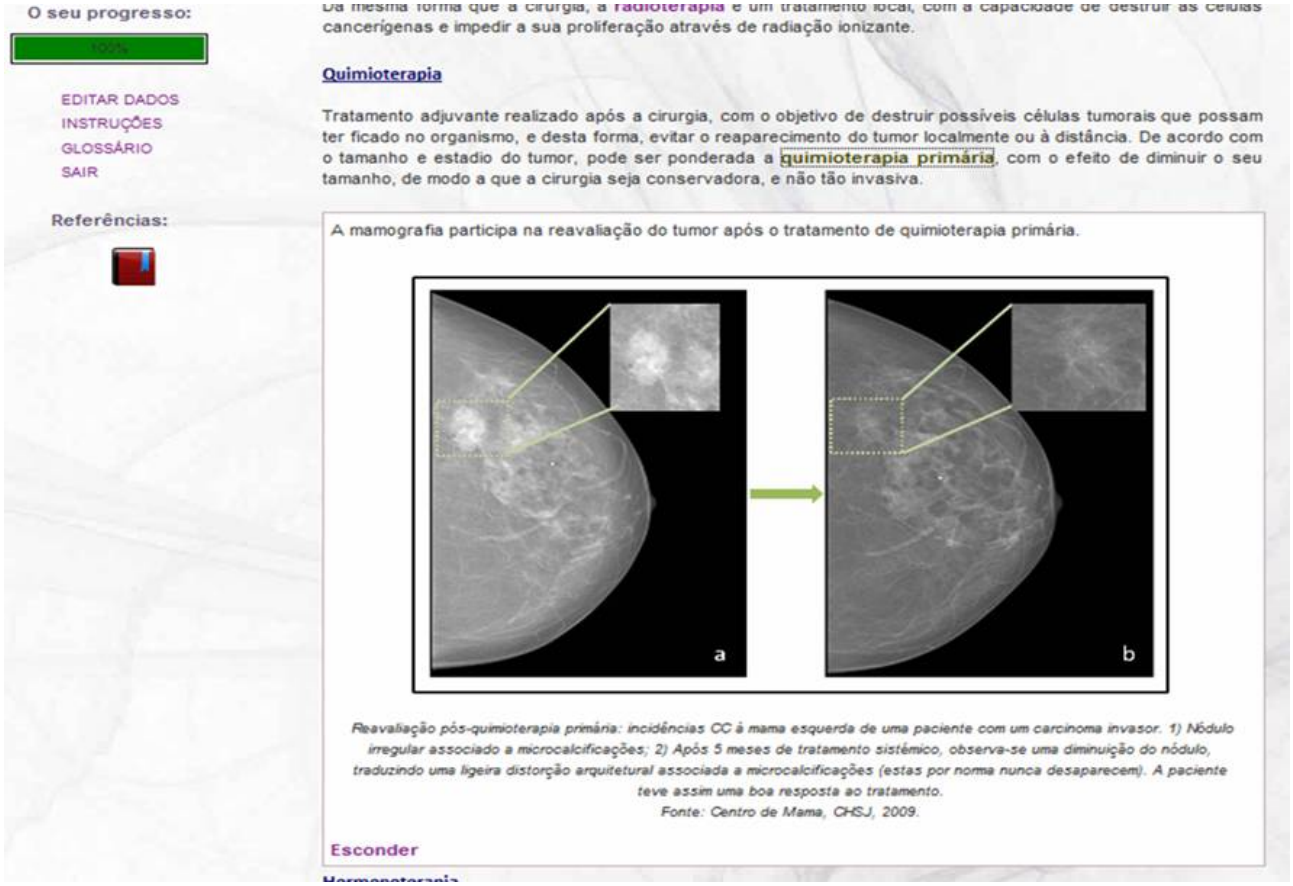
Given the asynchronous characteristics of the course, learners could monitor the evolution of their learning through a status bar, giving feedback about the self-learning. At the end of each module, a summary of the key points and a self-assessment test of 6 multiple-choice questions were presented; correct answers were immediately available. The posttest was administered at the completion of the course. This posttest was a final assessment sent by email and available for 5 days after mail delivery. After successful completion, a certificate of attendance was sent to the participants.

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Figure 2. Screenshot of a Prezi presentation in the e-learning course.



Figure 3. Screenshot of mammography views in the e-learning course.

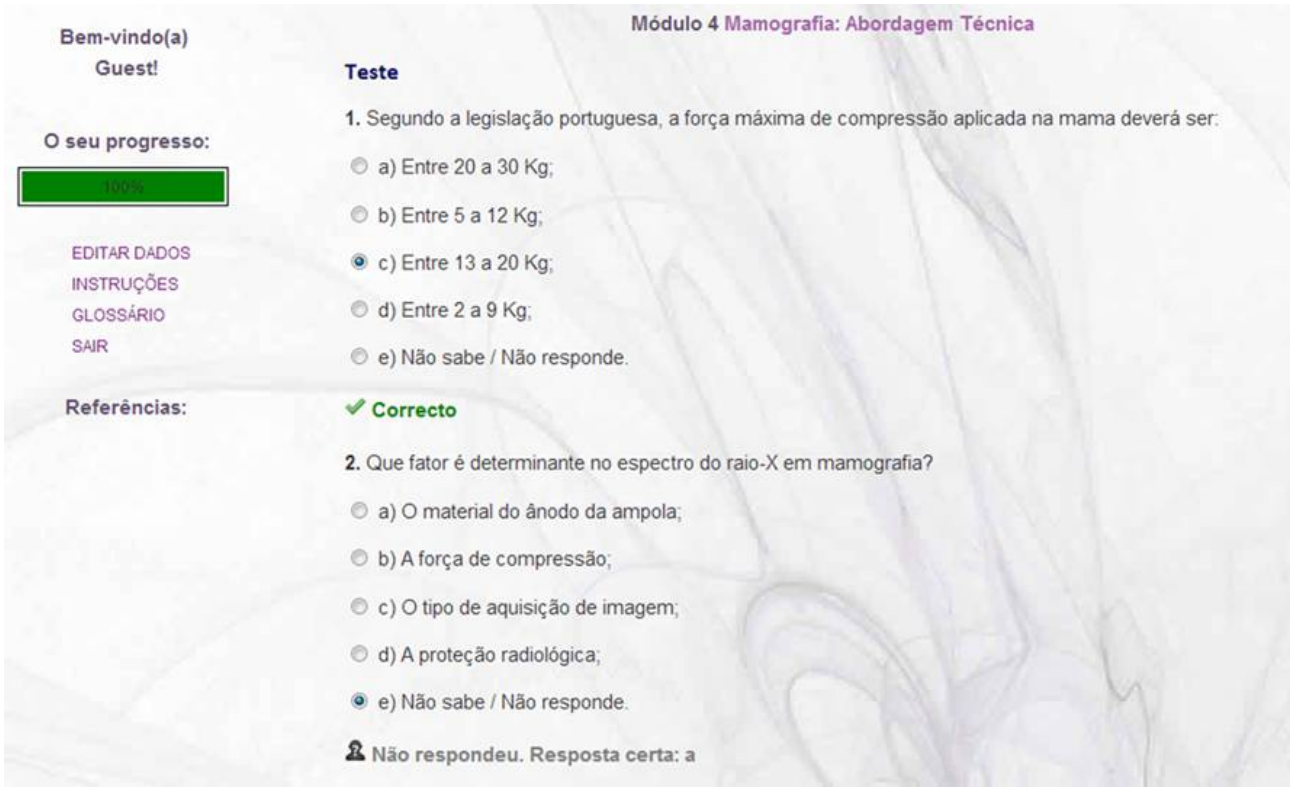


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Figure 4. Screenshot of mammography views and schemes in the e-learning course.



Figure 5. Screenshot of one of the four self-assessment tests included in the e-learning course.



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Pre- and Post-Knowledge Tests

Each test was structured with 8 multiple-choice questions related to the course modules (Table 1). Questions from pre- and post-knowledge tests were different but had the same level of difficulty. To ensure this condition, a pilot study was done with a convenience sample of 8 radiographers not included in the final sample.

Participants were asked to answer in an honest manner, without consulting external sources. This study consisted of two phases. In the first step, 4 individuals received one test, and the other 4 received the other test. The random delivery of the tests was accomplished, highlighting the independence of the questionnaires in relation to being the first or the second test answered. Then, in a second step, when an individual submitted the answers 24 hours later, the other test was sent. This pilot study was done between February 18 and March 1, 2012.

The focus of the data analysis was to determine whether there was a significant difference between the questions presented in the first and the second tests. For this observation, we used paired Wilcoxon tests to compare the number of incorrect answers of each individual between the first and the second test. As the questions were organized by themes, related to the modules of the course, the tests were also organized for each set of questions. The statistical analysis was performed using IBM SPSS Statistics software version 17.0, and the significance level was .05.

Through the data analysis, we can conclude that there are no differences among the modules in one test and the other: module 1 (P=.083), module 2 (P=.096), module 3 (P=1.000), and module 4 (P=.317). Apart from the non-existence of differences, some questions and multiple choices were readjusted in order to make them clearer.

Demographic information such as age, gender, academic qualifications, years of professional experience, and routine mammography, as well as opinions regarding the need for continuing education and the receptivity of e-learning programs on any topic of professional interest, were also gathered.

The Web resource GoogleDocs was used to create and deliver online the tests, assigned to individuals randomly as pre- or post-knowledge tests.

Satisfaction Questionnaire

Given the lack, to the best of our knowledge, of a questionnaire in Portuguese, we used the questionnaire proposed by Wang [28], after translation by an expert bilingual translator.

Assessment of Outcomes

The primary outcome was the knowledge evolution observed between pre- and post-knowledge tests (each measured by the percentage of correct answers and failure defined using 50% cut-off), using a paired analysis the difference between pre- and post-knowledge test percentage of correct answers (referred to as “evolution” and measured in percentage points [pp]).

Effectiveness was assessed through the proportion of participants who completed the intervention. Satisfaction was mainly assessed through the last two items of the questionnaire.

Statistical Analysis

Analysis was mostly performed according to the intention-to-treat strategy [30]. Normality was tested with the Kolmogorov-Smirnov test (total sample) and the Shapiro-Wilk test (for each group), beyond the visual analysis of histograms.

The sample was described by average (μ) and 95% confidence intervals for normally distributed variables, and median, 25 and 75 percentiles (P_{25}; P_{75}) for the remaining.

Homogeneity between the two groups was assessed using the Mann-Whitney U test. Differences in the outcome of the two groups were assessed using the Student’s t test. Chi-square test or Fisher’s exact test were used to examine the association between nominal variables.

We considered a significance level of .05, and the analysis was carried out in IBM SPSS Statistics software, version 17.0.

Results

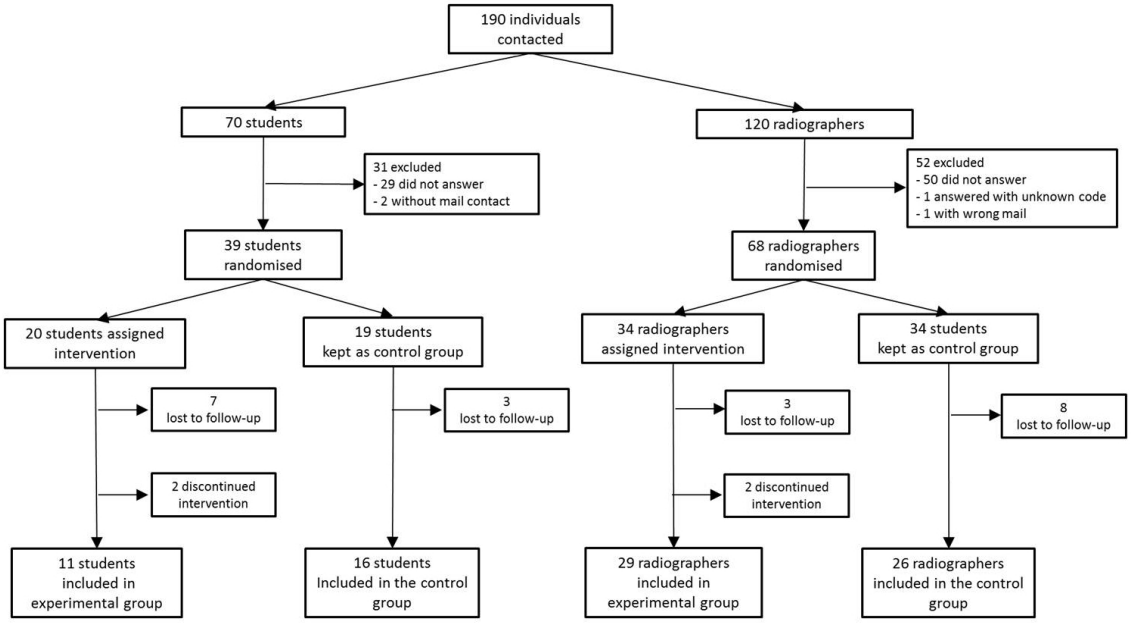
Summary

Globally, 190 individuals were considered for inclusion (120 radiographers and 70 students) from which a total of 107 enrolled and answered the pre-knowledge test (68 radiographers and 39 students). The average time spent (in days) between study’s milestones can be observed in Figure 1. Likewise, the participants’ flow including dropouts (“lost to follow-up” and “discontinued interventions”) is shown in Figure 6.

According to the intention-to treat strategy, the intervention group included 2 radiographers and 2 students identified as lost to follow-up, as well as 1 radiographer and 1 student identified as “discontinued intervention” who answered the post-knowledge test. Globally, 46 individuals were included in the intervention group (14 students and 32 radiographers) and 42 in the control group (16 students and 26 radiographers).

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Figure 6. Participant flow diagram showing enrolled sample and respective dropouts. Individuals who did not answer the participation request were considered "lost to follow-up"; participants who did not finish the course were considered “discontinued intervention”.



Sample Description

Of the 107 participants, 36.4% (39/107) were students and 63.6% (68/107) were radiographers; 79.4% (85/107) were female. The median age was 21 years old (P_{25}=21; P_{75}=22) for students, and 33 years old (28; 40) for radiographers. Overall, 10.3% (11/107) were third-year students, 26.2% (28/107) were fourth-year students, 1.0% (1/107) was credited due to professional experience, 7.5% (8/107) had bachelor’s degrees, 50.5% (54/107) had graduated, and 4.7% (5/107) had a master’s degree.

In the radiographer group, the median professional experience was 12 years (5; 17); 31% (21/68) individuals did not perform mammography at all, 53% (36/68) performed fewer than 30 per week, 6% (4/68) performed between 30 and 40 per week, and 10% (7/68) performed more than 40 per week.

In the pre-knowledge test, there was a failure rate of 14.0% (15/107). We observed that 51.4% (55/107) of the results were between 50-75% and 34.6% (37/107) had results better than 75%. In the post-knowledge test, the failure rate was 5.6% (6/107); 25.2% (27/107) of the results were between 50-75%, and 51.4% (55/107) had results better than 75%.

Intervention and control groups were globally comparable, with a difference only in female proportion in both groups for the radiographer stratum (88% vs 68%, *P*=.041).

Efficacy

Both intervention and control groups had similar results in the pre-knowledge test (63% vs 63%, *P*=.159), with also no differences per stratum (63% vs 63%, *P*=.626).

The intervention group obtained better results in the post-knowledge test compared to the control group (88% vs 63%, *P*<.001), and no differences were found between the two strata (75% vs 75%, *P*=.261).

Participants had an overall positive evolution (μ=13 pp, 95% CI 8-18), which is higher in the intervention group (21 pp vs 4 pp, *P*<.001) but similar between students and radiographers (11 pp vs 14 pp, *P*=.601). Furthermore, the control group had an inconclusive evolution (95% CI -3 to 11).

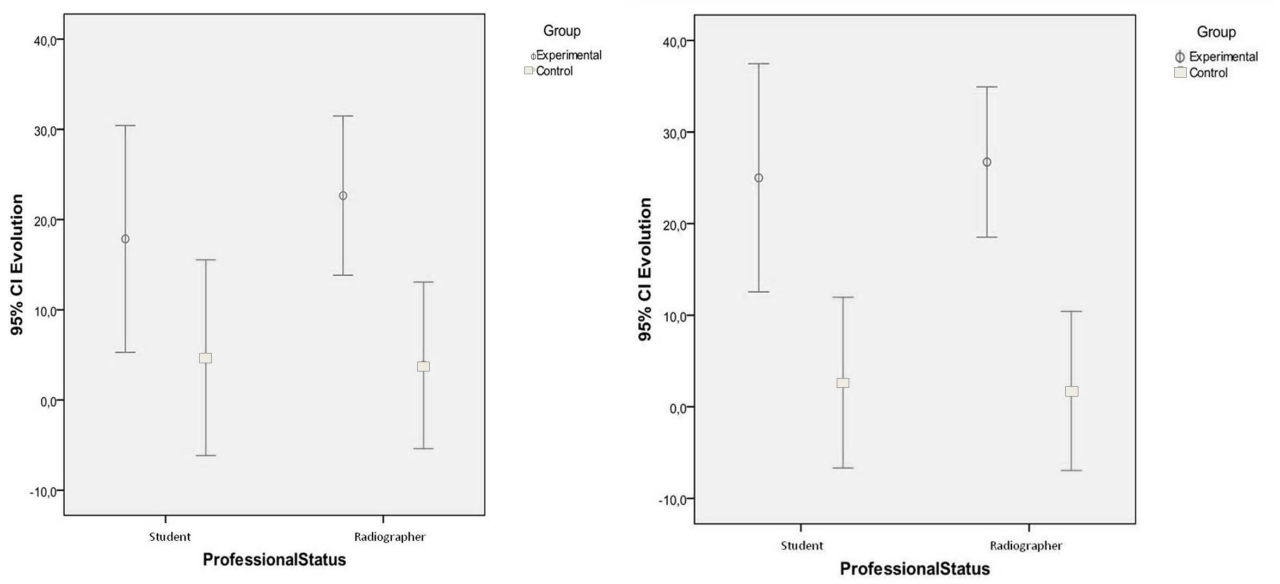
Stratifying the results (left plot of Figure 7), the difference in the evolution of students, although favorable to the intervention group is not statistically significant (18 pp vs 5 pp, *P*=.098), while in the radiographers, the effect of the course is clear (23 pp vs 4 pp, *P*=.004). There were no differences in the evolution between students and radiographers both in the intervention group (18 pp vs 23 pp, *P*=.531) and in the control group (5 pp vs 4 pp, *P*=.905).

Considering a per-protocol analysis (right plot of Figure 7), those who were considered “lost to follow up” (n=10) and “discontinued intervention” (n=4) in the intervention group were allocated to the control group. As a result of this strategy, the overall evolution was found positively different in the two groups (26 pp vs 2 pp, *P*<.001).

Significant differences in students could then be observed between intervention and control (25 pp vs 3 pp, *P*=.004), along with a reinforced difference in radiographers (27 pp vs 2 pp, *P*<.001).

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Figure 7. Improvement stratified by professional status. Left plot (intention-to-treat): Inconclusive result for students but clear effect for radiographers. Right plot (per-protocol): Clear effect for both students and radiographers.



Effectiveness and Satisfaction

Most participants (81%, 44/54) in the intervention group agreed to take the course (13 students and 31 radiographers), and only 9% (4/44) did not attend the full course: 2 students and 2 radiographers.

All participants who completed the e-learning course answered the satisfaction questionnaire (n=40). Considering global measures, 85% were satisfied with the e-learning system (students vs radiographers: *P*=.570) and 88% considered the system successful (*P*=.660). Detailed results were described in [31].

Of all e-learners, 10% (4/40) had previous e-learning experience, and 5% (2/40) performed it in the health area. However, the overall satisfaction did not differ between these participants and those who had no previous experience of e-learning (*P*=.191).

Discussion

Principal Findings

Comparing students and radiographers, we did not find any significant differences besides age and academic qualifications, and therefore no additional confounding factors were considered for adjustment. Overall improvement was observed and attributed to the course.

Although the effect was not clear in students, we found differences in post-knowledge test results between the intervention and control groups, whereas such differences were absent in the pre-knowledge test. This result could be explained by the smaller sample size or higher proportion of individuals lost to follow-up, which could have resulted from being enrolled in other learning activities at the same time during the academic year. In addition, students were probably more prone to self-learning from other sources, or there was interest from students in the control group in learning more after performing the pre-knowledge test.

Regarding radiographers, those who were allocated to the intervention group significantly improved more than the controls did, which supports the importance of continuing education throughout their working lives.

The per-protocol analysis enhanced the influence of the course, exposing a significant effect on the students' stratum. Considering that the real course effect is probably in between the two statistical analyses, we can conclude that this randomized controlled trial showed that the e-learning course improved the knowledge of those who attended (even if only part of) the intervention.

Overall, the developed course is efficacious, especially for radiographers, which highlights the need for continuing education, foreseeing also e-learning as an increasingly viable complement to the traditional method, especially since the technologies involved do not need heavy hosting requirements. This study also proved that the course is effective, since only 10% of the learners dropped out. Moreover, the course showed to have a high level of satisfaction, for both radiographers and students.

Limitations

Since it was not possible to find in the literature any satisfaction questionnaire for e-learning systems in Portuguese, the validity of this satisfaction evaluation should be carefully considered, given the translation. A validation of the questionnaire used in this work could be a future project.

Another limitation of this work is the single learning institute with moderate sample size, affecting the generalizability of the results.

Another restraint is related to the learning and evaluation strategy, since we faced the risk of individuals resorting to external sources in order to provide correct answers to the tests. This situation creates a slight bias that is difficult to control considering the study design.

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Nevertheless, randomization was performed after completing the pre-knowledge test, which yielded that the same willingness of participants to enter the study was demonstrated, regardless of the group where they were allocated.

Conclusions

Globally, this study underlines the importance of the radiographer as the health care professional who interacts first with women during the breast cancer screening process. We consider the high rate of participation an important aspect in our study (57% of radiographers and 56% of students), which reflects the great interest shown by these professionals to participate in scientific research, thereby promoting their professional category. They took advantage of learning opportunities, which shows that they are health care professionals committed to responding to the constant challenges of the profession.

This study contributes to the Portuguese radiographers' continuing education, since we did not find any similar course related to breast imaging. It would be interesting to conduct additional assessments to demonstrate effective consolidation of knowledge gain. Future developments may include collaborative activities; for this first assessment, we believe such activities would confound the efficacy results.

Our main finding illustrates the knowledge improvement in senology that our e-learning course gave radiographers. We believe that this study highlights the importance of e-learning as a training platform, especially in light of budget constraints associated with the current economic climate. E-learning should be considered for continuing education, and directors should invest in it to improve the skills of their professionals and consequently enhance health care services [32,33].

Acknowledgments

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Authors' Contributions

All the authors have made a significant contribution to this manuscript and have approved the final paper, thus meeting the criteria for authorship. All those entitled to authorship are listed as authors.

Conflicts of Interest

None declared.

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Abbreviations

EUSOMA: European Society of Breast Cancer Statistics
LMS: Learning Management Systems
pp: percentage points
RCT: randomized controlled trial

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Original Paper

Designing and Evaluating an Interactive Multimedia Web-Based Simulation for Developing Nurses' Competencies in Acute Nursing Care: Randomized Controlled Trial

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Abstract

Background: Web-based learning is becoming an increasingly important instructional tool in nursing education. Multimedia advancements offer the potential for creating authentic nursing activities for developing nursing competency in clinical practice.

Objective: This study aims to describe the design, development, and evaluation of an interactive multimedia Web-based simulation for developing nurses' competencies in acute nursing care.

Methods: Authentic nursing activities were developed in a Web-based simulation using a variety of instructional strategies including animation video, multimedia instructional material, virtual patients, and online quizzes. A randomized controlled study was conducted on 67 registered nurses who were recruited from the general ward units of an acute care tertiary hospital. Following a baseline evaluation of all participants' clinical performance in a simulated clinical setting, the experimental group received 3 hours of Web-based simulation and completed a survey to evaluate their perceptions of the program. All participants were re-tested for their clinical performances using a validated tool.

Results: The clinical performance posttest scores of the experimental group improved significantly (P<.001) from the pretest scores after the Web-based simulation. In addition, compared to the control group, the experimental group had significantly higher clinical performance posttest scores (P<.001) after controlling the pretest scores. The participants from the experimental group were satisfied with their learning experience and gave positive ratings for the quality of the Web-based simulation. Themes emerging from the comments about the most valuable aspects of the Web-based simulation include relevance to practice, instructional strategies, and fostering problem solving.

Conclusions: Engaging in authentic nursing activities using interactive multimedia Web-based simulation can enhance nurses' competencies in acute care. Web-based simulations provide a promising educational tool in institutions where large groups of nurses need to be trained in acute nursing care and accessibility to repetitive training is essential for achieving long-term retention of clinical competency.

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KEYWORDS

acute nursing care; authentic learning; clinical competency; deterioration; multimedia; instructional strategies; simulation; Web-based simulation

Introduction

Acquiring nursing competencies in assessing and managing acutely ill patients has been identified as a crucial learning goal in the acute care hospital to reduce the occurrence of adverse events such as cardiopulmonary arrest [1,2]. Previous studies have shown the benefits of using mannequin-based simulation in acute nursing care training [3,4]. As simulation places the learners in a realistic situation, it is considered an authentic learning activity to prepare learners for their real-life work. Lebow described authentic activity as "experiences of personal relevance that permit learners to practice skills in environments similar to those in which the skills will be used" [5]. The authentic learning activities embedded in simulation enable the learners to develop knowledge, skills, and attitudes in an integrative whole, which facilitates the transfer to future real-life work settings [6]. However, developing and implementing an authentic learning environment using simulation is often limited by the availability of simulation facilities, the requirement for trained simulation instructors, and the small numbers of learners involved in the training at one time [7]. Given the resource-intensive nature of simulation, it would be a challenge for institutions that need to train large groups of nurses. Nonetheless, such limitations could be eased with the development of Web-based learning (WBL) technology.

With technological advancements, WBL can provide an authentic learning context that responds to nurses' needs and experiences in clinical practice. WBL is endorsed as an essential educational tool for lifelong learning and professional development [8]. Previous studies did not show any differences between WBL and face-to-face learning in the acquisition of knowledge, skills, and satisfaction [9]. Additionally, nurses perceived that WBL was suited to meeting their working conditions and needs including conflicting work schedules and intensive workload [10].

Advances in multimedia technology make the design of authentic learning activities increasingly feasible in WBL. Multimedia refers to technology for presenting visual and verbal material [11]. Instructional designers can use media such as text, graphics, audio, and video to simulate real-world environments where learners can perform authentic tasks. In addition, multimedia technology makes it possible for situating simulations in WBL (known as Web-based simulation). One approach is for learners to play roles in goal-based scenarios driven by assessment [12]. Web-based simulations using virtual patients are now popular in health care education for simulating authentic clinical experiences [13].

A review of literature between 2000 and 2014 identified 18 Web-based simulation programs in nursing education with most involving teaching an aspect of procedural patient care and others on interpersonal communication skills or technique skills for equipment use. Descriptive studies reported high levels of acceptance of Web-based simulations by nursing students [14]. Using experimental studies, some of the Web-based simulations were tested by comparing them with mannequin-based simulation. These studies revealed that Web-based simulations are at least as good as, if not better than, mannequin-based simulations in teaching the necessary skills and knowledge to develop competent nursing students [15,16]. As the existing Web-based simulations have a predominant focus on pre-registered health professional education [14], further study is recommended to explore the use of Web-based simulation in continuing health professional education [17].

It appears Web-based simulation is more cost-effective than mannequin-based simulation for training large groups of hospital nurses. The successful implementation of mannequin-based simulation for undergraduate nurses in acute nursing care has prompted us to develop an alternative authentic learning strategy in continuing nursing education of hospital nurses [18]. The use of WBL is still fairly new in the field of acute nursing education. WBL instructional design methods vary considerably, and research is needed to find the most effective method [19]. Thus, the aim of this study is to describe the design, development, and evaluation of an interactive multimedia Web-based simulation for developing nurses' competencies in acute nursing care.

Methods

Overview

The instructional design model developed by Smith and Ragan [20] was used to guide the design, development, and evaluation of the interactive multimedia Web-based simulation. The model focuses on three key activities: analysis, strategy, and evaluation.

Analysis

Learners

The targeted learners were registered nurses (RNs) who have acquired either a diploma or baccalaureate nursing degree. In caring for acutely ill patients, RNs play an important role in recognizing patient deterioration, conveying their assessments to health care staff, and providing timely and appropriate intervention before the arrival of appropriate help.

Learning Objectives

With the analysis of nurses' roles in caring for acutely ill patients, three specific learning objectives were identified: (1) understanding the underlying physiological signs of patient deterioration, (2) recognizing and managing deteriorating patients, and (3) communicating effectively about patient deterioration.

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Learning Tasks

An important learning task to help nurses recognize the early signs of patient deterioration involves understanding the physiological compensatory mechanism and pathophysiology underpinning changes in vital signs. Here, the "ABCDE" (Airway, Breathing, Circulation, Disability and Expose/Examine) and "ISBAR" (Identity, Situation, Background, Assessment and Recommendation) mnemonics provide frameworks to guide nurses in assessing, managing, and reporting on patients' deterioration. Specifically, the ABCDE mnemonic encourages a systematic approach to recognizing and responding to deteriorating ward patients. The ISBAR mnemonic provides a structured communication tool for nurses to report on patients' deterioration. A panel of national experts developed an evaluation tool that assessed the suitability of tasks to be performed by ward nurses in response to patient deterioration. The learning tasks were adapted from this evaluation tool. An international panel of nursing and medical experts further validated the evaluation tool [21].

Learning Context

An educational program using simulation was implemented in a Singapore acute care hospital to support early recognition of and intervention in patient deterioration. Despite the benefits of simulation training, there are logistical and resource issues in implementing this kind of training for a large group of nurses. Nurse educators and hospital administrators highly recommended an alternative effective learning strategy that can overcome these difficulties and be accessible to all the hospital nurses.

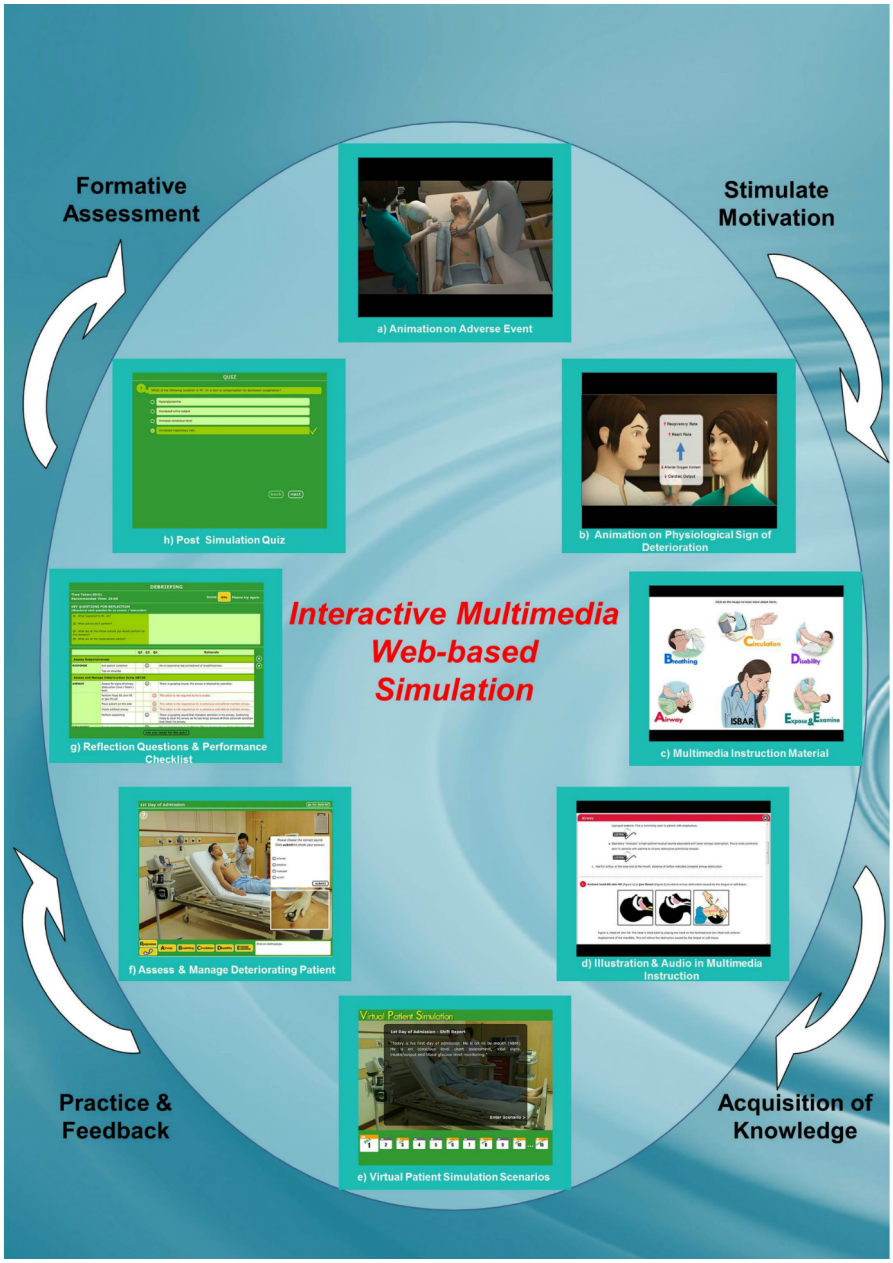
Strategy

Overview

The learning objectives guided the development of the learning content. As shown in Figure 1, the content delivery sequence includes four key events: (1) stimulate motivation, (2) acquisition of knowledge, (3) practice and feedback, and (4) formative assessment (see Multimedia Appendix 1 for a video). These are facilitated through a variety of instructional activities including animation video, multimedia instructional material, virtual patient simulation, and online quizzes.

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Figure 1. Instructional activities in Web-based simulation.



Stimulate Motivation

To arouse the learners' motivation to learn, a narrative about a patient experiencing an adverse event (cardiopulmonary arrest) is presented through an animation video. The narrative highlights that such an event can be prevented through the early recognition of patient deterioration (Figure 1a).

Acquisition of Knowledge

Information about the underlying physiological signs of patient deterioration is presented in an animation showing two nurses in conversation (Figure 1b). Onscreen text and illustrations are used to explain the tasks involved in assessing, managing, and reporting on the acutely ill patient. These performance steps are organized using evidence-based mnemonic strategies (Figure 1c). The ABCDE mnemonic is employed to help organize the steps of assessing and managing the deteriorating patient, while the ISBAR mnemonic is used to show the steps for reporting on the deteriorating patient. Rationales from evidence-based practice on these steps are elaborated to help learners understand why these steps are important as well as how to understand them. Illustrations and audio lung sounds are employed to assist users in understanding the facts (Figure 1d).

Practice and Feedback

Virtual patient simulation is designed to give learners the opportunity to gain practical experience related to the information being learned. Common deteriorating conditions (ie, airway obstruction, breathlessness, hypotension, tachycardia, oliguria, altered consciousness, and abnormal temperatures) associated with acute medical conditions are embedded in five simulation scenarios pertaining to events occurring on different days of the virtual patient's admission (Figure 1e). In each scenario, the learner emulates the role of a nurse assessing and managing the deteriorating virtual patient by selecting actions from the ABCDE control menus. Immediate feedback, including

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physiological changes, is programmed into the system to respond to the learner's actions. ISBAR control menus are used to aid learners in reporting on the virtual patient's deterioration (Figure 1f). At the end of each scenario, the learners are asked debriefing questions to help them reflect on their experiences. In addition, using an evaluation tool, the learners receive feedback on the appropriate and inappropriate actions taken in the simulation scenario (Figure 1g).

Formative Assessment

Formative assessment is seamlessly integrated with the simulation activity. The learners' performances in each scenario are scored using a validated evaluation tool. Multiple-choice questions related to each simulation scenario are constructed to assess learners' knowledge of the subject content (Figure 1h).

Evaluation

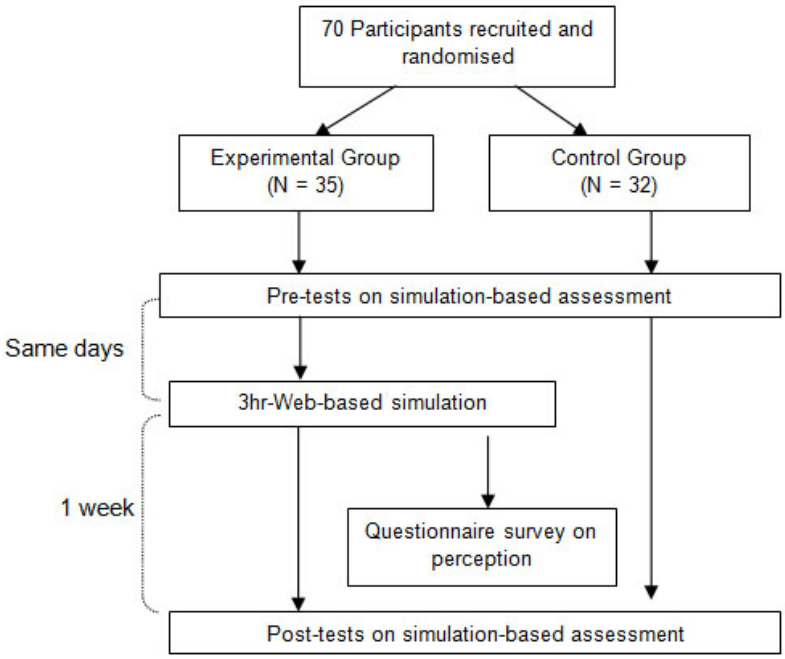
Design and Sample

A prospective, randomized controlled trial (RCT) with a pretest-posttest design was conducted from November to December 2013. The National University of Singapore Institutional Human Research Ethics Board approved the study. A total of 70 registered nurses, with less than 5 years of work experience and who were working in general ward units, were recruited from an acute care tertiary hospital in Singapore. A sample of 60 participants (30 from each group) was considered adequate to achieve statistical power at the 5% level of significance [20]. Allowing for an attrition rate of 10%, a total of 35 participants were recruited to each arm. They were randomly assigned to an experiment group (N=35) and a control group (N=35) using a computerized random number generator. However, three participants from the control group did not turn up for the study, leaving that group with 32 participants. All participants were given a participant information sheet that explained the purpose of the study.

Procedure

Figure 2 depicts the flow of the study procedure. All participants completed a questionnaire on demographic information. The participants undertook a performance pretest consisting of a simulation-based assessment that took place at the university simulation laboratory. They hid their identities from the raters by putting on caps, gowns, and masks. Following an orientation to the simulation set-up, each participant was given a test scenario with the patient simulator displaying signs and symptoms of clinical deterioration. Each participant was given 15 minutes to assess and manage the deteriorating patient simulator. The entire simulation process was recorded on video. Immediately after the performance pretest, the participants in the experimental group were brought individually into a room with a computer set-up to undertake a 3-hour Web-based simulation. After completing the learning, the participants were asked to complete a questionnaire to evaluate their perception of the Web-based simulation. About a week after the pretests and intervention, the participants from both groups were scheduled to undertake the performance posttests on simulation-based assessment individually, which were similar to the performance pretests.

Figure 2. Flow of data collection.



Data Collection and Instruments

Research staff observed and rated the recorded performance using a validated tool known as the RAPIDS (Rescuing a Patient in Deteriorating Situations) tool. The psychometric properties of the RAPIDS tool, including content and construct validity, and interrater reliability were tested and supported in a previous study [21]. Of the recorded videos, 30% (20/67) were randomly selected in this study for rerating by another member of the research staff. There was excellent interrater reliability between

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the 2 raters, with a high intraclass correlation coefficient (ICC) of .98 (95% CI 0.95-0.99).

An 18-item scale with four subscales (system quality, information quality, user satisfaction, and net benefit) was administered to explore the participants' perception of the Web-based simulation. This scale was adapted and modified from the e-learning systems success (ELSS) scale [22]. The study obtained a high internal consistency of this scale with Cronbach alpha at .97. Two questions were added to allow for open-ended comments.

Data Analysis

Descriptive statistics were computed for the demographic variable and participants' perceptions of the Web-based simulation. Differences in demographic characteristics between the two groups were examined by a chi-square test and *t* test. Interrater reliability was assessed using ICC. Changes between baseline and posttest scores were determined by a paired *t* test. Analysis of covariance (ANCOVA) was performed to evaluate the posttest scores between groups with baseline scores as a covariate. The comments for the two open-ended questions were coded and analyzed for recurring themes.

Results

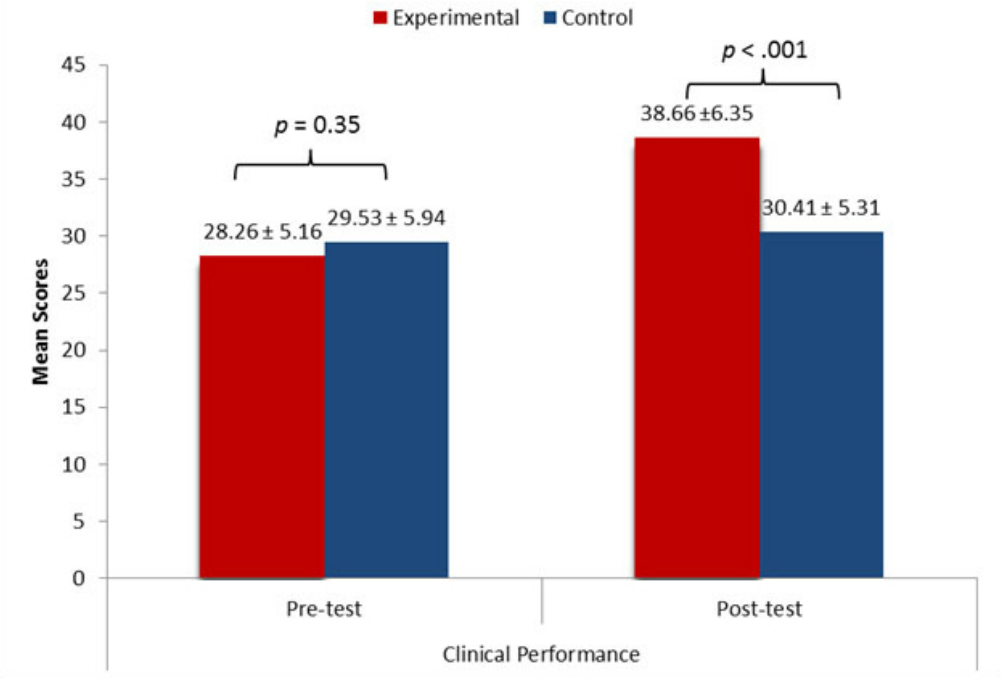
Most of the participants were female (97%) and Chinese (62.7%), with an average age of 25.58 years (SD 3.19). Demographic characteristics including gender (P=1.00), ethnicity (P=.98), age (P=.12), years of work experience (P=.10), and highest qualification (P=.40) were similar for both groups of participants. This supported the randomization and homogeneity of the participants between the groups.

Figure 3 shows that the clinical performance pretest scores did not differ significantly between the experimental and control groups. Within the groups, the clinical performance posttest scores for the experimental group were significantly higher than the pretest scores (P<.001). No significant difference was found between the clinical performance pretest and posttest scores for the control group. Between-group comparisons found significantly higher clinical performance posttest scores (P<.001) for the experimental group than the control group after controlling the pretest scores.

The mean scores from the participants' rating (experimental group) on the 7-point scale indicated that that they were highly satisfied with the Web-based simulation (mean 6.00, SD 0.79), positive about the quality of the system (mean 6.04, SD 0.68) and information (mean 5.13, SD 0.62), and thought highly of the net benefits (mean 6.11, SD 0.71) of the program.

Three themes with categories emerged from the written comments on the most valuable aspects of the Web-based simulation: (1) relevance to practice as it provides useful information (ie, "provide specific information which is very useful for us nurses") and allows application in a practice setting (ie, "can apply in real-life situation"), (2) instructional strategies including animation, e-simulation, and mnemonics (ie, "ABCDE and ISBAR" make it simple and clear to understand") fostering problem solving through knowledge gained (ie, "understand the signs and symptoms of early deterioration"), and (3) the use of critical thinking (ie, "utilizes critical thinking to choose appropriate nursing assessment and intervention"). Three main themes emerged on ways to improve the WBL program: more variation, more information, and technical features.

Figure 3. Pretests and posttests scores on clinical performance.



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Discussion

Principal Findings

This randomized controlled study provided evidence of the effectiveness of a Web-based simulation in improving hospital nurses' acute care competencies. The development of these competencies required the hospital nurses to apply and integrate a broad range of knowledge, skills, and attitudes. In this study, we developed a Web-based simulation that provided opportunities for the learners to work on authentic nursing activities in an authentic learning environment. Authentic activities are tasks learners perform in solving real-life problems [23]. An authentic environment resembling a hospital ward was developed to enhance the learning experience. By providing a context that reflects the way knowledge and skills will be used in actual life, the authentic learning environment stimulates the learners to develop competencies relevant to their working lives [24].

Apart from real-world relevance, a variety of instructional strategies that were drawn from instructional design models were incorporated into the Web-based simulation to develop the nurses' clinical competencies. The nurses valued the instructional strategies as well as the problem-solving skills fostered through the learning process. The learning process applied theories from a range of fields including cognitive overload, motivation, and multimedia learning, The process began by stimulating the learners' motivation followed by the acquisition of factual knowledge of the learning tasks using multimedia such as animation video, texts, audio, and illustrations. The importance of incorporating a variety of activities to gain and sustain learner attention was identified as a key element in a motivation model of instructional design [25]. The acquisition of factual knowledge was supported by the use of mnemonics (ABCDE and ISBAR) to assist the learners with mental models and cognitive aids [26].

Drawing on the experiential learning theory [27], the virtual patients in the Web-based simulation provided opportunities for the learners to apply their knowledge through practice in multiple scenarios. Each scenario involved the application of knowledge to problem solve the deteriorating virtual patient by collecting and integrating patient assessment data to arrive at a nursing diagnosis and provide nursing interventions. The use of virtual patients in professional health education has been attributed to the development of clinical reasoning [28-30]. The outcome of this study sheds light on the effectiveness of applying several instructional design strategies based on tested theories in the acquisition of clinical competency. This calls on educators to apply these strategies in the design and implementation of e-learning.

Our findings are consistent with several previous studies that demonstrated the effectiveness of WBL in improving learning outcomes when compared with no intervention [9,31]. Although evidence from previous studies did not indicate the superiority of WBL over other non-computer training methods, it has been shown to be at least as good as, if not better than, instructor-led methods [32] including mannequin-based simulation [15]. Our study demonstrated that, with advances in multimedia, the features of mannequin-based simulation can be built into the Web-based simulation through the use of virtual patients. A systematic review identified that the use of instructional design features including interactivity, practice exercises, repetition, and feedback can favorably influence learning outcomes [32]. These features, which are also used in mannequin-based simulation, were employed in the design of the virtual patients. Learners had the opportunity to engage with the virtual patient in multiple and varied scenarios to enable them to gain repetitive practice. The ability to give various types of feedback, including verification (eg, verifying the learners' actions) and elaborated feedback (eg, elaborate explanation-style feedback), was incorporated into the design of virtual patients. "Deliberate practice with multiple examples and feedback" has been highlighted as the best approach to the acquisition of clinical competency [33]. Hence, it is evident that the virtual patient in this Web-based simulation has a significant impact on improving the learners' clinical competency.

Participants' positive evaluation of the Web-based simulation, along with improvement in their learning outcomes, is consistent with research findings relating to the efficacy of mannequin-based simulation in acute nursing care training [2,3]. However, compared with mannequin-based simulation, Web-based simulation would be a viable option in institutions where large numbers of learners have to be trained. Given the requirements for simulation facilities, facilitators, and small-group learning, mannequin-based simulation has constraints in providing scalable and sustainable training [34]. In contrast, Web-based simulation allows repetitive training, which is absolutely essential for achieving long-term retention of clinical competency [7]. Although Web-based simulation has fewer constraints than mannequin-based simulation, it should not be seen as a substitute for mannequin-based simulation. Unlike Web-based simulation, mannequin-based simulation provides "hands on" kinesthetic learning in a realistic and dynamic situation, which is considered to prepare nurses well for their real-life work. Both are different learning strategies but could be used as complementary learning tools, forming part of a blended-learning strategy to optimize clinical competency gains [7,35].

Strengths and Limitations

A rigorous research methodology, RCT, was used to evaluate the learning outcomes. However, the quality of the evidence could be limited by the no-intervention control group. Given that this study is looking at the development of a new WBL program for hospital nurses, the no-intervention controlled study is still considered valuable in the early stages of an innovation. The survey evaluation, particularly the qualitative data, shed light on the value of the program and ways to enhance it. Comparisons of other WBL instructional designs could be conducted in future studies to enhance the program in the future. We tested the learners' clinical performances using a validated and tested instrument. However, due to logistic constraints, we did not measure the long-term retention of clinical performances, which can deteriorate over time. Future studies could evaluate this competence over a longer period of time. The present study may have shown the effectiveness of Web-based simulation in the context of transferring learning from the Web-based to the

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simulated environment. Moving forward, future studies could determine the higher-order outcomes of the program on actual clinical practice by evaluating nurse behaviors in practice and their effects on patient care.

Conclusions

Changes in health care delivery mean that nurse educators need to ensure the competency of all hospital nurses in acute nursing care for optimal patient care outcomes. In this study, we described how Web-based simulation can be effectively implemented to create an authentic nursing activity for developing hospital nurses' competencies in acute nursing care. A broad array of instructional strategies based on tested theories, including animation video, multimedia instructional material, virtual patient, and online quizzes, were incorporated into the interactive multimedia Web-based simulation. Using a randomized controlled study, we demonstrated the effectiveness of the Web-based simulation in developing nurses' clinical competencies. This study provides evidence for the acceptance of this Web-based simulation for continuing nursing education among hospital nurses. Nurse educators can use Web-based learning technology to improve the efficiency and effectiveness of educational intervention in the face of pedagogical challenges, especially those posed by mannequin-based simulation. More research is needed to inform the effective use of Web-based simulation by aligning and optimizing its use with other educational technologies, as part of a blended-learning strategy.

Acknowledgments

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Conflicts of Interest

The first author is the owner and developer of the simulation software.

Multimedia Appendix 1

Multimedia interactive Web-based simulation.

[MP4 File (MP4 Video), 8MB - jmir_v17i1e5_app1.mp4]

Multimedia Appendix 2

CONSORT-EHEALTH checklist V1.6.2 [36].

[PDF File (Adobe PDF File), 983KB - jmir_v17i1e5_app2.pdf]

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Abbreviations

ABDCDE: Airway, Breathing, Circulation, Disability, and Expose/Examine
ANCOVA: analysis of covariance
ELSS: e-learning systems success
ISBAR: Identity, Situation, Background, Assessment, and Recommendation
RAPIDS: Rescuing a Patient in Deteriorating Situations
RCT: randomized controlled trial
RN: registered nurse
WBL: Web-based learning

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Original Paper

Knowledge Translation in Men's Health Research: Development and Delivery of Content for Use Online

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Abstract

Background: Men can be hard to reach with face-to-face health-related information, while increasingly, research shows that they are seeking health information from online sources. Recognizing this trend, there is merit in developing innovative online knowledge translation (KT) strategies capable of translating research on men's health into engaging health promotion materials. While the concept of KT has become a new mantra for researchers wishing to bridge the gap between research evidence and improved health outcomes, little is written about the process, necessary skills, and best practices by which researchers can develop online knowledge translation.

Objective: Our aim was to illustrate some of the processes and challenges involved in, and potential value of, developing research knowledge online to promote men's health.

Methods: We present experiences of KT across two case studies of men's health. First, we describe a study that uses interactive Web apps to translate knowledge relating to Canadian men's depression. Through a range of mechanisms, study findings were repackaged with the explicit aim of raising awareness and reducing the stigma associated with men's depression and/or help-seeking. Second, we describe an educational resource for teenage men about unintended pregnancy, developed for delivery in the formal Relationship and Sexuality Education school curricula of Ireland, Northern Ireland (United Kingdom), and South Australia. The intervention is based around a Web-based interactive film drama entitled "If I Were Jack".

Results: For each case study, we describe the KT process and strategies that aided development of credible and well-received online content focused on men's health promotion. In both case studies, the original research generated the inspiration for the interactive online content and the core development strategy was working with a multidisciplinary team to develop this material through arts-based approaches. In both cases also, there is an acknowledgment of the need for gender and culturally sensitive information. Both aimed to engage men by disrupting stereotypes about men, while simultaneously addressing men through authentic voices and faces. Finally, in both case studies we draw attention to the need to think beyond placement of content online to delivery to target audiences from the outset.

Conclusions: The case studies highlight some of the new skills required by academics in the emerging paradigm of translational research and contribute to the nascent literature on KT. Our approach to online KT was to go beyond dissemination and diffusion

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to actively repackage research knowledge through arts-based approaches (videos and film scripts) as health promotion tools, with optimal appeal, to target male audiences. Our findings highlight the importance of developing a multidisciplinary team to inform the design of content, the importance of adaptation to context, both in terms of the national implementation context and consideration of gender-specific needs, and an integrated implementation and evaluation framework in all KT work.

(J Med Internet Res 2015;17(1):e31) doi:10.2196/jmir.3881

KEYWORDS

men's health; knowledge translation; development of online content

Introduction

Background

The term Knowledge Translation (KT), as conceptualized by the Canadian Institutes of Health and Research (CIHR) in 2000, describes the dynamic interaction between researchers, health care providers, policy makers, and end-users in applying research evidence in practice. While the terminology and definitions of KT vary somewhat across the English-speaking world (eg, [1-3]), the underlying philosophy implied is similar [4]. Its fundamental aim is to move research evidence into action [5] in order to narrow the gap between what is known from research and knowledge syntheses and the implementation of this knowledge by key stakeholders [6].

The field of KT is a young science that is fuelled by the desire of the custodians of public funding to more clearly demonstrate the added value of scientific research for the citizens of society. While this nascent science has much to learn from the more well-established science of intervention design and implementation [7], KT is broader in scope. KT is intended to be the business of all academics, and the activities of KT stretch across the continuum from the development of initiatives for improved and wider dissemination of research beyond academic audiences through to the embedding of new policies and practices in fields such as industrial design, constitutional design, or as in our case, health promotion.

The application of new information communication technologies opens up new mechanisms for knowledge transfer and for breaking down the traditional asymmetry between expert and lay health communication [7,8]. The combined application of information communication technologies to KT is referred to as Technology-Enabled Knowledge Translation (TEKT) [9-11], or more simply e-KT [12]. Ho et al [10] explain how technology can function as a medium for delivery of health research (eg, websites, podcasts, and video conferences) and for evaluation (eg, discussion boards and online surveys). This also includes mobile health, or mHealth, which is the use of mobile tools in distributing health information and accessing health services [13,14]. The shift in the online environment from a passive, unidirectional "read-only" information distribution to a more engaged, multidirectional communication has contributed to its growing popularity (eg, [15-19]). This interactive shift has also led to the emergence of Health Web Science [20], which is not only concerned with how the Web is used for health-related purposes, but also the study of the impact of the Web's health-related uses on the design, structure, and evolution of the Web itself.

The online environment has particular relevance in the field of men's health, where historically research has shown that men are less likely to attend primary health care services than women (especially for mental or sexual health problems), yet remain interested in health [21]. While it is acknowledged that men are diverse, researchers have consistently demonstrated that a pervasive aspect of masculinity is a belief that a man's body and mind should remain strong. This can create cultural barriers to male help-seeking in relation to both mental and physical ill health [22,23]. It is thought that the Internet may have particular appeal for men as a means of help-seeking that does not compromise masculine norms, such as stoicism, and complements their needs for privacy and convenience [24], in large part, because of the private nature and accessibility of electronic mediums [25]. However, the Internet can also be a brokering mechanism to open up help-seeking in relation to health matters [24]. For example, many men use the Internet to access health information in order to maximize the quality of their own care [26-30], and increasingly, both men and women are demanding greater involvement in decisions surrounding their health care [7,19,20].

Despite their promise, however, Internet technologies have not been used to their highest potential for KT on a widespread basis [31-33]. There remains little clear guidance on how to present health-related knowledge online in a way that facilitates understanding among end-users [19,20]. In addition, we know little about how academic researchers, in particular, develop the skills required for successful implementation of online KT strategies or how researchers and stakeholders might work together to ensure maximum impact in this regard. The challenge for many academics faced with such a myriad of new Internet-based technologies is the simple question: What are the strategies I can use to develop the content of my research for lay audiences using Internet-based technologies?

The aim of this paper is to chronicle KT processes used in two distinctly different online case studies in the field of men's health, delivered in different countries. The case studies we offer share the common ground of aiming to develop content specifically for men's health promotion and both broadly adopt arts-based approaches to the development of online content using video and film production based on original qualitative research. The primary differences in the case studies is that one (the Men's Depression: Help Yourself website) is entirely Web-based and the other (If I Were Jack) is not. The latter case study uses an online environment to deliver content into school classrooms. We further understandings of the science of KT by focusing specifically on the design of content for interactive online delivery. Together, the case studies give insight into

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some of the richness of different methods and approaches while drawing out the broader principles learned. There is currently a dearth of literature that can give other researchers an understanding of some of the choices and challenges behind the online pages that are available to view and a better understanding of how the findings of academic and publicly funded research can be better communicated to the public and used for health promotion.

The structure of the remainder of the paper is as follows. We begin by briefly summarizing some models of KT. We then outline the two case studies, broadly based on one model of KT. We focus on specific choices and decisions reached before drawing conclusions about the benefits and challenges of developing content for interactive online delivery in the field of men's health—as a means to guiding the future efforts of others. In the discussion section, the processes, practices, and challenges experienced across the case studies are compared and contrasted, illuminating the value of the Internet as a platform for KT in the field of men's health.

Models of Knowledge Translation

A number of KT models exist (eg, [5,34]), and most agree that the process should begin with identification of the "gap" between evidence and practice and an analysis of the potential barriers and facilitators of successful KT [32]. Ideally, this evidence should come from quality practice guidelines, systematic reviews, and knowledge syntheses [35] and additionally should engage relevant stakeholders in needs assessment. Indeed, a central underlying feature of KT is the involvement of all important stakeholders (including policy makers, practitioners, and end-users) so that they have shared ownership of the research agenda and KT process [36]. A further key principle following the influence of systems thinking [37,38] is an awareness that the interpretation of information and knowledge is contextually influenced [39,40]. Context-based barriers to KT include issues such as time constraints of end-users, readiness for implementation, and lack of compatibility between the intervention and context.

Graham et al's integrated KT model [5] is useful in that it presents a "road-map" for those interested in KT from academic research. The process can be summarized into three phases of the knowledge-to-action cycle: (1) Knowledge creation involving background research and knowledge synthesis followed by the design and development of the content, (2) Application of knowledge: adaptation, implementation, and initial evaluations, and (3) Sustainability: How the knowledge can reach the target audience and lead to changes in practice over the medium to longer term. Below we describe how our KT case studies map onto this model before describing some lessons learned through content development.

Methods

Case Studies

Case Study 1: The "Men's Depression: Help Yourself" Website

Overview

The "Men's Depression: Help Yourself" (MDHY) website [41] was built with the aim of providing an engaging and interactive online resource focused on men's depression management. The primary goals were to repackage and share findings drawn from a research program addressing masculinities and men's depression as a means to (1) support men who experience depression and their families, (2) inform health care providers about how best to identify and treat men's depression, and (3) raise public awareness and de-stigmatize men's depression. Given the dramatic increase in the uptake of eHealth resources [42-44], population increases in Canadian-based residents' daily Internet use (ie, increased from 68 to 80% between 2005 and 2009 [45]), and data indicating that 61% of North American mobile phone owners use smartphones [46], we were excited by the prospects of better understanding how men's mental health promotion and depression management could be advanced online.

Knowledge Creation: Background Research, Knowledge Synthesis, and Content Development

The rates for diagnosed depression are steadily increasing worldwide [47-49], and depression has become a public health concern that is known to significantly increase the risk for suicide [50-52]. In Western countries, men are diagnosed with depression at half the rate of women [53]. Yet, suicide rates for men are up to four times higher than for women [54,55]. Emergent research suggests that the lower reported rates of depression among men may be due to the widespread use of generic diagnostic criteria that are not sensitive to men's depression [56-58] as well as men's reluctance to express concerns about their mental health and seek professional health care services [59,60].

This discordant relationship between men's low rates of depression and high suicide rates prompted our interest to examine the connections between masculinities and men's depression. Since 2007, we have conducted a series of qualitative research studies with the overarching goal to better understand men's depression across men of varying ages. Individual interviews with 120 participants (26 college men, 38 middle-aged men and 26 female partners, and 30 older men) revealed an array of experiences linking masculinities and men's depression, and these findings were chronicled in peer-reviewed journal articles [61-67].

While these publication-based KT efforts constitute dissemination, whereby findings were shared with a broad audience (albeit primarily academics and professionals), we were hopeful that by strategically using interactive Web strategies, we could move toward application [5] through targeting men concerned about depression to raise awareness of our findings and men's depression more generally. Hence,

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the MDHY website invites men to "help themselves" as well as reduce stigma and support recovery among men who experience depression.

In an effort to transition our findings toward men-centered interventions, we secured a 1-year end-of-grant KT grant from CIHR (grant# 11R67284). This funded the planning, design, and development of the site, which was launched on May 1, 2013. Based on evidence that interactive Web apps can facilitate engagement online by supporting group interactions and fostering a greater sense of community [68], we incorporated streaming videos, podcasts, online brochures, evites, and a blog to bolster our KT efforts. The site content is accessible from an array of interfaces (eg, personal computers, mobile phones, tablets). Specifically, our overarching aim, to design and develop an interactive KT website, included the development of video clips of 3-4-minutes featuring 10 participants (men who experienced depression, health care providers); journal article author podcasts; interactive plain language booklets to highlight the specific study findings related to college, middle-aged, and older men; e-postcards to invite people to visit the website; and a blog where registered participants could participate by posting comments.

The knowledge synthesis of this background research involved identifying salient experiences related to depression represented in our findings and drawing on principles of men's health promotion that we had distilled from our ongoing research [67]. We summarized key findings in the brochures and also conducted video interviews with health care providers and individuals experiencing depression to solicit their views about specific articles and findings drawn from our research.

The use of video clips was a purposeful focus to reduce the amount of text and introduce diverse perspectives from both those who experience depression and those who treat men's depression. We were influenced to include authentic testimonials based on evidence that men respond positively to the sharing of others—especially when they are not themselves under explicit pressure to reciprocate [67]. Bearing this in mind, we captured and edited head and shoulder footage to distil key perspectives about experiencing, as well as treating, men's depression. All participants were invited to read and respond to some questions related to specific papers detailing findings drawn from the research. Video participants were sourced through researchers' professional and personal contacts and by contacting participants from earlier men and depression projects (2007-2011) who had agreed to be contacted about future studies. This approach enabled video participants to talk about their perspectives in relation to what others had said and the results of the studies. In this way, opportunities were afforded to participants to differ from, align with, refute, or resonate with what they had read—all as a means to sharing their experiences. This strategy is also known to elicit talk from men who otherwise might be uncertain about the value of such conversations or disclosures [69].

Application of Knowledge: Adaptation, Implementation, and Evaluation

Reflecting the substudies in the men's depression research program, we disaggregated the findings via age groups comprising (1) college men, (2) middle-aged men, and (3) older men as a means of guiding visitors toward the content most relevant to them. Within this context, short videos relating to the men's experiences and treatment of specific subgroups were bundled and housed under the video tab. Recognizing that a webpage filled with thumbnail images of videos might be off-putting, we also developed e-brochures for each of the age-based subgroups embedding media such as the relevant videos and author podcasts. We also included a "help yourself" button that linked to the videos and our YouTube channel, which also hosted the videos. In offering an array of entry points to view the videos, we hoped to overcome any navigation issues and maximize the exposure of the videos. In terms of evaluation, we were, for the most part, reliant on Google Analytics to draw conclusions about the acceptability of the online content. So, rather than being able to report behavior change or influence exerted by the content, we could describe only the traffic to the site, hypothesizing and comparing the usefulness of the content. In briefly summarizing some of those findings below, we acknowledge the limitations of what can be reasonably claimed.

In the first 12 months (May 2013 through April 2014), there were a total of 4913 visits, resulting in 13,989 page views. Of these visits, 72.64% (3569/4913) were new visits, and the average duration of these visits was 2:52 minutes with a bounce rate (ie, visitors leaving the website directly from the home page) of 53.90%. Direct traffic (ie, visitors typing in the website address because they heard about it) led to a third of visits (32.46%, 1595/4913). Search engine keyword searches accounted for 35.92% of visits (1765/4913) and 31.61% (1553/4913) were referred via other websites (eg, a university men's health research website [70]) and social media. In terms of the geographical locale (see Figure 1), most of the visits originated from Canada (63.10%, 3100/4913), the United States (17.36%, 853/4913), the United Kingdom (8.30%, 408/4913), and Australia (3.54%, 174/4913)—all English-speaking countries.

The depth of visit as indicated by the page views revealed an average of 2.9 page views per visit. In terms of visitor loyalty, over a quarter of visitors (27.35%, 1344/4913) of visitors returned to the site more than once. This suggests that the site content was somewhat engaging. The most viewed pages were the homepage (31.28%, 4377/13,989), middle-aged men's page (12.75%, 1784/13,989), followed by the study page (6.60%, 924/13,989). Our blog page was viewed 588 times. Of 33 blog posts, "men's help seeking for depression—why they do and don't" generated the most interest; while we received ten comments to our blog posts. In addition, while the evite page was viewed 149 times, only four evites were sent. Perhaps this indicates that visitors used other means to share content through our Facebook or Twitter options, or perhaps the stigmatized representation of depression, as noted earlier, impeded the communication of invitations to others to join in the conversation on the presented materials.

The 72 videos were viewed 11,709 times in total, and only 970 (8.28%) of these views took place on the MDHY website. The majority (91.71%, 10,739/11,709) took place on our YouTube site/channel (see Figure 2), and 70.74% (7597/11,709) of the YouTube views were made by men 18 years and older (sourced

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through viewers being logged into their YouTube account at the time of watching). The three most popular videos were the "Men's depression and recognizing symptoms" (17.47%, 2046/11,709), "Men's depression and work" (6.17%, 723/11,709), and "Anger and aggression as depressive symptoms" (6.15%, 720/11,709). The podcast page was visited 601 times; yet the 11 podcasts were accessed only 367 times in total. The "Depression, men and masculinities: A review and recommendations" (19.9%, 73/367) and "Masculinities and men's depression in a northern resource-based Canadian community" (13.6%, 50/367) were the most popular podcasts. In total, the three online brochures were read 1327 times, specifically, College Guys (24.64%, 327/1327), Middle-aged Men (53.96%, 716/1327), and Older Men (21.40%, 284/1327).

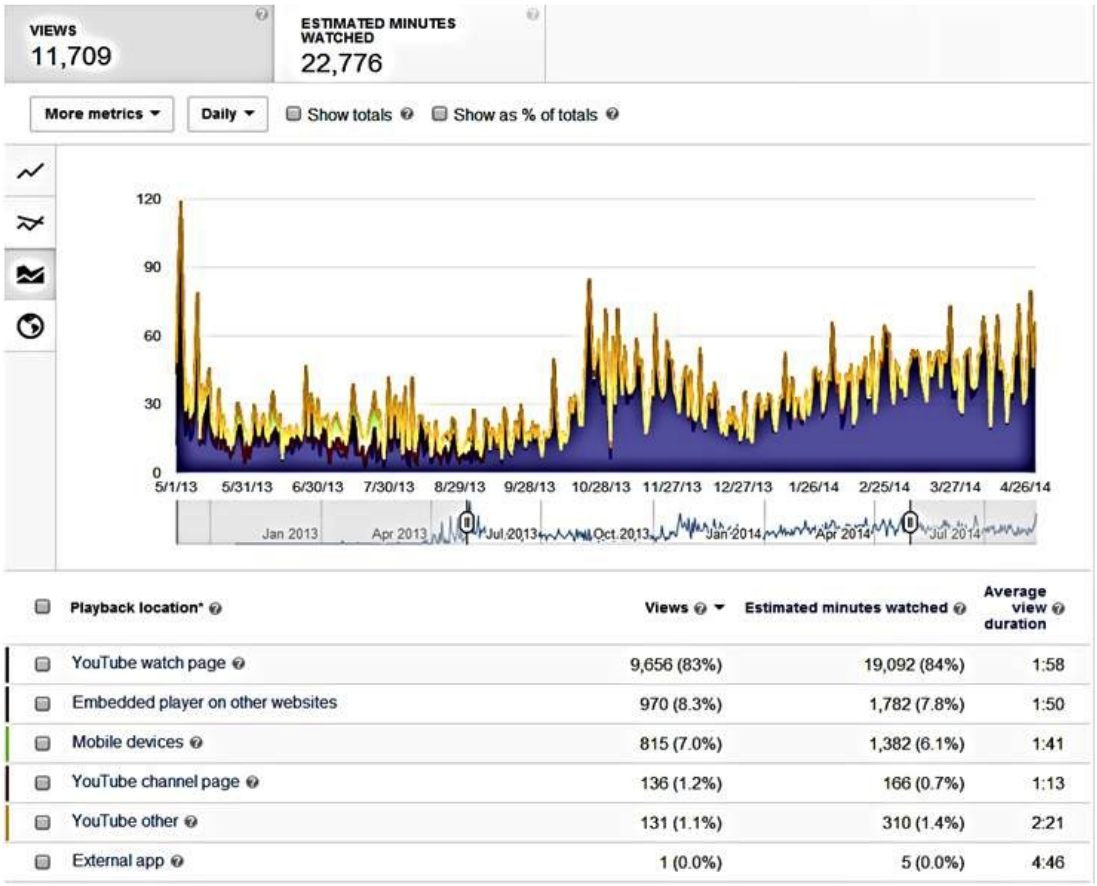
In summary, the website did seem to attract men more than women. While all the media platforms used in the MDSY website have the same principle of sharing information and raising awareness of men's depression, the popularity of our short series of composite videos featuring men's narratives and reflections was evident, and this finding is consistent with the findings of other research addressing men's use of the Internet for health promotion [26-30]. That said, some visitors also read the website content more deeply, for example, by accessing the online brochures. This suggests some benefit to providing a range of avenues to access content as a means to broadening the appeal and reach of the website.

Figure 1. Visitors' pathways by geographic locale.

Country / Territory	Acquisition			Behavior		
	Sessions ↓	% New Sessions	New Users	Bounce Rate	Pages / Session	Avg. Session Duration
	4,913 % of Total: 100.00% (4,913)	72.64% Site Avg: 72.18% (0.65%)	3,569 % of Total: 100.65% (3,546)	53.90% Site Avg: 53.90% (0.00%)	2.85 Site Avg: 2.85 (0.00%)	00:02:52 Site Avg: 00:02:52 (0.00%)
1. Canada	3,100 (63.10%)	63.19%	1,959 (54.89%)	42.68%	3.44	00:03:24
2. United States	853 (17.36%)	90.50%	772 (21.63%)	74.21%	1.92	00:02:25
3. United Kingdom	408 (8.30%)	87.25%	356 (9.97%)	70.34%	1.86	00:01:36
4. Australia	174 (3.54%)	91.38%	159 (4.46%)	75.29%	1.65	00:01:02
5. Ireland	34 (0.69%)	64.71%	22 (0.62%)	88.24%	1.24	00:00:12
6. India	31 (0.63%)	90.32%	28 (0.78%)	58.06%	1.81	00:01:27
7. New Zealand	28 (0.57%)	78.57%	22 (0.62%)	57.14%	2.07	00:02:11
8. Japan	26 (0.53%)	61.54%	16 (0.45%)	46.15%	3.58	00:03:33
9. Germany	18 (0.37%)	94.44%	17 (0.48%)	94.44%	1.06	00:00:05
10. Philippines	17 (0.35%)	94.12%	16 (0.45%)	82.35%	1.29	00:00:04

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Figure 2. Youtube playback locations.



Playback location*	Views	Estimated minutes watched	Average view duration
YouTube watch page	9,656 (83%)	19,092 (84%)	1:58
Embedded player on other websites	970 (8.3%)	1,782 (7.8%)	1:50
Mobile devices	815 (7.0%)	1,382 (6.1%)	1:41
YouTube channel page	136 (1.2%)	166 (0.7%)	1:13
YouTube other	131 (1.1%)	310 (1.4%)	2:21
External app	1 (0.0%)	5 (0.0%)	4:46

Sustainability

While sustaining the use of the MDHY website has been supported in part via social media and other outreach strategies to bring men, families, and health care providers to the site, keeping the site fresh with new information and resources is more challenging without recurrent budget. This work, however, laid an important foundation for extending approaches to address men's depression and suicide [70]. In collaboration with both academic and non-academic partners, a successful Movember grant application has enabled us to extend the online men's depression help resources.

Case Study 2: The Development of an Internet-Based Interactive Video Drama on Teenage Men and Unintended Pregnancy for Implementation Within School Curricula

Overview

"If I Were Jack" is a research-informed, culturally sensitive educational resource especially targeting teenage boys to increase their awareness and intentions to avoid an unintended pregnancy. This Internet-based intervention is designed for delivery within sex education or relationship and sexuality education (RSE) in second-level schools to boys as well as girls who are at least 14 years of age. The project website [71] hosts online versions of the resource materials (freely accessible to participating schools) and promotional material including expert videos and practitioner podcasts, which aim to increase the credibility of the resource with users, specifically teachers, young people, and parents. The resource is currently being rolled out in schools in Ireland by the Department of Education, and an Australian version is being used in South Australia by Shine (RSE provider). In Northern Ireland, the acceptability and feasibility of nationwide roll-out is undergoing further investigation through a feasibility cluster randomized controlled trial (trial registration NCT02092480).

Knowledge Creation: Background Research, Knowledge Synthesis, and Content Development

The educational resource was developed in response to an identifiable deficit of educational resources that address the sexual health needs of young men [72-77]. Young men are much less likely to receive pregnancy-related RSE, and when they do receive it, they are likely to encounter interventions that are not specifically designed for them [55].

The research knowledge for this KT project began with a systematic review of the literature on adolescent men's attitudes and decision making in relation to an unintended pregnancy [78]. This was followed by primary research with young men in Ireland examining the psychosocial determinants of their responses to the hypothetical pregnancy scenario [79] and further qualitative research (interviews and focus groups) with educational specialists, teachers, and young people to scope relevant and appropriate RSE materials [80]. The aim of these studies was to redress the longstanding and widespread gender bias in research and interventions on teenage pregnancy, which reports adolescent women's attitudes and the predictors of their pregnancy resolution choices but largely neglects men's roles

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and perspectives [78]. It built upon earlier comparable research in Australia [81-83] described below. However, effective KT also requires knowledge of change mechanisms, therefore, the final stage of the preliminary research also involved learning about developing effective interventions in the field of RSE [84-90] and underlying models of behavioral change [91-94].

The knowledge synthesis of this background research involved the following steps: (1) clearly articulating the need for an educational resource for teenage men, (2) articulating why the school curriculum might be a good place of delivery and thinking through how online delivery would enhance the reach and accessibility of the resource, and (3) developing material based on our background research. While the first case study was able to use interview data to re-develop it for online content, it was the underlying methodology that provided the inspiration for our content. We had already developed an arts-based approach, that is, an interactive film, as a methodology for data collection in the underlying empirical study [79]. Below, we describe how we went on to specifically further develop this methodology as part of an online educational resource.

The design and development phase was partly funded by a KT grant provided by a UK Economic and Social Research Council knowledge exchange research grant (grant #RES-189-25-0300). Central strategies for ensuring successful KT included close consultation with key stakeholders and a focus on optimizing the credibility of the intervention and its acceptability to users including user gate-keepers such as policy makers, health and education experts, and school management, as well as end-users, teachers, pupils, and parents. During the planning phase, we enlisted project partners from the Departments of Health and Education in two countries/jurisdictions (Ireland and Northern Ireland) that would continue to contribute to the KT process throughout and, as we describe further below, enhanced the overall sustainability of the project. Together we decided on the following goal at the outset: to develop an educational resource for post-primary school pupils aged from 14 years addressing teenage men and unintended pregnancy and suitable for delivery as part of the official curricula of schools in Northern Ireland and Ireland.

Together and gradually over time, we also agreed that the components of the resource would be:

- The If I Were Jack interactive video drama (IVD), which asks pupils to put themselves in Jack's shoes and consider how they would feel and what they would do if they were Jack
- Classroom materials for teachers containing four detailed lesson plans with specific classroom-based and homework activities that include group discussions, role-plays, worksheets, and a parent-pupil exercise
- 60-minute face-to-face training session for teachers wishing to implement the intervention
- 60-minute information and discussion session for parents/guardians delivered by RSE teachers
- Detailed information brochures and factsheets about the intervention and unintended teenage pregnancy in general for schools, teachers, teacher trainers, young people, and parents

In this section, we describe the processes and key choices relating to the first two core components. The production of the Northern Irish and Irish versions of the IVD was based on an earlier Australian version entitled "If I Were Ben" [81]. The Australian research team at Flinders University developed a script for their film by drawing on transcripts of paired and focus group interviews with young men and young women in South Australia on the topic of unintended pregnancy and decision making around keeping the baby and abortion. This original IVD was designed as a research tool for a larger quantitative study [81,82]. While we could have elected to use the Australian version of the IVD, research has suggested the educational advantages of having culturally specific interventions [95] to increase authenticity and to allow for the greatest possibility for young people to identify with the situation. This is also consistent with KT theory, which suggests that knowledge users prefer materials that address their particular realities [33]. Furthermore, our key policy stakeholders, while highly valuing the original Australian IVD, agreed with the merits of a culturally sensitive intervention. We therefore adapted the original script based on consultations with young people in Ireland and Northern Ireland and meetings with our stakeholder partners in the Departments of Health and Education. The main changes arising from the stakeholder meetings were the inclusion of adoption as a third pregnancy resolution option (along with "abortion" and "keep the baby") and advice on how to deal with particular sensitivities around abortion in both countries. For example, in the section where the young people have to consider all the options, we removed the terms "good things" and "bad things" about abortion, keeping the baby, and adoption in favor of the terms "advantages" and "disadvantages". The consultation with young people was centered on young people in socially diverse drama groups and drew on the techniques of interactive and embodied drama of Augusto Boal [96] and the Playback Theatre of Jonathan Fox [97]. Using these techniques, young people acted out and creatively adapted the language and scenes to reflect life in Ireland and Northern Ireland for young people, for example, replacing surfing with soccer and driving cars with riding bikes and introduced nuances to friendship relationships. Using university media services, we then shot the movie using Irish actors recruited from youth drama groups and Irish settings. We shot the film "over the shoulder" of the main character to emphasize the possibility of the participants moving through the actor's world: "You won't see me but you'll see the world through my eyes". Reflecting the importance of culturally sensitive interventions and the historical conflict between Irish and British communities in Northern Ireland, it was necessary to produce Northern Irish and Irish versions using different actors. Excerpts from the IVDs can be viewed on the Jack project website [71].

A further issue that we addressed was the gender-sensitive nature of the intervention. The Australian IVD, when initially developed as a research tool, was for boys only. However, our intervention would be used in mixed-sex classrooms. While we added some questions about the lead female actor: "What might Emma be thinking now?", we retained the focus on the young man's perspective in order to use this counterpoint to problematize some of the gender-divisions on the topic and to

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invite consideration of teenage boys', as well as teenage girls', responsibilities.

We then developed the program for the Web using the university's website content management system to combine videos with basic multiple choice questions. Acting on the advice of project stakeholders and teachers, we disabled the "save" function and background data collection database used in the original research tool. Since the program was being used in schools and due to the sensitive nature of the questions, this was deemed more desirable because it allows young people greater confidentiality. We simultaneously developed paper-based lesson plans to accompany the IVD, which we uploaded to our website. The lesson plans addressed the key learning outcomes of the educational intervention developed through the use of a theory of change logic model and were theoretically informed by the Theory of Planned Behavior [91-93] and the best available evidence regarding RSE practice [84-90]. As these were primarily concerning offline materials uploaded to the Internet, we chronicle the development of these in a separate paper [98].

Application of Knowledge: Adaptation, Implementation, and Evaluation

Inspired by our progress, the Australian research team then also converted their IVD for use as an Internet-based intervention in schools in South Australia by developing a partnership with SHINE SA, the primary providers of sex education in schools in South Australia [99]. Establishing partnerships with RSE providers and, in the case of the Irish and Northern contexts, statutory RSE providers, was deemed crucial to mobilize dissemination off the Internet shelf and to provide universal access to the resource to schools. Thus, in Ireland and Northern Ireland, implementation of this resource means opening up two main gates: the first is the statutory custodians of RSE education (and in both countries, this is a mix of both the Departments of Health and Education). The second is the school gate, which we discuss next.

Despite the fact that RSE is a mandatory subject in post-primary schools, implementation of RSE is known to be low priority in some schools [100]. Thus, we also used the project website to post videos of stakeholder testimonies, podcasts with teachers, and information for parents along with stakeholder logos. In particular, it was important for us to reassure schools with a different religious ethos that although all pregnancy resolution options are discussed, none are presented as optimal and that the resource reflected the legal situation in relation to the availability of abortion in each country. The intervention also allowed schools to express their school ethos in relation to abortion within the context of the overall discussion materials. Finally, in terms of implementation, we sought approval from the custodians of the schools' Internet server in each country to allow schools to access the materials—otherwise the child safety blocks might prevent access. In summary, implementation of this Internet-based resource relied upon it appearing "safe", "sensitive", and "sanctioned".

While the resource will undergo further evaluation in terms of its effectiveness in increasing young people's understanding of the issues as well as increasing their intentions to avoid an unintended pregnancy using randomized controlled trial (RCT) methodology, data from a mixed-methods cross-sectional study confirms that the educational intervention is already achieving key educational and health promotion outcomes. Table 1 presents results based on a sample of 746 boys drawn from a stratified random sample of schools in South Australia and Ireland. These results suggest that nearly three-quarters of the Ireland sample (n=284) and Australian sample (n=271) achieved increased awareness in relation to the issue of teenage pregnancy, and nearly three-quarters in both country samples (n=284 in Ireland; n=266 in Australia) said it helped them to think they should avoid an unintended teenage pregnancy. The key aims of the planned (RCT) evaluation will be to test the feasibility of the intervention for use in different UK contexts and to adapt it as necessary. If the intervention is found to be both acceptable and effective, it has the potential to benefit all pupils aged 14-16 in Northern Ireland and the rest of the United Kingdom.

Table 1. Knowledge-users' evaluation of the impact of the educational resource [83].

Impact on adolescents	Ireland (n=360)	Australia (n=386)
	Strongly agree/agree, %	Strongly agree/agree, %
Got me involved in Jack's/(Ben's) situation	72	60
Made me think about issues I hadn't thought about before	79	70
Helped me understand the effect an unplanned pregnancy would have on a guy like me	85	72
Made me think that I should never get myself in that situation	79	69
Made me aware that I could talk to a counseling service if I were in Jack's situation	84	n/a

Sustainability

Throughout this paper we have referred to collaboration with stakeholders, which we would argue was key, along with having a very sound evidence base, to achieving the degree of sustainability that has been achieved (so far, roll-out through a state provider in Ireland into the curriculum, roll-out through a private provider of RSE in Australia, and further testing of the resource in Northern Ireland). However, it is worth opening up the black box of *how* we collaborated for other researchers interested in KT. While we described underlying research with young people and timed consultations with young people in

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developing this resource, for us the central plank of collaboration was with the statutory stakeholders of RSE. An application to a third body for a KT grant was our reason for talking with key personnel within the Departments of Health and Education in Ireland and Northern Ireland, asking them to come on board and work with us to develop an educational resource suitable for delivery in the curriculum. The "coming on board" also happened incrementally, as one stakeholder recommended another and, in some cases, recruited others. Once the project started, meetings with stakeholders happened face to face twice a year in the university. Once stakeholders were involved, we then fostered a team approach to the development of the resource, making any changes the stakeholders suggested because we recognized them as the experts in implementation. The diverse range of stakeholders from two government departments and two different countries around the table meant that issues raised were debated in the context of conversations between experts rather than as ultimatums for the researchers. In summary, the lessons we learned in terms of recruiting and collaborating with stakeholders are as follows. Collaborating with researchers to produce evidence-based practice resources is a fruitful approach with policy makers. Researchers need to be aware that policy makers, especially statutory policy makers, usually operate in more highly governed workplaces than academics do and authorization for their involvement takes time and effort. Building in travel money for stakeholders may be essential. Face-to-face meetings build trust and, finally, having the stakeholders and not the researchers represent the joint work, for example in online videos, is a signifier of knowledge translation.

Results

Creating Engaging Interactive Materials

In both case studies, the original research generated the inspiration for the interactive online content. While the limitations of qualitative research in changing health practices is often acknowledged [101], a key strength of qualitative research is the ways that it can generate language, imagery, and intonation to meaningfully communicate key health messages to others. In a scoping review of arts-based health research, Boydell et al [102] highlighted that the arts and qualitative research share common ground, recognizing the significance of rich description and the subjective nature of human experience. Bringing these arts-based approaches to online KT to fruition involved a multidisciplinary team of researchers together with video, media, Internet, and drama experts but remained a research-led enterprise. For the MDHY website, content and characters challenged the stigma men can experience talking about depression and/or help-seeking. Videos were made of men who experienced depression and their family, as well as health care providers who work with men with depression. In these videos, participants reflected on their own experiences as well as their reactions to the overall findings of the Men and Depression studies, thereby re-telling their stories and sharing their advice to help men to help themselves. These stories became the basis of the online interaction, provoking almost 5000 visits in the first year of the site, the majority of which were by men, to listen in on the conversation.

In relation to the If I Were Jack website, we built on the earlier qualitative research conducted by a different team of researchers that had led to the development of a computer-based interactive video drama on a young man's experience of an adolescent pregnancy for use in further primary research. Through the use of interactive theater techniques in youth drama groups, we adapted the script of the original IVD, reproduced two further versions and adapted them for online delivery within classrooms. These arts-based approaches to translating qualitative research into online health promotion content drew on psychological research that suggests the value of episodic thinking—an exercise of the imagination that allows one to "pre-experience" an event in order to adaptively prepare [103,104] (eg, from Jack: "I want you to imagine you're me"), as well as research that suggests the value of understanding our own self-care through an understanding of the experiences of others [105,106].

Developing Gender and Culturally Sensitive Interventions

Both research teams set out to engage men by disrupting stereotypes about men's stoicism and reluctance around sharing vulnerabilities with others. We attempted to engage with men less through humor or sexual imagery and more through producing authentic voices and faces that our target audiences could identify with. Recognizing the important role women can play in men's health [107], and in acknowledgment of findings from our own research of the value in breaking down gender stereotypes of men's health [66,79], we also wanted to engage women in the websites, so in both cases, there is clear representation of women and invitations for women to participate. For example, the interactive video on the If I Were Jack website is designed to be used by females as well as males and invites females to also imagine being a male in this situation. Both males and females are asked to further consider what Jack's girlfriend, Emma, would also be thinking.

The issue of designing culturally sensitive content was also something both teams thoughtfully considered. For the *Jack* team, we decided it was necessary to make two different versions of Jack (an Irish version and a Northern Irish version, in addition to the original Australian version) because identification with the lead character is central to the exercise of the imagination: "You'll see the world through my eyes, you'll be me. I want you to make some decisions for me because things are about to get tough around here". The MDHY website had the opportunity to include more faces and more stories, and the team sought to represent the diversity of Canadian society. The team also designed flexible and user-friendly routes through the website to stories and related resources designed for specific target groups of men, such as older men and college men.

Achieving Sustainability of Knowledge Translation Over the Longer Term

Both case studies drew attention to the necessity to think beyond placement of content online to delivery to targeted audiences from the outset. The lesson here is the need to work collaboratively with stakeholders, gate-keepers, and potential partners. For the *Jack* team, the issue was ensuring the website could get beyond the school gate and this required careful collaboration in content development with the main custodians

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of sex education/RSE in schools in our target countries. In the case of the MDHY website, it meant developing a community of practice with other major charities and provincial providers of health promotion so as to achieve an online and offline reference community. While we were clearly thinking of implementation from the outset of the KT process, and both case studies have achieved footholds in online and offline communities, arguably now researchers should be thinking about KT and implementation processes from the outset of research process.

Discussion

Summary

We have described how our KT case studies map onto the model of the knowledge-to-action cycle and its three phases. Some lessons learned through content development have also been discussed.

To date, much of the published research on KT has focused on developing a unified definition of KT [1,3] or developing general models and road-maps to guide researchers [5,108], leaving unanswered questions about how to creatively develop online KT content from research. This paper adds flesh to the bones of this science and illustrates how basic social science research can be transitioned into accessible, interactive, informative, and user-friendly online content to support KT. In this paper, we have demonstrated how we used a model of KT to inform a pathway for development of e-KT, while illustrating some of the challenges we encountered including choices to be made in making appealing content that was culturally and gender-sensitive, and in achieving sustainability using two case studies that span a number of countries. The work also builds on men's health research and especially emerging research on how best to deliver eHealth to men [12,109,110].

Limitations

If we were to start all over again, we would refer to Normalization Process Theory, which is a nascent science building on implementation theory, which, in its application to eHealth, seeks to explain and predict the success or failure of the implementation and integration of new eHealth technologies into everyday practices [7]. While this theory is targeted to researchers developing and implementing interventions rather than the broader activities encompassed under KT, as noted earlier, the field of KT has much to learn from this scholarship in relation to the processes of translating research into practice. More generally, a limitation of developing online content for KT is the necessity to keep content fresh and relevant and to regularly monitor the target audience to see if it is attuned to their needs. Again, this implies partnerships with non-academic audiences to sustain knowledge translation. Finally, in this paper we have not presented a longitudinal or comparative systematic evaluation of these online men's health KT strategies. The focus has been on the design of the content rather than on rigorous evaluation. Although we have presented evaluation data that can suggest the impact of the Internet-based men's health interventions, future papers will more fully develop this aspect of the research [111].

Conclusions

There has been limited success with conventional approaches in engaging men in health promotion. Our case studies illuminate (1) the importance of working with a multidisciplinary team of academics, creative practitioners, stakeholders, and the target group itself to inform the transition of research findings into meaningful and accessible online content to improve men's health, (2) the power of qualitative research with men in leading the direction of creatively developing gender and culturally sensitive communication with men about health issues, (3) the importance of engaging stakeholders from the outset to secure relevant adaptation to context and delivery to targeted audience, and (4) the importance of thinking about KT strategies from the outset of a research project and developing an integrated process and impact evaluation framework in all KT work.

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Conflicts of Interest

None declared.

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Abbreviations

CIHR: Canadian Institutes of Health and Research
IVD: interactive video drama
KT: knowledge translation
MDHY: Men’s Depression: Help Yourself website
RSE: relationship and sexuality education
TEKT (or e-KT): technology-enabled knowledge translation

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Original Paper

Evaluations of Dentists on a German Physician Rating Website: An Analysis of the Ratings

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Abstract

Background: Physician rating websites have been gaining in importance in both practice and research. However, no evidence is available concerning patients' ratings of dentists on physician rating websites.

Objective: The aim of this study is to present a comprehensive analysis of the ratings of dentists on a German physician rating website over a 2-year period.

Methods: All dentist ratings on a German physician rating website (Jameda) from 2012 and 2013 were analyzed. The available dataset contained 76,456 ratings of 23,902 dentists from 72,758 patients. Additional information included the overall score and subscores for 5 mandatory questions, the medical specialty and gender of the dentists, and the age, gender, and health insurance status of the patients. Statistical analysis was conducted using the median test and the Kendall tau-b test.

Results: During the study period, 44.57% (23,902/53,626) of all dentists in Germany were evaluated on the physician rating website, Jameda. The number of ratings rose from 28,843 in 2012 to 47,613 in 2013, representing an increase of 65.08%. In detail, 45.37% (10,845/23,902) of dentists were rated once, 43.41% (10,376/23,902) between 2 and 5 times, and 11.21% (2681/23,902) more than 6 times (mean 3.16, SD 5.57). Approximately 90% (21,324/23,902, 89.21%) of dentists received a very good or good overall rating, whereas only 3.02% (721/23,902) were rated with the lowest scores. Better ratings were given either by female or older patients, or by those covered by private health insurance. The best-rated specialty was pediatric dentistry; the lowest ratings were given to orthodontists. Finally, dentists were rated slightly lower in 2013 compared to 2012 (P=.01).

Conclusions: The rise in the number of ratings for dentists demonstrates the increasing popularity of physician rating websites and the need for information about health care providers. Future research should assess whether social media, especially Web-based ratings, are suitable in practice for patients and other stakeholders in health care (eg, insurance providers) to reflect the clinical quality of care.

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KEYWORDS

physician rating website; dentist; patient experience; Internet; quality of care

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Introduction

Over the past 20 years, the Internet has increasingly gained in importance and has acquired a key role in society as a central means of communications and an information platform. At the beginning of 2014, 76.6% of the German population aged 10 years or older used the Internet. Among the group of users aged 10-39 years, this number amounted to nearly 100% [1]. Health issues seem to be a major field of interest. A German study has shown that 37.7% of the population and 64.5% of Internet users use online research to look for health-related information [2]. In the United States, 88% of adults looked for information concerning health issues on the Internet [3]. In another representative survey in Germany, 11% of the people questioned stated that they had researched dental issues on the Internet at least once [4]. In summary, this illustrates a change in the patient's role from passive receiver to active user of health-related information on the Internet [5].

This may also reflect the trend in patients wishing to be informed more effectively about the content and quality of medical care provision. However, a balanced and robust judgment of the quality of medical treatment is rarely possible for patients because of a lack of publicly accessible information [6]. Family, friends, and acquaintances still appear to be the most important source of information when looking for a doctor [7,8]. Public reporting has helped to increase the transparency of the quality of medical care [9-12], yet this offer is only accepted hesitantly at the moment [13]. A lack of understanding of the offered medical information, a lack of confidence in the information, and several other reasons might explain a patient's inability to use the existing platforms on the Internet [14].

Although the existing research has increasingly dealt with patient satisfaction, an overall supply of information about doctors, practices, or hospitals is still missing [15]. Because social media are easily available, easy to use, and are used by the majority of the population, a growing number of people share health care experiences online or rate their health care provider on physician rating websites [16]. Of the nearly 28 million German users of physician rating websites, 56% are female and 44% are male [17]. Despite some studies dealing with physician rating websites [3,18-21], neither national nor international research regarding the rating of dentists on physician rating websites have been published. The intention of this paper is to present the first study on dentist ratings on a German physician rating website (Jameda) analyzing (1) the characteristic features of both dentists and patients, (2) the number and distribution of rating results, (3) the influence of characteristics of dentists rated and rating patients on the submitted grades, and (4) the development of dentist ratings on a physician rating website over 2 consecutive years.

Methods

Overview

This study extends the results of a previous study in which ratings for all German physicians from the German outpatient sector (except dentists) were evaluated [18]. Physician rating website Jameda was chosen as the data source because it likely plays the most important role in the German physician rating website movement (see [18]).

The total number of ratings in 2012 and 2013 was 76,456 ratings, which were given by 72,758 patients for 23,902 dentists. The dataset contained information concerning gender, age, and medical specification of the dentists, as well as gender, age, and the type of health insurance of the patients. The rating system on Jameda consists of 5 questions, each rated according to the grading system in German schools from 1=very good to 6=insufficient. The questions are about (1) satisfaction with the treatment offered (Q1), (2) information and presentation of facts with regard to illness and treatment (Q2), (3) the relationship of trust with the dentist (Q3), (4) the amount of time spent on a patient's concerns (Q4), and (5) the friendliness of the dentist (Q5). An average score is derived subsequently on the basis of the 5 single grades.

Statistical Analysis

All statistical analyses of the data were carried out with SPSS v21.0 (IBM Corp, Armonk, NY, USA). The median test was applied to nonparametric data of groups with different distributions. The Kendall tau-b test was used to analyze the correlation between both the performance of a dentist and the number of ratings per dentist and the number of ratings per patient compared to the mean overall performance given by this patient. Differences were considered to be significant if $P<.05$ and highly significant if $P<.001$.

Results

Number and Distribution of Ratings

The number of dentist ratings posted on the physician rating website Jameda increased from 28,843 in 2012 to 47,613 in 2013, representing an increase of approximately 65.08%. See Figure 1 for a screenshot of a dentist search on the German physician rating website, Jameda. In 2012, the total number of dentists in Germany was 53,626 [22] and the number of rated dentists was 23,902; therefore, 44.57% (23,902/53,626) of all dentists were rated at least once within the 2-year study period. In more detail, 45.37% (10,845/23,902) of the dentists were rated once, 43.41% (10,376/23,902) received between 2 and 5 ratings, and 11.21% (2,681/23,902) were rated more than 6 times. This led to a mean 3.16 ratings per rated dentist (SD 5.57, range 1-215) (Figure 2). Most patients left only a single rating (95.67%, 69,608/72,758) and there were only a few who delivered 2 or more ratings (4.33%, 3150/72,758). The mean number of ratings was 1.05 ratings per rating patient (SD 0.25, range 1-15). Regarding the latter, this does not necessarily mean that 15 different dentists were rated; it can imply that 1 dentist was rated more than once by 1 rating patient.

The distribution of the ratings concerning dental treatment revealed that 89.21% (21,324/23,902) of the rated dentists received a 1=very good or 2=good overall evaluation, only 3.02% (721/23,902) were rated 5=deficient or 6=insufficient according to the grading system used in German schools (Table 1). The overall mean result was very good (mean 1.42, SD 0.97), ranging from 1.55 for question 3 (the relationship of trust with the dentist) to 1.37 for question 5 (the friendliness of the dentist).

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Table 1. Evaluation results of all rated dentists on Jameda from 2012-2013 (N=23,902).

Performance range	Overall performance	Question (Q)[a]				
		Q1	Q2	Q3	Q4	Q5
Rating, n (%) [b]						
1	18,649 (78.02)	18,302 (76.57)	17,528 (73.33)	17,706 (74.08)	17,878 (74.80)	18,979 (79.40)
2	2675 (11.19)	2846 (11.91)	3714 (15.53)	3039 (12.71)	3498 (14.63)	2848 (11.89)
3	1262 (5.28)	1088 (4.55)	1205 (5.04)	1212 (5.07)	1181 (4.94)	974 (4.07)
4	592 (2.48)	781 (3.27)	734 (3.07)	874 (3.66)	671 (2.81)	597 (2.50)
5	492 (2.06)	356 (1.49)	363 (1.52)	401 (1.68)	331 (1.38)	217 (0.91)
6	229 (1.00)	529 (2.21)	358 (1.50)	670 (2.80)	343 (1.44)	287 (1.20)
Mean (SD)	1.42 (0.97)	1.48 (1.08)	1.48 (1.01)	1.55 (1.15)	1.46 (0.98)	1.37 (0.90)
Median (range)	1.00 (1.00-6.00)	1.00 (1.00-6.00)	1.00 (1.00-6.00)	1.00 (1.00-6.00)	1.00 (1.00-6.00)	1.00 (1.00-6.00)
Skewness	2.79	2.83	2.77	2.62	2.89	3.28
Kurtosis	7.79	7.91	8.04	6.56	8.81	11.73

[a] Q1: satisfaction with the treatment by the dentist; Q2: education about the illness and treatment; Q3: relationship of trust with the dentist; Q4: time the physician spent for the patient´s concerns; Q5: friendliness of the dentist.

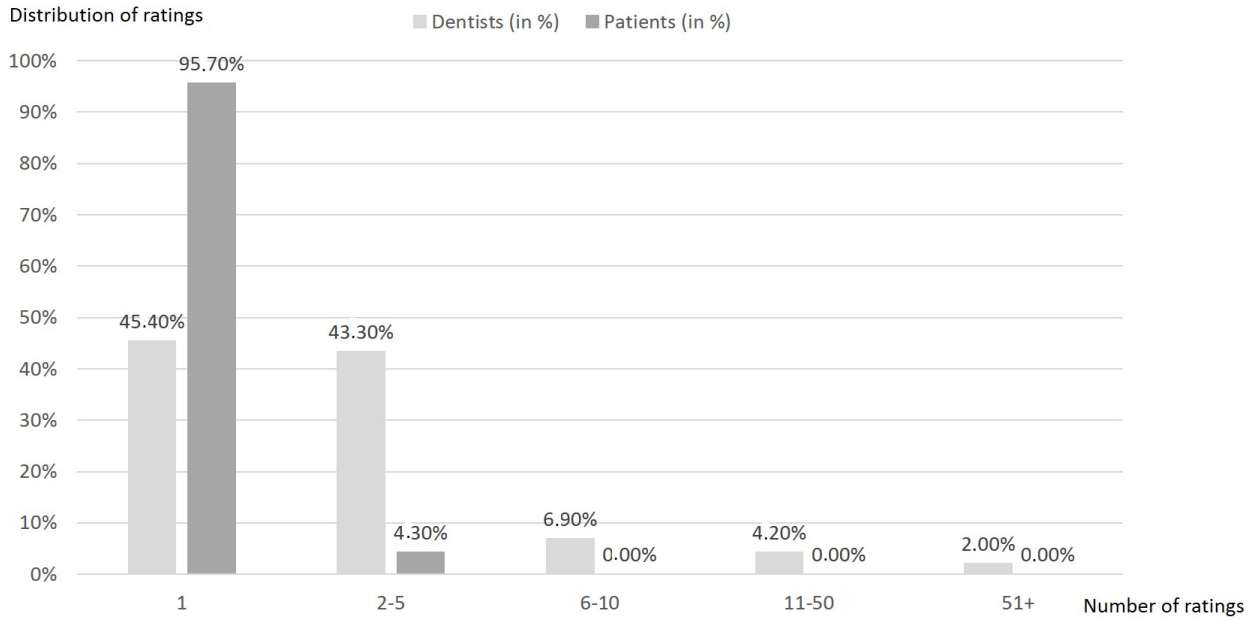
[b] German school-based rating system (1=very good; 2=good; 3=satisfactory; 4=sufficient; 5=deficient; 6=insufficient).

Figure 1. Screenshot of a dentist search on the German physician ratings website, Jameda (translated from German to English with Google Translate).



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Figure 2. Overview of the rating distribution for both physicians and patients.



Evaluation

With regard to gender, male dentists were more likely to be rated compared to their female counterparts (Table 2); 31.89% (7621/23,897) were female (the average proportion of female dentists as a percentage of all German dentists in 2012 was 37.2%). In contrast, 54.41% (26,915/49,465) of the rating patients were female and 45.59% (22,550/49,465) were male (the remainder did not provide this information). The age group of patients with the largest proportion of ratings was between 30 and 50 years (53.60%, 25,015/46,673), and most were covered by statutory health insurance (78.77%, 37,139/47,147). As shown in Table 2, female dentists received better ratings compared to their male colleagues (P<.001) and female patients also gave better ratings (P<.001). Considering the different age groups of patients, the older the patients, the higher the proportion of good ratings (P<.001). Furthermore, those covered by private health insurance gave more favorable ratings than those covered by statutory health insurance.

Further analysis was carried out on the basis of ratings covering all dental subdisciplines concerning the entire 2-year study period (2012 and 2013). Regarding the overall rating for dental subdisciplines, pediatric dentists and periodontologists received significantly better ratings than orthodontists did.

Table 3 illustrates a slight worsening of the ratings in 2013 in comparison with the previous year (P<.05). We observed a marginal decline in the ratings for female dentists in 2013 (P<.05). Regarding the dental subdisciplines, no significant improvement was seen. In contrast, a significant worsening for periodontologists and endodontists was determined.

Finally, we assessed the correlation between the mean overall performance of a dentist and the number of ratings per dentist. In Figure 3, dentists who received a higher number of ratings were shown to have statistically significant overall better ratings (Kendall tau-b=0.185, P<.001). This significant correlation could also be determined for all 5 mandatory questions (P<.001; data not presented here). A significant correlation between the number of ratings per patient compared to the mean overall performance given by this patient (Kendall tau-b=0.148, P<.001) was found also. Again, this was true for all 5 mandatory questions (P<.001; data not presented here).

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Table 2. Rating differences for dentist and patient characteristics from 2012-2013.

Characteristics	n	>Median, n	≤Median, n (%)	*P* [a]
Dentist				
Gender				.001
Female	7621	3462	4159 (54.57)	
Male	16,276	7784	8492 (52.17)	
Medical specialty				<.001
Pediatric dentistry	84	36	48 (57.14)	
Not specified	12,608	5535	7073 (56.10)	
Periodontology	4556	2060	2496 (54.78)	
Naturopathy	159	75	84 (52.83)	
Endontology	275	132	143 (52.00)	
Oral surgery	715	354	361 (50.49)	
Implantology	3614	1925	1689 (46.73)	
Esthetic dentistry	562	332	230 (40.93)	
Orthodontics	1284	771	513 (39.95)	
Laser dentistry	45	29	16 (35.56)	
Patient				
Gender				<.001
Female	26,915	6426	20,489 (76.12)	
Male	22,550	5811	16,739 (74.23)	
Age				.001
<30	8746	2727	6024 (68.87)	
30-50	25,009	6116	18,898 (75.56)	
>51	12,908	2645	10,263 (79.51)	
Health insurance				.001
Statutory health insurance	37,283	9408	27,875 (74.77)	
Private health insurance	9995	2360	7635 (76.39)	

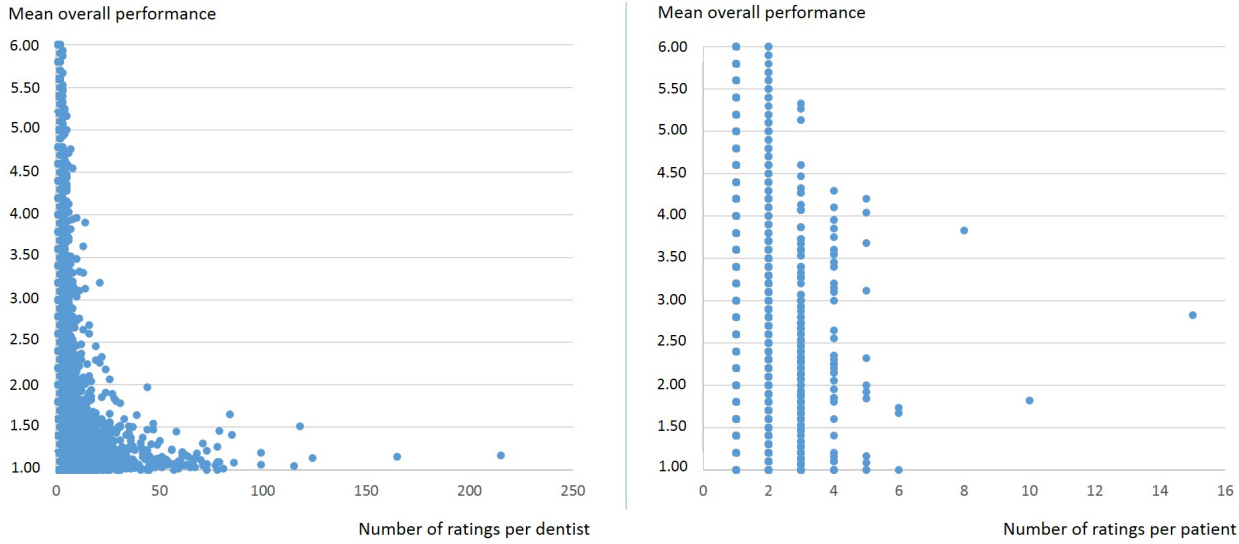
[a]Median test: a nonparametric test that is used to determine whether the medians of two or more groups differ.

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Table 3. Rating differences of dentists for the time period of 2012-2013.

Characteristics	2012		2013		*P*
	n	≤Median, n (%)	n	≤Median, n (%)	
Gender					
Female	7711	5643 (73.18)	12,833	9221 (71.85)	.04
Male	21,105	15,674 (74.27)	34,772	25,610 (73.65)	.11
Total	28,843	21,342 (73.99)	47,613	34,836 (73.16)	.01
Medical specialty					
Pediatric dentistry	131	113 (86.26)	298	242 (81.21)	.26
Not specified	11,952	8738 (73.11)	18,223	13,193 (72.40)	.18
Periodontology	4840	3561 (73.57)	7565	5437 (71.87)	.04
Naturopathy	199	149 (74.87)	297	219 (73.74)	.86
Endontology	464	389 (83.84)	1033	817 (79.09)	.04
Oral surgery	1120	834 (74.46)	2051	1571 (76.60)	.19
Implantology	6564	5018 (76.45)	11,470	8633 (75.27)	.08
Esthetic dentistry	1662	1344 (80.87)	3352	2651 (79.09)	.15
Orthodontics	1723	1050 (60.94)	3073	1882 (61.24)	.86
Laser dentistry	187	145 (77.54)	250	191 (76.40)	.87

Figure 3. Scatterplot (bivariate) of the number of ratings per dentist (left) and patient (right) with the mean overall performance for a rated dentist.



Discussion

Currently, most patients seek advice from friends or relatives, or choose a doctor within their vicinity when searching for a physician [7,23]. This behavior, however, could be changing because of the increasing use of physician rating websites, which have been shown to be gaining in attention and importance [15]. The latter statement can be backed by the results of this study, showing an increase in the number of ratings of 65.08% within 2 years. This increase is in contrast with the attitude of German dentists toward physician rating websites. In a survey performed in 2012, only 14.4% of German dentists questioned thought that being rated on a physician rating website was of great or comparatively great relevance for their practices. However, 64.7% of the participants believed that physician rating websites will become more important in the future [24].

According to our results, 33.69% (18,069/53,626) of all German dentists have been rated at least once in 2013. Comparing this figure with the results of the previously published study [18], this percentage is only slightly lower than for other physicians in Germany (37%). Compared with additional national or international literature dealing with ratings on physician rating websites, the percentage of rated dentists rated in Germany is fairly high. According to a study by Gao and colleagues [19], approximately 16% of all doctors listed were rated on the Canadian physician rating website RateMDs between 2005 and 2010, whereas Lagu and colleagues [25] determined a percentage of 27% in the case of 300 doctors. An analysis of

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different German physician rating websites showed that between 3% and 28% of doctors had been rated at least once on different German physician rating websites in 2012 [21].

The mean number of ratings per dentist was 2.06 (SD 2.99) in 2012, slightly lower than for other German physicians at 2.37 [18]. Strech and Reimann [21] analyzed several German physician rating websites and calculated a mean between 1.1 and 3.9 ratings per physician. Results for websites in the United States show similar results: 2.35 [25], 2.4 [26], and 3.2 [19]. In 2012, 61.96% of dentists had been rated once; this number declined to 54.72% in 2013. Thereby, the percentage of dentists with between 2 and 5 ratings increased from 32.92% in 2012 to 36.54% in 2013. In the comparative study, 49.7% of doctors were rated only once and 43.7% of the doctors received between 2 and 5 ratings [18]. In both studies, the percentage of doctors with 10 or more ratings was less than 5%. An analysis of the United States portal, RateMDs, showed similar results; half of doctors received 1 evaluation and 12.5% were rated more than 5 times [19].

In general, these results show positive rating results for German dentists (eg, 89.21% of all ratings were in the top 2 categories). These results are in-line with the results of a nationwide survey on public attitude to, and assessment of, dental care in Germany. This indicates that dentists enjoy a very good reputation. On a 4-stage scale, 91% of the people questioned are either “rather satisfied” or “very satisfied” with their dentist [4]. In another study addressing patient perspective on the quality of oral health care in Germany, the overall satisfaction with dental care was 4.66 (SD 0.55) on a 5-point scale ranging from 1 (poor) to 5 (excellent) [27]. Other studies have also previously shown a tendency toward good ratings on physician rating websites in Germany [18] and in the United States [19,25,26]. The results presented by MacKay and colleagues [28] were slightly lower; 70% of the comments on RateMDs were favorable toward Canadian physicians. Similar results were provided from a study on the usage of NHS Choices, a United Kingdom government website that encourages patients to rate the quality of physician practices. Between October 2009 and December 2010, approximately 61% of family practices were rated and the practice was recommended in 69% of the ratings [11]. According to the authors, governmental websites may create a selection bias toward less satisfied patients.

In our study, the median score of all questions was 1.00 (mean 1.42) which is in-line with the other literature. Strech and Reimann [21] calculated an average score of between 1.1 and 1.5 on a 3-stage scale (1=good; 3=bad) for different German physician rating websites. In the comprehensive analysis conducted by Kadry and colleagues [3] regarding the 10 most frequently visited physician rating websites in the United States, a mean rating of 77 (based on a 100-point scale), 3.84 (based on a 5-point scale), and 3.1 (based on a 4-point scale) was shown.

Female dentists received better ratings. This might be explained by the fact that female physicians engage in significantly more active partnership behaviors, positive talk, psychosocial counseling, psychosocial question asking, and emotionally focused talk. Medical visits were shown to be 2 minutes longer with female physicians than those with male physicians [29]. Furthermore, female patients tend to evaluate more positively compared to their male counterparts. Götz and colleagues [27] also found that female patients showed a higher overall satisfaction with dental care than male patients did. This is in contrast to another German analysis of physician rating websites showing that male patients tended to rate more positively [30]. Furthermore, it could be shown that privately insured patients tend to give better ratings more often than those covered by statutory health insurance do (P<.001). One reason for this could be seen in the easier access to medical services. In-line with the comparative study, middle-aged patients (aged between 30-50 years) gave the most ratings [18]. Furthermore, better ratings were most likely to be seen in the oldest age group (older than 50 years), which is similar to findings in another study showing higher overall satisfaction scores with oral health care in older patients [27].

Furthermore, our analysis revealed a slight but significant deterioration in ratings (P<.05). Regarding the dental subdisciplines, only periodontologists and endodontists showed a slight but significant decline in rating level. The reason for this change cannot be derived from the data available. In 2012 and 2013, orthodontists (who generally treat children and youths) were rated lowest. One possible explanation might be that orthodontic treatment is a long-term process that is often partly or fully financed privately. The copayment might lead to dissatisfaction and consequently lower ratings. In their survey with more than 8000 patients about the quality of oral health care, Götz and colleagues [27] found the domain “costs of care” was rated least positively and they subsequently recommended adequate explanation and information about treatment costs as an essential aspect of dental care. However, noncompliance by patients leading to unsatisfactory results should also be considered a possible reason. According to the estimations of two-thirds of German orthodontists, 30%-60% of their patients develop problems of cooperation during the orthodontic treatment. Up to 15% of patients even cancel their therapy [31]. Another explanation for the relatively low ratings for orthodontists might be found in the rating patients’ expectations. It might add value in this context to assess whether the ratings were given by the children themselves or their parents. In case the parents left a rating, one might argue that parents want the very best for their children and could be disappointed much more easily compared to when they visit a doctor for themselves. In contrast, children might be more critical because they want to have good-looking teeth (eg, no braces), preferably in a very short period of treatment. This, however, is not feasible because orthodontic corrections need time. Regarding the age distribution of the rating patients, the latter seems to be more likely. The proportion of rating patients aged 30 years or younger is by far the highest among all dental subdisciplines. Here, approximately 44.74% of the rating patients were aged 30 years or younger, whereas only 6.95% were aged 50 years or older (see Table 4).

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Table 4. Age distribution of the rating patients according to the dental subdisciplines (N=20,194).

Dental discipline	Age range (years), n (%)		
	<30	30-50	≥50
Pediatric dentistry	13 (16.46)	51 (64.56)	15 (18.99)
Not specified	1531 (18.24)	4634 (55.21)	2228 (26.55)
Periodontology	574 (16.70)	1948 (56.68)	915 (26.62)
Naturopathy	24 (15.29)	77 (49.04)	56 (35.67)
Endontology	64 (18.88)	202 (59.59)	73 (21.53)
Oral surgery	169 (20.86)	397 (49.01)	244 (30.12)
Implantology	733 (15.78)	2489 (53.57)	1424 (30.65)
Esthetic dentistry	192 (17.07)	664 (59.02)	269 (23.91)
Orthodontics	476 (44.74)	514 (48.31)	74 (6.95)
Laser dentistry	24 (16.78)	89 (62.24)	30 (20.98)
Total	3801 (18.82)	11,065 (54.79)	5328 (26.38)

The limitations to this study are as follows. Although the study was based on a large dataset and its results are in-line with other studies, the major limitation is the fact that only 1 physician rating website was included in our analysis; evaluations of other physician rating websites could lead to different results. Future studies should aim at comparing different German physician rating websites and analyzing the current number of ratings and the number of physicians rated, but also differences in rating patients and rated physicians. Applying those criteria might lead to other “most important” German physician rating websites. Unfortunately, a more in-depth analysis regarding the use of physician rating websites according to sociodemographic data was not possible because of a lack of data. In this context, a recently published study analyzing the variables which influence the usage of physician rating websites could demonstrate that sociodemographic variables alone do not sufficiently predict use or nonuse of physician rating websites; specific psychographic variables and health status additionally need to be taken into account [32]. Because rating is anonymous, rating values are not risk-adjusted and, therefore, vulnerable to fraud. People providing feedback on health care services via social media are presumably not always representative of the patient population in general. Next, we were not able to present an analysis over a longer period of time. However, our study is the first evidence from Germany covering 2 consecutive years. Finally, the purpose of this paper was to give further insight into the nature of dentists’ ratings, not to discuss the usefulness of the ratings for the patients when seeking a dentist. In this context, several studies have raised concerns about the helpfulness and support of such sites from a patient’s perspective [33-35]. A comprehensive overview of the major shortcomings of physician rating websites (eg, incomplete databases, low percentage of rated physicians, the potential to reflect the quality of care) was also recently provided by a systematic review [36].

In conclusion, an increasing trend toward the rating of physicians on a physician rating website in Germany is shown. The total number of ratings rose by 65.08% between 2012 and 2013. So far, 44.57% of all German dentists have been evaluated by patients at least once. However, this means that more than half of dentists in Germany are still without any evaluation. The increase in ratings over the 2-year study period indicates a growing interest among the population to evaluate the quality of oral health care providers. Many of the results presented here are in-line with the other national and international literature in this area. The overall satisfaction of patients with dentists seems to be comparable to other medical specialties. In a patient-centered approach, it is essential to assess the quality of health care from a patient’s perspective. Information available on social media (such as physician rating websites) has gained more attention in the literature recently (eg, [9,19,20]). Therefore, they may possibly have a positive effect on the encouragement of health competence and equal opportunities of patients [21]. So far, it remains unclear whether and how online rating may reflect the technical quality of care, the measuring of patient experiences and satisfaction, and how care is being assessed. Nevertheless, the existence of physician rating websites is likely to continue and will remain an important aspect of oral health care evaluation. physician rating websites might contribute to reducing the lack of publicly available information on the quality of care [18]. Future research should explore whether social media, such as physician rating websites, are suitable in practice for patients, health insurers, and governments to help them evaluate the quality of performance of medical professionals [16].

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Conflicts of Interest

None declared.

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Abbreviations

NHS: National Health Service

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Original Paper

Using Patient Experiences on Dutch Social Media to Supervise Health Care Services: Exploratory Study

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Abstract

Background: Social media has become mainstream and a growing number of people use it to share health care-related experiences, for example on health care rating sites. These users' experiences and ratings on social media seem to be associated with quality of care. Therefore, information shared by citizens on social media could be of additional value for supervising the quality and safety of health care services by regulatory bodies, thereby stimulating participation by consumers.

Objective: The objective of the study was to identify the added value of social media for two types of supervision by the Dutch Healthcare Inspectorate (DHI), which is the regulatory body charged with supervising the quality and safety of health care services in the Netherlands. These were (1) supervision in response to incidents reported by individuals, and (2) risk-based supervision.

Methods: We performed an exploratory study in cooperation with the DHI and searched different social media sources such as Twitter, Facebook, and healthcare rating sites to find additional information for these incidents and topics, from five different sectors. Supervision experts determined the added value for each individual result found, making use of pre-developed scales.

Results: Searches in social media resulted in relevant information for six of 40 incidents studied and provided relevant additional information in 72 of 116 cases in risk-based supervision of long-term elderly care.

Conclusions: The results showed that social media could be used to include the patient's perspective in supervision. However, it appeared that the rating site ZorgkaartNederland was the only source that provided information that was of additional value for the DHI, while other sources such as forums and social networks like Twitter and Facebook did not result in additional information. This information could be of importance for health care inspectorates, particularly for its enforcement by risk-based supervision in care of the elderly. Further research is needed to determine the added value for other health care sectors.

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KEYWORDS

social media; rating sites; patient safety; supervision

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Introduction

Social media has become a mainstream online tool that enables any individual to connect, create, consume, and control content, independently of time and place [1]. As a result, the Internet contains an abundance of user-generated content [2]. A growing number of people use social media for health care-related purposes such as finding health-related information. Research from the Netherlands showed that one in four adults would like to use social media to communicate with health care professionals [3]. Other studies demonstrated that an increasing number of patients share their experiences with health care providers or health care institutions via social media [4]. Experiences can also be shared by family [5]. This can be done using general social networks such as Facebook [6] or Twitter [7]. Other people use so-called "health care rating sites", such as physician rating sites [8]. Health care rating sites allow users to rate and discuss individual health care providers or organizations. This can often be done very easily, anonymously, and free of charge. Not surprisingly, the number of sites and ratings is growing [9-11], and this may be boosted by the appearance of health care rating apps for mobile devices [12].

Not surprisingly, the scientific community has become increasingly interested in social media and health care rating sites, and many studies have been conducted on this topic. It is clear that health care rating sites may affect choices that people make about their health care [13], and could affect the way that patients and professionals interact. For example, negative reviews may result in new policies or could trigger doctors to change the way they communicate [14]. Information about health care on social media could also be useful to monitor the quality and safety of health care. An extensive review published in this journal confirmed that there is a relation between information on social media and traditional measures of quality of care. Verhoef et al analyzed 29 studies and showed that information derived from social media and health care rating sites correlated to several measures of quality of care including patient experiences, mortality, readmission rates, and infection rates [15]. More recently, research showed that messages on Twitter (tweets) may also contain unique information about patients' experiences that cannot be acquired via other ways [16].

Although correlations are not always strong and several questions remain unanswered, social media seems to be a potential source of information about individuals' perspectives of the quality and safety of care. If so, it could be useful for organizations such as health care inspectorates that want to make use of these individuals' perspectives to supervise the quality and safety of care.

An example of such an organization is the Dutch Healthcare Inspectorate (DHI), an agency under the Ministry of Health, Welfare and Sport. It is the official regulatory body charged with supervising the quality and safety of health care services, prevention activities, and medical products in the Netherlands. The DHI has organized its supervision in several ways to ensure compliance with (professional) standards and guidelines and to ensure patient safety. The two most important ways are (1) incident-based supervision, and (2) analyses of various types of risk information, also known as risk-based supervision [17]. For several reasons, supervisory bodies such as the DHI might be interested in patient experiences shared on social media. First, health care inspectorates have the responsibility to supervise a huge number of health care suppliers, which makes it difficult to collect information. For example, the DHI supervises around 40,000 health care-related institutions and 800,000 health care professionals [18]. Therefore, social media could be an additional source of information that enables the DHI to prioritize and supervise organizations in a more efficient way. Second, the DHI is looking for more current information, since there is usually a time lag between the actual incident itself and the availability of information about the incident for health care inspectors from conventional sources such as care-related quality indicators. For example, quality indicators are usually collected only once a year. A third goal to pursue regarding information on social media is to stimulate citizen or consumer participation in supervising the quality and safety of health care services [19]. This has gained popularity in the past few years and can result in valuable information [20,21]. Therefore, in close cooperation with relevant health care inspectorate employees of the DHI, we explored the following research question: What is the added value of information on social media for supervising health care services, in both incident-based and risk-based supervision?

Methods

Design and Setting

To the best of our knowledge, the use of social media in supervising the quality and safety of health care services by health care inspectorates has not been studied intensively. Consequently, we performed an exploratory study, which consisted of two parts. The first part was aimed at identifying added value of social media, for supervision based on incidents reported to the health care inspectorate. We searched social media sources to find additional information about incidents for which insufficient information was available. Health care inspectors determined the potential value of the information found. The second part of this study was focused on the added value of social media for risk-based supervision after assessment of specific risks of health care providers. We searched social media to find additional information to identify whether it could function as an indicator for high-risk providers. Experts from the health care inspectorate determined the potential additional value of the information found.

Selection of Social Media Sources and/or Monitoring Tools

First, we identified usable, efficient, and reliable social media sources or tools to search social media. Social media sources consisted of individual original sources such as Twitter or Facebook, and tools consisted of standard search engines such as Google or specific social media monitoring tools (SMMTs). SMMTs are tools that allow users to search several social media sources at the same time. Social media sources and tools to search social media were selected by going through three operational steps. First, two researchers with past experience

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in performing online searches in academic and grey literature, determined the following inclusion criteria for use in this study: (1) related to the Dutch language, (2) ability to search for messages posted up to at least 2 years back, since the DHI takes into account reports about incidents that took place within the past 2 years, (3) accessible, since private social networks are inaccessible, and (4) supporting Boolean search. The latter is a technique that allows the creation of specific search strings making use of operators like “AND”, “NOT”, and “OR” [22].

Second, we searched for search tools on the Internet and asked experts to share their best options. We also screened an existing online list of SMMTs for relevant tools [23]. Furthermore, we used information and experiences about SMMTs obtained during previous projects performed by the DHI. We created a list of potentially relevant tools and verified that they met pre-defined inclusion criteria.

Third and last, test searches were performed with all social media sources and/or tools that corresponded to the criteria. Two researchers individually performed three test searches for randomly selected health care providers. They developed a search strategy to find any information about this health care provider that was available online, such as experiences or ratings. Relevant features and/or findings were added to a table and results and experiences were discussed together. This step not only allowed the researchers to get acquainted with the selected tools, but also to identify any issues regarding reliability, specificity, or usability. For example, if a tool was hosted on a website that was extremely slow and if it was clear that this problem could not be solved, the researchers could decide to exclude the tool. For practical reasons, we aimed at selecting three to five of the most suitable social media sources and/or tools for use in this study. For the second search, we selected social media sources and/or tools based on the results of the first search and removed sources or tools that had not resulted in any new information from the list.

Searches for Information for Incident-Based Supervision

We started by creating searches for 20 reported incidents, which were randomly selected from the DHI database. Random selection was needed to keep a wide focus and to assure that the analysis could apply to different sectors such as elderly care, hospital care, and non-hospital care. Two researchers (TB and LV) individually studied the summaries of the first five reported incidents and created search queries for each incident. Summaries were found suitable for this purpose since they contained all information needed for this study, including a description of the incident, date, name of the person that reported the incident, health care provider, specialty, and organization. For each search strategy, the goal was to find additional information (within social media sources) related to the reporting individual, the disease or treatment, the health care provider, and/or the organization that could be of value for the DHI in determining the relevance of the reported incident. We then tailored the search queries to each social media source or tool, since every source or tool had different options such as rules and use of search operators. To reduce inter-researcher variability, the researchers discussed and improved the search queries and results for the first five searches, until they both agreed on the search query.

Next, one of the two researchers (TB) created search queries for the 15 incidents remaining and performed the searches. Any issues were resolved by consulting another researcher (LV). Furthermore, the second researcher screened search queries, in order to make sure that the basics of each query were identical and operators (eg, AND, NOT) were used in the right way. Print-screens were made for all searches. In the case of many hits, only print-screens of the first two pages with results were saved.

Finally, all results related to the original reported incident were summarized in a text file and shared with DHI inspectors. Per sector, one inspector determined the additional value (eg, information leads to specific actions or may influence a decision) of the information found. They were asked to choose between “0: No additional value of the information found” or “ 1: Information is relevant and contains additional information”. Furthermore, an explanation of each answer was retrieved.

We also performed searches for incidents after purposive sampling: four reported incidents in one of the five major health care sectors to retain a wide focus (hospital care, primary care, mental care, long-term care, and home care). We asked the DHI to select incidents for which it was unclear whether action by the health care inspectorate was necessary. The search queries were developed and results were summarized using the same procedure as the first search. Since the first round taught us that two options for categorization did not provide enough differentiation, we added two categories. Inspectors could determine the relevance of all information found by selecting one of the following options: Relevant, information leads to immediate action (3), Relevant, information leads to further investigations (2), Relevant, information found leads to a signal in the file of the organization (1), or No additional value (0). A description of each option is provided in Multimedia Appendix 1.

Searches for Information for Risk-Based Supervision

First, we asked DHI experts to select high-risk themes for which additional information was preferred. Second, one researcher (TB) developed a search query for each high-risk theme, which was peer-reviewed by a second researcher (LV). After discussion and improvement, a DHI expert working on the selected high-risk themes peer-reviewed the queries, which resulted in the final search strategies. Third, we performed searches for the high-risk themes and presented results in a spreadsheet. In case a result concerned a rating, the ones without a textual description or ratings ≥7 (on a scale from 1 “extremely bad” to 10 “excellent”) were excluded. The latter was done since we reasoned that the useful information for inspectorates would be found in ratings <7. Subsequently, both researchers independently filtered results based on relevance by reading individual results and comparing it to the search query. All results for which no relation to the search could be determined were excluded. For example, if the search included “long-term elderly care”, results about providers working in other sectors such as care delivery by a local GP were excluded. Fourth and last, one expert per theme determined the relevance of each

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result following the same procedure and the same options as described above and in Multimedia Appendix 1.

Ethical Approval

Since this study used anonymous data from the public domain and without patient involvement, no ethical approval was needed in the Netherlands. More specifically, all data we used from the rating site ZorgkaartNederland.nl are publicly available. Furthermore, we obtained permission from the DHI to perform the study and acquired the data needed for this study.

Results

Incident-Based Supervision

We identified 11 possible tools that could be used to find additional information for incident-based supervision. Based on each tool's features, we selected four tools to perform our searches: Coosto, Google, Addictomatic, and ZorgkaartNederland. Further information about each tool's features and the selection of tools is provided in Multimedia Appendix 2.

Table 1 shows the results of the searches for incident-based supervision. The 20 searches performed for randomly selected incidents (Round 1) resulted in additional information for six cases. Following review by the inspectors of the DHI, the additional information led to adding a "signal" in three cases. A signal implies that information about specific cases or issues is added to the DHI's files, allowing the DHI to keep track of relevant issues over time. All relevant results were found via the source ZorgkaartNederland, a major Dutch rating site. Therefore, we only consulted ZorgkaartNederland in Round 2. The 20 searches performed for the non-randomly selected incidents resulted in additional information for three cases. After assessment, the additional information found led to adding a signal in two cases. In one case, the information found led to further investigation into the case.

Table 1. Added value of information for incident-based supervision.

	Incident-based supervision, Round 1 (n=20)	Incident-based supervision, Round 2 (n=20)
Immediate action required	0	0
Information leads to further research	0	1
Information leads to signal	3	2
Information found but no added value	3	0
No information found	14	17

Risk-Based Supervision

Regarding the searches for risk-based supervision, the DHI selected the high-risk sector long-term elderly care, combined with four specific themes that form major safety risks: hygiene, professional expertise, medication safety, and restriction of freedom. Based on results from the searches for incident-based supervision, Coosto was selected as the preferred tool to perform all four searches. ZorgkaartNederland was selected as the preferred source since the first part taught us that it was the only source that provided us with relevant results. Table 2 provides detailed information about the number of hits, ratings that remained after exclusion, and the results after assessment by a health care inspector. The added value of the information varied between the four themes: restriction of freedom (100%, 2/2), hygiene (88%, 22/25), medication safety (76%, 16/21), and expertise (47%, 32/68).

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Table 2. Added value of information for risk-based supervision.

		Indicator 1: Long-term elderly care and hygiene	Indicator 2: Long-term elderly care and expertise	Indicator 3: Long-term elderly care and medication (safety)	Indicator 4: Long-term elderly care and restriction of freedom
		n (%)			
Hits (n)		79 (100%)	117 (100%)	49 (100%)	11 (100%)
Results remaining after exclusion of ratings 7 or higher		38/79 (48%)	90/117 (77%)	34/49 (69%)	7/11 (64%)
Results remaining for assessment by health care inspector after exclusion ratings not related to search query		25/79 (32%)	68/117 (58%)	21/49 (43%)	2/11 (18%)
Results after assessment by DHI					
	Immediate action required	0/25 (0%)	0/68 (0%)	0/21 (0%)	0/2 (0%)
	Information leads to further research	9/25 (36%)	1/68 (1%)	1/21 (5%)	0/2 (0%)
	Information leads to signal	13/25 (52%)	31/68 (46%)	15/21 (71%)	2/2 (100%)
	No added value of the information found	3/25 (12%)	36/68 (53%)	5/21 (24%)	0/2 (0%)

Discussion

Principal Findings

In this study, we showed that a Dutch health care rating site can be used to identify additional information for supervising quality and safety, especially in long-term elderly care. These findings indicate that social media may enable supervisory bodies to include the patients' perspective in a more efficient way. Regarding incident-based supervision, social media provided relevant additional information in six of 40 incidents, and for risk-based supervision, social media provided relevant additional information in 72 of 116 cases. Additional information led to a signal or to further research. Although these numbers are promising for supervisory bodies looking for an efficient way of collecting information from the patients' perspective on health care providers, several things need to be discussed.

In keeping with our approach, we aimed at including all Dutch social media sources. It appeared that the rating site ZorgkaartNederland was the only source that provided information that was of additional value for the DHI. It may seem surprising that only one social media source, among the plethora of other sources such as forums and social networks like Twitter and Facebook, resulted in additional information. Apparently, Dutch people are not likely to share their experiences with health care in combination with the name of their health care provider in tweets or public Facebook posts. Regarding ZorgkaartNederland, it should be considered that it is the only Dutch website with a list of all officially registered health care providers and organizations, which aims to collect as many ratings as possible. Furthermore, ZorgkaartNederland is a non-commercial initiative supported by the Dutch Federation for Patients and Consumers. As a result, people willing to share a rating or their experiences are likely to use ZorgkaartNederland. There are hardly any serious competitors. Therefore, ZorgkaartNederland could be, at least at the present time, a valuable source of information for the DHI. It would be worthwhile to explore the possibility of creating a direct link between relevant social media sources such as ZorgkaartNederland and the DHI (eg, via an open API), allowing the DHI to make a selection of ratings available for use in daily practice. In fact, the DHI is already implementing a system in which information from ZorgkaartNederland is imported into a risk database for its daily supervision.

In this study, we performed searches for the two most used instruments by health care inspectorates: supervision in response to reported incidents and risk analysis. The results show that the searches for risk-based supervision resulted in more relevant information than searches for reported incidents. This can be explained by the search goals for every search. Regarding searches for supervision based on reported incidents, searches were created using the information from the reported incident only, and we aimed to find information that could indicate similar events or structural problems regarding one provider or organization only. Regarding the searches for supervision led by risk analysis, we created searches aimed at finding relevant information about a specific theme in a group of health care providers or organizations within an entire sector. The added value of the information varied strongly: restriction of freedom (100%), hygiene (88%), medication safety (76%), and expertise (47%). This might be explained by the extent in which lay people are able to judge health care situations (eg, it is easy to see that toilets are dirty, but it is harder to determine whether you were given the correct dosage of medication). Searching for additional information for an entire theme with one search (risk analysis) is less time consuming than creating a unique search for every individual case (reported incidents).

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Future Research

In the present study, we performed searches for risks in four sectors in part one and one sector in part two. Therefore, future projects should investigate the generalizability to other health care sectors. This seems to be particularly relevant since the use of rating sites may be different for different demographical groups [24]. In contrast to the present study in which we used social media in a passive way, we feel that it would also be worthwhile to explore the use of social media in an active way, especially since social media facilitate interaction [1]. Besides, some other Dutch inspectorates already use social media interactively. For example, the Dutch Inspectorate for Social Affairs and Welfare uses a mobile phone app to enable consumers to share information about local asbestos conditions [25]. Furthermore, the Dutch Food and Consumer Product Safety Authority crowdsources information about plants that cause hay fever [26]. A hypothetical way of interactive use of social media by the DHI is actively requesting information from for example staff, patients, or relatives via social media, in preparation for inspections.

Limitations

The use of social media for supervision of health care has some limitations, such as the lack of sufficient information, which has been recognized before [27]. A minimum amount of information is needed to provide robust predictions. Although this is investigated for tweets and not for ratings, it seems likely that the similar principle goes for ratings. As a result, there may be sectors with insufficient numbers of ratings to be of value for the DHI. Therefore, caution is advised and it is important to verify the number of ratings. A second limitation is related to our study design. Following our approach, only one expert per sector or theme determined the added value of social media. Since we have discussed the results with several other DHI experts, we think this has not affected our results significantly. However, future studies should aim to determine the value of the information based on at least two DHI experts by, for example, determining the inter-rater variability. A third limitation is related to the timeliness of the results found. In this study, only the source ZorgkaartNederland provided relevant information. In the Internet era, social media networks and rating sites can rapidly appear or disappear. Therefore, other sources can become more relevant for the DHI in the near future, and future studies should aim to keep their focus wide to assure that all relevant sources are searched. Another opportunity to look for information could be to explore specific (popular) sources with tailor-made research designs. This has recently been done for Twitter [16]. Last, we add that the generalizability of this study to other countries should also be explored since every country has its own systems of supervision and rating sites will be different.

Conclusion

We conclude that social media could be used to include the patient's perspective in supervision. This information could be of importance for health care inspectorates, particularly for its enforcement by risk-based supervision of elderly care. Further research is needed to determine the added value for other health care sectors.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Scoring options to indicate the value of the information found.

[PDF File (Adobe PDF File), 4KB - jmir_v17i1e7_app1.pdf]

Multimedia Appendix 2

Features of the potential search tools.

[PDF File (Adobe PDF File), 3KB - jmir_v17i1e7_app2.pdf]

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Abbreviations

DHI: Dutch Healthcare Inspectorate
SMMT: social media monitoring tool

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Original Paper

Health Checkup and Telemedical Intervention Program for Preventive Medicine in Developing Countries: Verification Study

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Abstract

Background: The prevalence of non-communicable diseases is increasing throughout the world, including developing countries.

Objective: The intent was to conduct a study of a preventive medical service in a developing country, combining eHealth checkups and teleconsultation as well as assess stratification rules and the short-term effects of intervention.

Methods: We developed an eHealth system that comprises a set of sensor devices in an attaché case, a data transmission system linked to a mobile network, and a data management application. We provided eHealth checkups for the populations of five villages and the employees of five factories/offices in Bangladesh. Individual health condition was automatically categorized into four grades based on international diagnostic standards: green (healthy), yellow (caution), orange (affected), and red (emergent). We provided teleconsultation for orange- and red-grade subjects and we provided teleprescription for these subjects as required.

Results: The first checkup was provided to 16,741 subjects. After one year, 2361 subjects participated in the second checkup and the systolic blood pressure of these subjects was significantly decreased from an average of 121 mmHg to an average of 116 mmHg (P<.001). Based on these results, we propose a cost-effective method using a machine learning technique (random forest

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method) using the medical interview, subject profiles, and checkup results as predictor to avoid costly measurements of blood sugar, to ensure sustainability of the program in developing countries.

Conclusions: The results of this study demonstrate the benefits of an eHealth checkup and teleconsultation program as an effective health care system in developing countries.

(J Med Internet Res 2015;17(1):e2) doi:10.2196/jmir.3705

KEYWORDS

public health informatics; preventive medicine; teleconsultation; body area network; sensor; developing countries

Introduction

The prevalence of non-communicable diseases (NCDs), such as heart disease, stroke, cancer, chronic kidney diseases, and diabetes mellitus, has been increasing rapidly worldwide. The World Health Organization reported that NCDs accounted for 63% (36 million) of the 57 million global deaths in 2008 and approximately 80% of all NCD-related deaths occurred in low- and middle-income countries [1]. In these developing countries, 29% of NCD-related deaths occurred in the working-age group (in people aged <60 years). This rate is higher than that for high-income countries (13%) and contributes to declining labor productivity in developing countries. The total number of annual NCD-related deaths is estimated to reach 55 million by 2030 [2]. NCDs are no longer just a problem for high-income countries, but a problem that affects all countries.

Preventive medicine is the key to combat NCDs. Preventive medicine comprises three levels: primary prevention (maintaining a healthy condition), secondary prevention (avoiding the development of NCDs), and tertiary prevention (preventing the progression of NCDs into serious medical conditions). Over time, the focus of medical services in developed countries has changed from acute and serious diseases to the management of chronic diseases. Developing countries have the opportunity to follow a different path, through the implementation of low-cost preventive and compassionate health care/medical services based on information and communication technology (ICT) [3].

In this study, we aimed to evaluate the impact of our preventive health care/medical program consisting of primary, secondary, and tertiary prevention services provided to >10,000 subjects in Bangladesh. We selected Bangladesh as the research area because, while there are few medical institutions in rural areas, there are many pharmacies and the mobile Internet network has spread throughout the nation, as is the case in many developing countries.

We conducted the research over 2 years, applying eHealth solutions and telemedical interventions in an attempt to ensure an accurate stratification balance and assess the effects of intervention after 1 year in >2000 subjects.

The target diseases in this program are chronic NCDs including diabetes mellitus and hypertension, which are rapidly increasing in developing countries. Sensor devices, including blood glucose meters and blood pressure meters, have been developed for the management of these diseases and are widely available. The World Bank Group's *Disease Control Priorities in Developing Countries* has also emphasized the paramount importance of risk management of chronic NCDs [4]. Using machine learning, we attempted to establish a method to decrease the cost of health checkups by predicting the results of expensive health check tests.

Methods

Overview

We developed an eHealth system named the Portable Health Clinic (PHC). PHC comprises a set of sensor devices in an attaché case, a data transmission system linked to a mobile network, and a data management application. The system can be used by operators with minimal information technology literacy to provide health checkup services, even in rural areas. We included a teleconsultation service using Skype over the mobile network to gather data on health. To assess the usability and sustainability of the system, we designed a study model including local pharmacies to provide a teleprescription service. We conducted a field study from July 2012 to March 2014 (first year: July 2012-February 2013; second year: June 2013-March 2014).

The Portable Health Clinic

We selected sensor devices based on international information standards and approved by Japanese pharmaceutical law. If a device did not have a standard transmission format, we attached a body area network (BAN) interface to the sensor. The BAN was published as IEEE802.15.6 in 2012 and uses frequency bands approved by national medical and/or regulatory authorities and the industrial, scientific, and medical (ISM) band [5]. In addition to the dedicated medical bands, it provides quality service, extremely low power, and a data speed of up to 10 Mbps, supports medical security, and emergency data handling.

For easy portability, we put the components into an attaché case. The attaché case was equipped with an Android tablet, consumable goods, including urine and blood sugar test strips, batteries, paper, and pens. The total weight of the attaché case and contents was approximately 10 kg (Figure 1).

An Android tablet served as a data input terminal, aggregating data via BAN and manual input and communicating with the sensor server. Results of individual health checkups, including the stratification level, were shown on a local site. The main server in a medical call center in Dhaka, the capital of Bangladesh, stored all sensor data. Data was available to doctors through the call center.

Local servers temporarily stored data from the Android tablet via wireless-LAN and synchronized data with the main server

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when an Internet connection was available. This use of local servers enabled PHC operators to upload their data even if an Internet connection was temporarily unavailable.

Figure 1. The Portable Health Clinic System package.



Stratification Algorithm

Before the study commenced, we established "Bangladesh-logic" for risk stratification using international diagnostic standards [6-10] to rank the risk grade into four groups—green (healthy), yellow (caution), orange (affected), and red (emergent)—based on the results of each health checkup item (Table 1). The overall health condition of each subject was also determined by integrating the results of questionnaires into the four groups by the worst color of all health checkup items. Examples of the determination of overall health conditions based on the results of each health checkup item are as follows:

- Green, Orange, Green, …, Yellow → Orange
- Green, Green, …, Green (all Green) → Green

The presence or absence of arrhythmia was determined using a blood pressure meter. Data on smoking and time since the last meal were obtained from questionnaires.

Table 1. Bangladesh-logic: criteria for risk stratification.

		Green	Yellow	Orange	Red
Waist (cm)					
	Male	<90	≥90		
	Female	<80	≥80		
Waist/hip ratio					
	Male	<0.90	≥0.90		
	Female	<0.85	≥0.85		
Body mass index (kg/m^2)		<25	≥25, <30	≥30, <35	≥35
Blood pressure (mmHg)					
	Systolic	<130	≥130, <140	≥140, <180	≥180
	Diastolic	<85	≥85, <90	≥90, <110	≥110
Blood sugar (mg/dl)					
	Fasting	<100	≥100, <126	≥126, <200	≥200
	Postprandial	<140	≥140, <200	≥200, <300	≥300
Urine-protein		Negative	Trace	Positive	
Urine-sugar		Negative	Trace	Positive	
Urine-urobilinogen		Trace		Positive	
Pulse rate (bpm)		≥60, <100	≥50, <60 ≥100, <120	<50 ≥120	
Arrhythmia		No		Yes	
Smoking		None	+		
Body temperature (°C)		<37	≥37, <37.5	≥37.5	
Oxygen saturation (SpO_2) (%)		≥96	≥93, <96	≥90, <93	<90

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Questionnaires on First and Second Visits

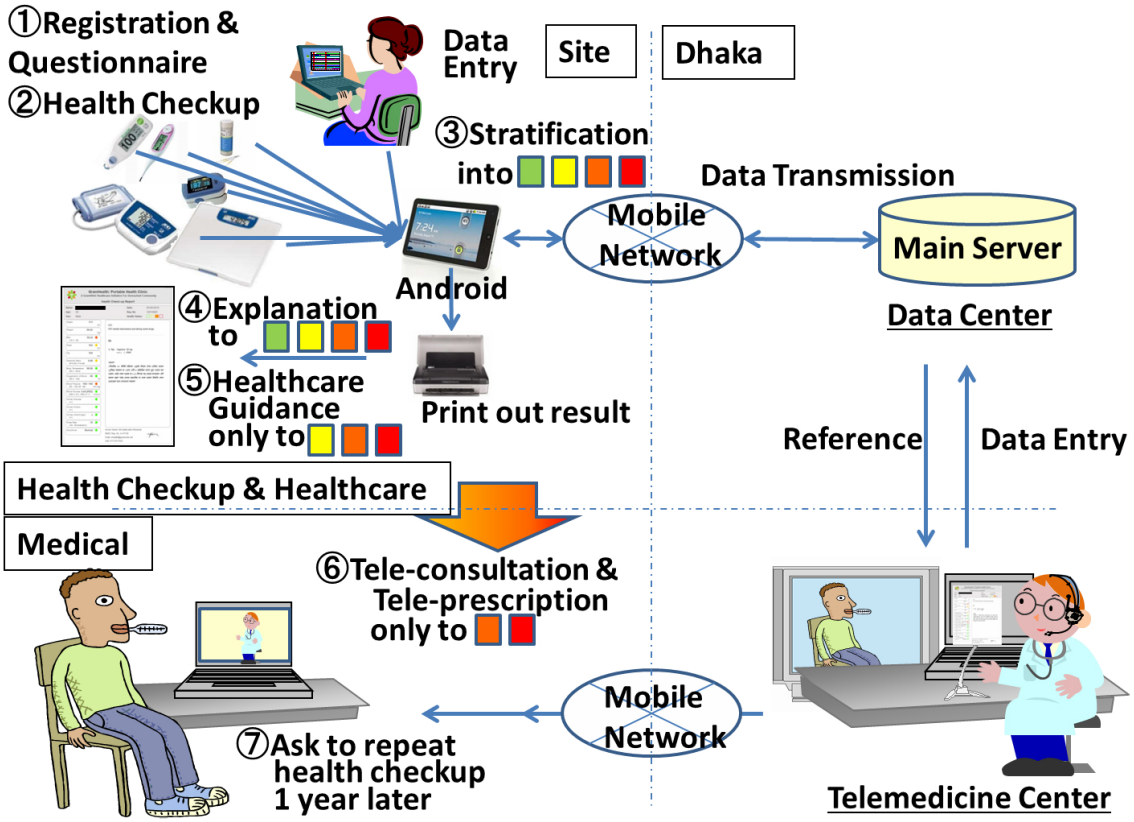
During health checkup visits, we surveyed subjects using questionnaires written in Bengali. Because the literacy rate is <60% in Bangladesh, a staff member read the questionnaire to the subjects and entered response data into the system. On the first visit, we asked about literacy, occupation, time since the last meal, present symptoms, past diseases, medication, smoking, weight change, exercise, walking speed, eating behavior, sleeping, and the desire to have a healthy lifestyle. For orange- and red-grade subjects, we administered the questionnaire for teleconsultation with questions including information on drug allergy and surgical history. For subjects who participated in both the first and second years, we administered a different questionnaire at the second visit with questions regarding memory and effects of the first health checkup, psychological (Prochaska's) staging, present symptoms, and medication.

System Operation

We provided a health care service for the study, including a health checkup using sensor devices in the PHC, data storage in the call center, a health report, health care guidance according to the situation of individuals, and a teleconsultation with a doctor in the medical call center (Figure 2). We conducted the study in five rural villages and five factories/offices in Bangladesh. In the first year, we conducted the study around Dhaka (Dhaka, Shariatpur, Chandpur, and Gazipur) because of a logistics problem. In the second year, we selected sites from all over the country to check the country's health status. The sites of the second year are Chittagong (south-eastern area), Rajshahi (western area), Thakurgaon (north-western area), and around Dhaka.

At the first visit, after registration, the subjects received an ID card with a barcode (Step 1 in Figure 2). After completing the questionnaire, the subject underwent the health checkup with the sensor devices in the PHC (Step 2). Both the blood glucose and urine tests were performed by qualified health care professionals, whereas the other tests were performed by trained staff. We cross-checked the urine test results of the workers every 2 or 3 months because this test requires visual judgment. Other devices, including blood glucose devices, display numerical results and we do not require calibration among workers. The data were stored in an Android tablet and in the main server in Dhaka. Categorized results for the four risk groups, graded from green to red according to the Bangladesh-logic, were printed out (Steps 3 and 4) and explained to the subject by the local staff (Step 4). A booklet was provided to all subjects graded yellow, orange, or red (Step 5). We provided telemedical intervention with a doctor in Dhaka for orange- and red-grade subjects (Step 6). Because we selected sites from around Dhaka in the first year, subjects in the village and factories/offices around Dhaka were asked to undergo the health checkup 1 year later to enable assessment of the effects of the program (Step 7).

Figure 2. Work flow (Steps 1–7) and data flow (arrows) of the service.



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Teleconsultation and Teleprescription

After the health checkup, we provided telemedical intervention for orange- and red-grade subjects via mobile network contact (Skype) with the medical call center in Dhaka. Because most areas in Bangladesh have Internet access (2G/3G), we brought laptop PCs or tablet PCs (iPad) with mobile routers to the checkup sites. The staff set up special rooms for teleconsultations at checkup sites and assisted subjects to communicate with remote doctors in Dhaka. Doctors had access to the results of health checkups via the Internet and they were able to provide advice on disease management and encourage subjects to visit a clinic. Where required, the doctors could send a teleprescription for anti-hypertensive medication via the network. In our program, subjects who received a teleprescription could visit their local pharmacy to purchase medication.

Booklet for Health Guidance

We provided an 11-page booklet to educate subjects graded yellow, orange, or red. The booklet contained information on the risks of NCDs, including obesity, hypertension, diabetes mellitus, smoking-related diseases, and chronic kidney disease. We prepared both English and Bengali versions of the booklet and provided the Bengali version to the subjects in the study. For subjects who could not read Bengali, a staff member explained the checkup results and provided health care guidance orally.

Ethical Considerations

The Kyushu University Institutional Review Board for Clinical Trials approved the protocol of this verification study in 2012. We applied for the IRB of Kyushu University, Japan, because participant groups in Bangladesh had no IRB. We prepared a consent form, etc, after discussing with the local doctors.

Results

Overview

There were 16,741 subjects assessed at the first health checkup, 9143 (54.61%) males and 7598 (45.39%) females (Table 2). There were 9309 (55.61%) subjects from urban areas and 7432 (44.39%) subjects from rural areas. Most of the subjects in urban areas were male (male/female=6299/3010), whereas female subjects were more numerous in the rural areas (male/female=2844/4588). Figure 3 shows images of the health checkup and teleconsultation process in a rural area.

Figure 4 shows the age distribution for rural and urban areas. There was a wide age distribution in rural areas, while there was a clear peak in the number of subjects aged in the late 20s in urban areas. The average age was 35.1 (SD 12.7) years for male subjects and 36.7 (SD 12.8) years for female subjects. The average age was 43.6 (SD 14.0) years for rural subjects and 29.6 (SD 6.9) years for urban subjects.

The results of the first health checkup are shown in Figure 5. Based on the assessment of overall health condition, we identified 5419 out of 16,741 subjects (32.37%) as affected (orange or red) and 9057 subjects (54.10%) as caution required (yellow). There were 10,879 subjects (64.98% of the total 16,741) graded yellow based on the waist/hip ratio, 5535 (33.06%) graded yellow or higher based on a blood pressure test, and 1402 (8.37%) graded yellow or higher based on a blood sugar test. Subjects were graded red (emergent) based on body mass index (BMI) (39 subjects), blood pressure (258), blood glucose (181), and oxygen saturation (SpO_2; 6). We provided a teleconsultation service to affected subjects (orange or red, n=4899).

Table 2. The number of subjects by sex and location (the number of subjects who participated in both the 2012 and 2013 checkups are indicated in parentheses).

Location	Male	Female	Total
Rural	2844 (177)	4588 (234)	7432 (411)
Urban	6299 (1412)	3010 (538)	9309 (1950)
Total	9143 (1589)	7598 (772)	16,741 (2361)

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Figure 3. Images of a health checkup and teleconsultation.

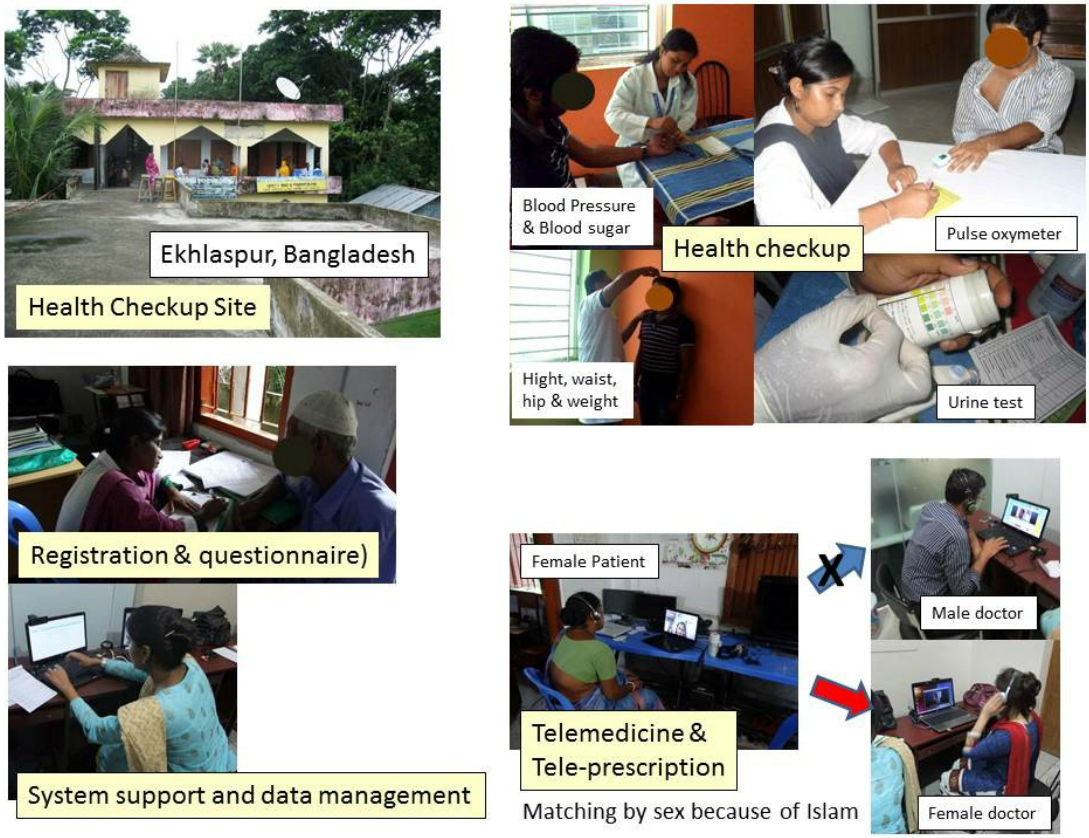
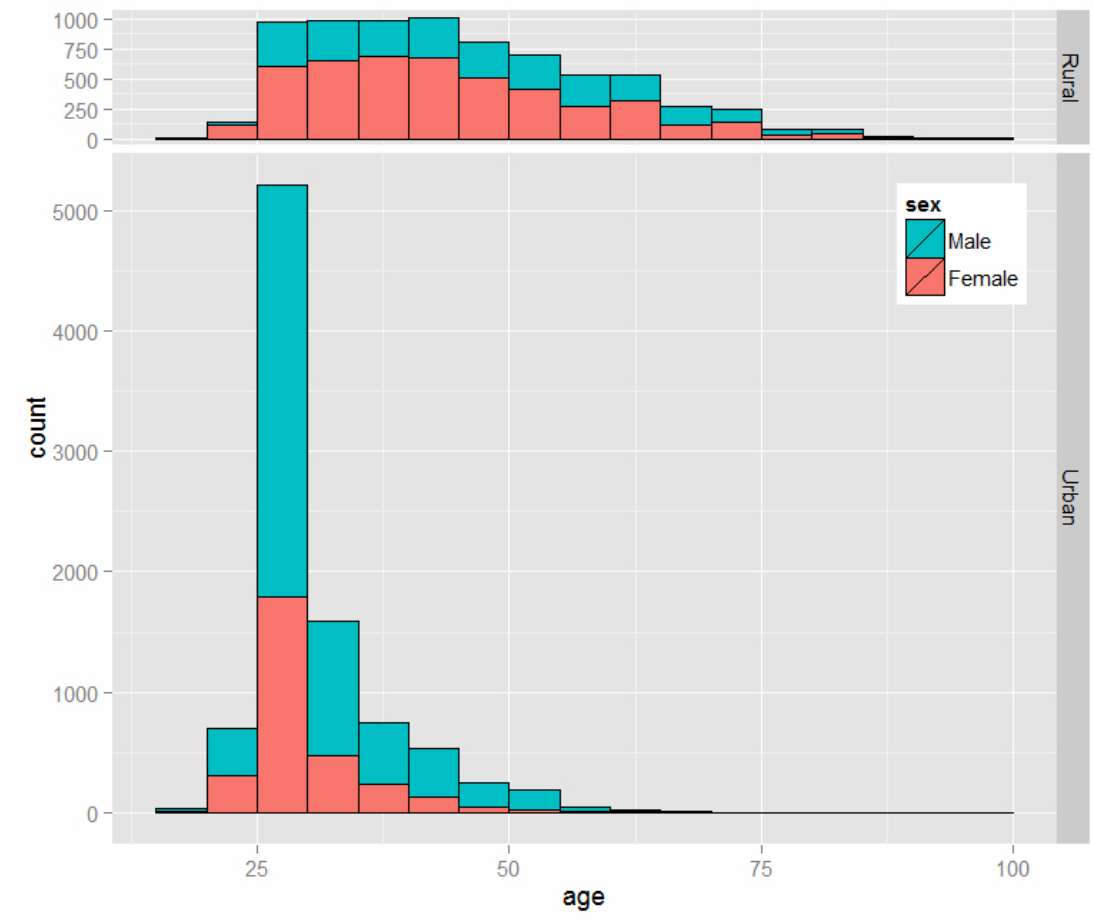
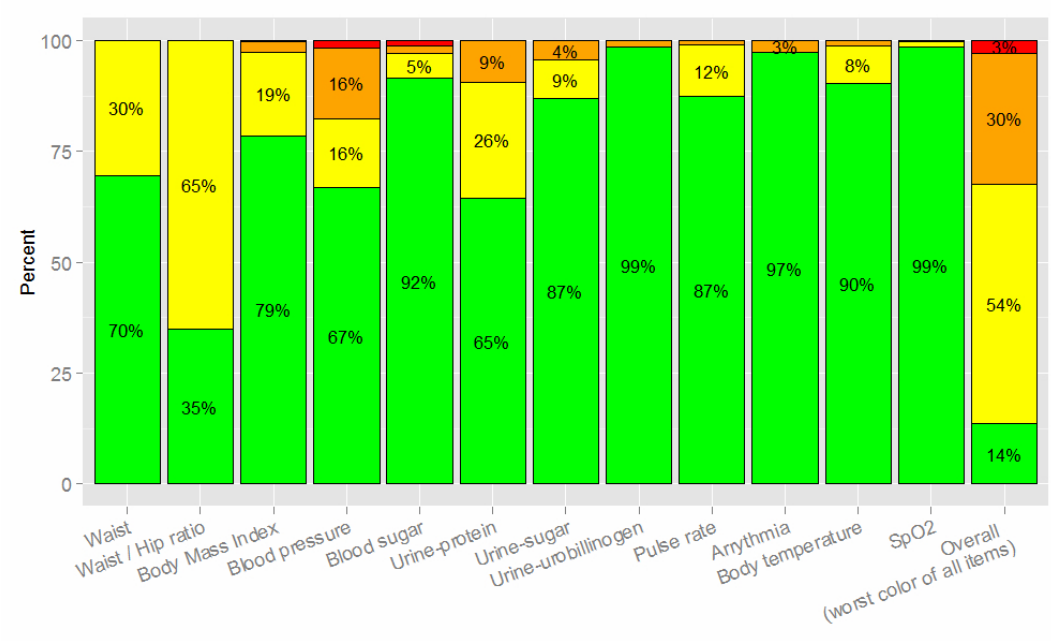


Figure 4. Age distribution for rural and urban areas.



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Figure 5. Detailed results showing grading (green, yellow, orange, or red) for each investigation.



Risk Factors Associated with Overall Health Condition

Figure 6 shows the overall results with regard to age, sex, and area. To identify risk factors for NCDs related to overall health condition results, we used logistic regression analysis with the overall result (orange/red: true or green/yellow: false) as the outcome and age, sex, site type, occupation, and literacy as independent variables (n=16,315). The results are presented in Table 3. Variables that were significantly associated with overall health condition (P<.05) are noted.

The results of the analysis indicate that older age, female, and living in a rural area were risk factors for NCDs. Contrary to our expectations, literacy (and not illiteracy) was also a risk factor. When we changed the outcome of logistic regression analysis from the overall result to the result of each individual checkup item, we found that literacy was also a risk factor for high BMI, blood pressure, blood glucose, and urine glucose. Conversely, there was no significant difference between literacy and illiteracy for urine protein and urobilinogen levels, pulse rate, arrhythmia, body temperature, and SpO_2.

Because significant variables were related to body mass, we generated the hypothesis that literate subjects: (1) earn more and tend to overeat, (2) do not get enough exercise because they use their own mode of transport or public transport, and (3) lack a basic awareness of health.

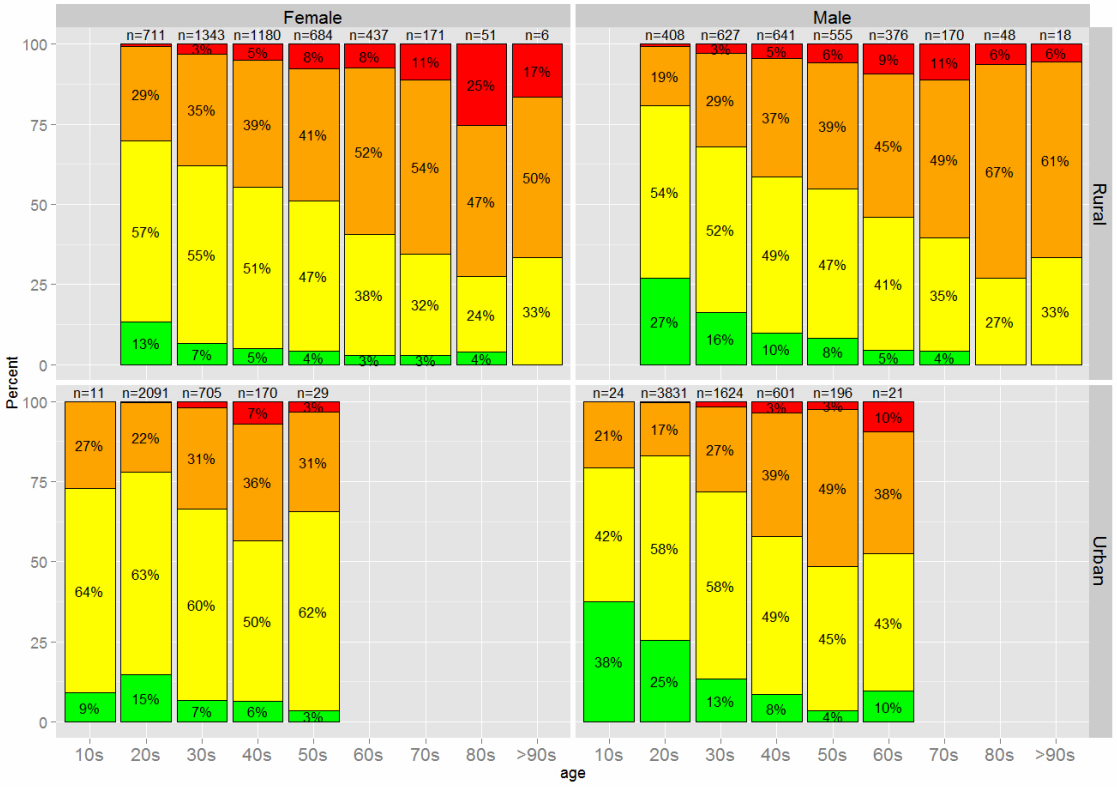
Table 3. Risk factors for NCDs associated with the overall health.

Variables		Odds ratio (95% CI)	*P* value
Age		1.04 (1.04-1.05)	<.001[a]
Sex (male)		0.78 (0.71-0.86)	<.001[a]
Area (urban)		0.66 (0.56-0.78)	<.001[a]
Occupation			
	Daily labor	0.56 (0.45-0.69)	<.001[a]
	Business	0.83 (0.68-1.01)	.063
	Private/government service	1.00 (reference)	–
	Student	0.43 (0.27-0.66)	<.001[a]
	Housewife	0.86 (0.71-1.03)	.108
	Unemployed	0.80 (0.64-1.01)	.055
Literacy		1.24 (1.14-1.36)	<.001[a]

[a]Variables were significantly associated with overall health condition (P<.05).

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Figure 6. Overall results by age, sex, and area (subject numbers are shown above the columns).



Comparison With Results of Health Checkups in Japan

Because NCD problems are spreading from advanced countries to developing countries, it is important for preventive medicine in developing countries to use past experiences in advanced countries. Moreover, experiences in developing countries could improve preventive medicine in advanced countries, the so-called “reverse innovation”. On the other hand, problems specific to each country exist and we need to cope with individual issues. In order to separate the problems, we compared the results of the present study with data from the 2012 National Health and Nutrition Survey in Japan (n>15,000), which was conducted by the Japanese Ministry of Health, Labor and Welfare [11]. The results of the present study were corrected to match the sex and age distribution of the Japanese dataset. Figure 7 shows the results of the comparison. The blue color in the BMI column indicates BMI <18.5 kg/m^2, meaning subjects were underweight.

The comparison shows that there were many underweight subjects (blue in BMI) in Bangladesh and that more Bangladeshi subjects were ranked green compared with Japanese subjects. However, the number of Bangladeshi and Japanese subjects ranked orange and red for BMI, waist/hip ratio, and blood pressure was similar, despite very different average income, living conditions, and eating habits in the two countries. Conversely, the results of blood sugar and urine protein tests were quite different between the two countries. This may be a result of regional differences because the results of the urine protein test differed among sites in Bangladesh (Figure 8). We would like conduct further research and learn to cope with the individual issues in Bangladesh.

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Figure 7. Comparison of health checkup results for Bangladeshi (BD) and Japanese (JP) subjects.

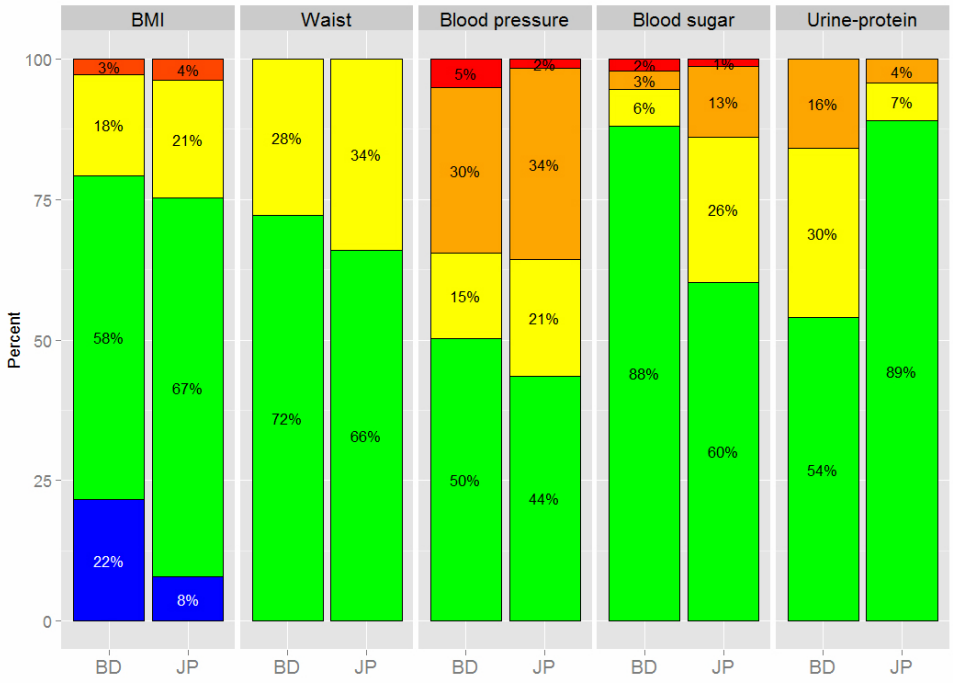
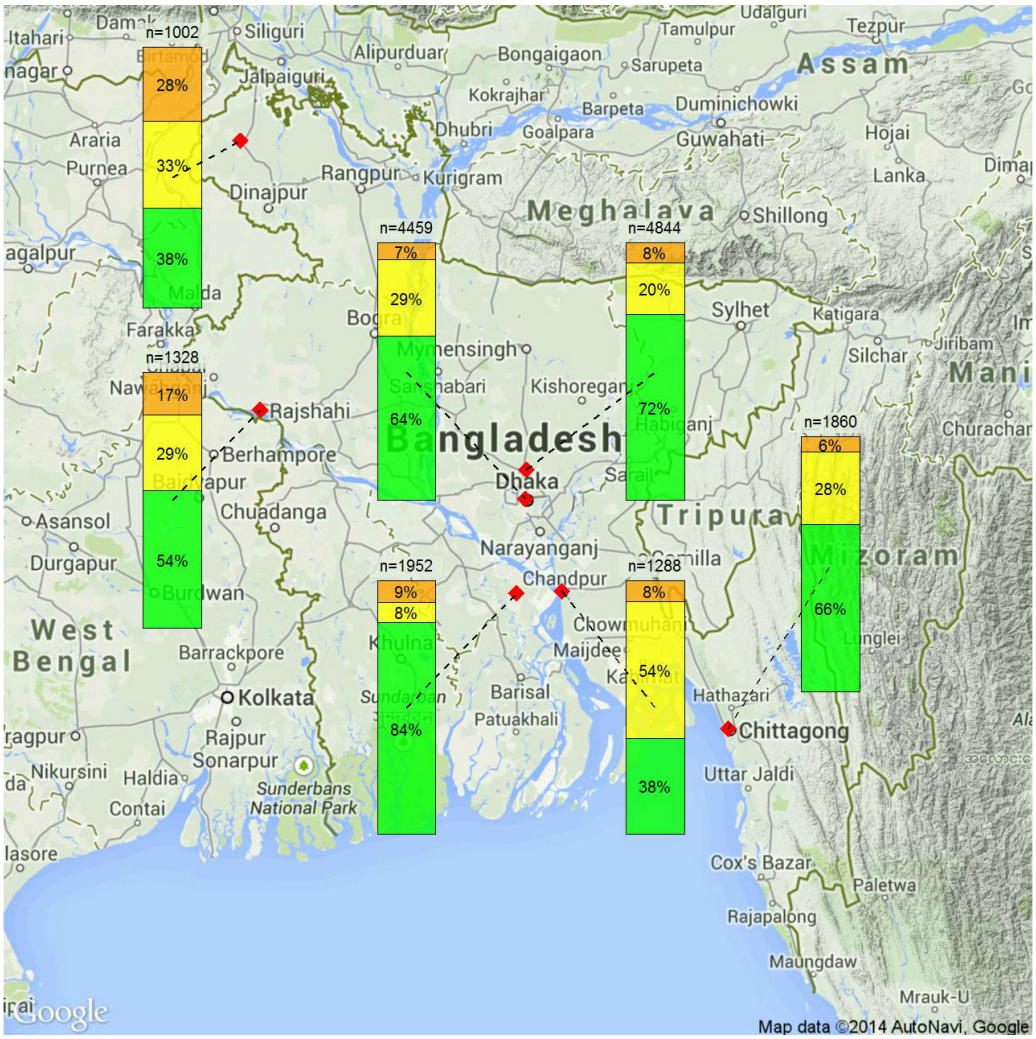


Figure 8. Results of the urine protein test for each checkup site in Bangladesh.



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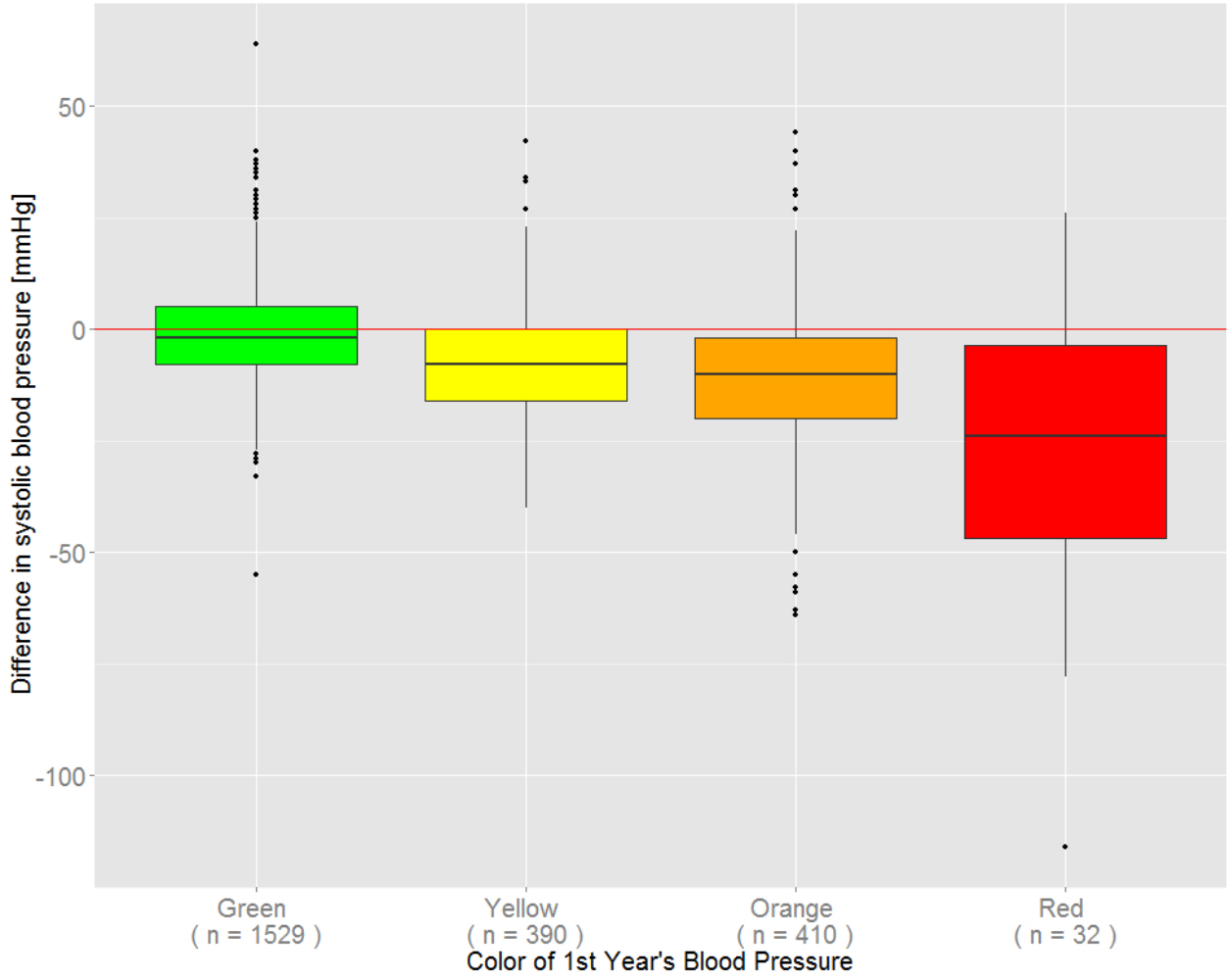
The Second Health Checkup

There were 2361 subjects who participated in both the 2012 and 2013 health checkups. The details are indicated in parentheses in Table 2. Mean systolic blood pressure (SBP) in the first year (2012) was 121 (SD 17) mmHg and in 2013 it was 116 (SD 15) mmHg. Figure 9 shows the difference in SBP between the 2 years arranged by the ranked color of the first blood pressure test. There was a significant decrease in SBP for all color rankings (P<.001).

To determine which subjects showed improved health over the study period, we attempted to predict which subjects would have better health at the second checkup. There were 2110 subjects who had a medical interview at the first checkup and 640 of those subjects were graded as red or orange. Of those 640 subjects, 326 improved their health to green or yellow in the second year.

To further investigate the subjects with improved health, we applied a machine learning technique, the random forest method [12], using the medical interview, subject profiles, and checkup results as the explanatory variables. From the 640-subject dataset, we separated 60% as training sets and 40% as test sets without replacement and ran the estimation. The area under curve (AUC) for 20 trials was 0.7676 (SD 0.0267). The main factors that contributed to the estimation were age, BMI, waist/hip ratio, urine protein, and blood pressure. Based on these findings, we proposed a preferred intervention to help subjects to improve their health.

Figure 9. Difference in systolic blood pressure based on color ranking at the first checkup.



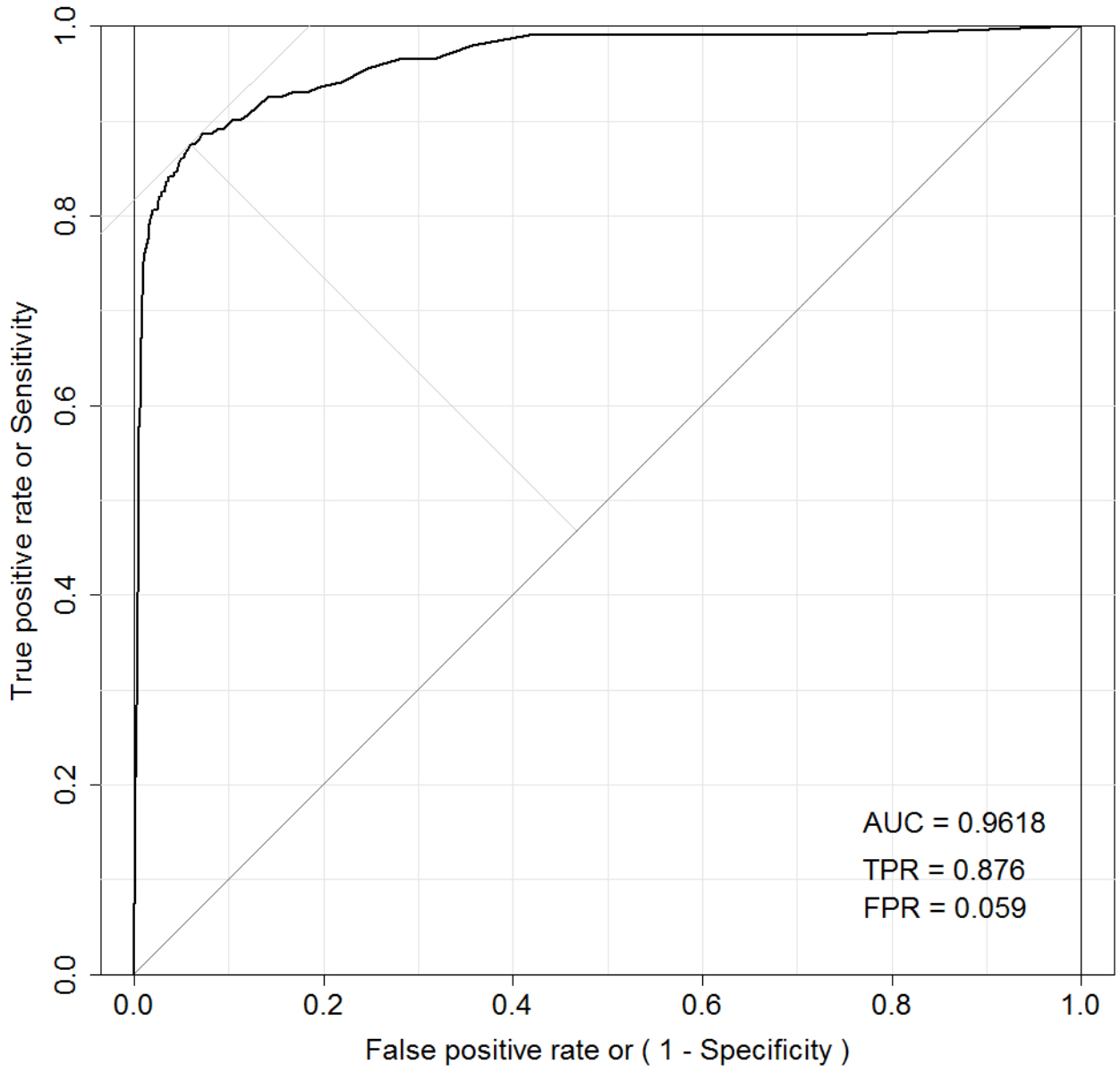
Predicting Blood Glucose Test Results

We applied the random forest method [12] using the medical interview, subject profiles, and checkup results (excluding the blood glucose test result) as explanatory variables to estimate the Bangladesh-logic ranking of red and orange based on the blood glucose test. From the 15,705-subject dataset (true/false=462/15,246), we separated 60% as training sets and 40% as test sets without replacement, and ran the estimation. AUC for 20 trials was 0.9565 (SD 0.0072). Figure 10 shows a receiver operating characteristic (ROC) curve (AUC=0.9618).

Based on Youden's index, which maximizes the distance from the 45° line on the ROC curve (the upper left point in Figure 10), the true positive rate was 87.6% and the false positive rate was 5.9%.

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Figure 10. ROC curve for predicting blood sugar.



Discussion

Comparison With Prior Work

In recent years, there have been many projects aimed at improving health care in developing countries. Some projects have focused on more specialized and technical approaches, including immunological or enzymatic assays for bacterial toxins [13], and retinal photography, Doppler imaging, biothesiometry, and electrocardiography to detect diabetic complications [14]. Ramachandran et al [15] showed that lifestyle modification could prevent type 2 diabetes in Asian Indian subjects. We targeted the general population and focused on primary prevention; therefore, our eHealth system comprised only basic biosensors to conduct the health checkup.

In this study, we detailed the design of our health care program and presented the results of the study conducted in five villages and five factories/offices in Bangladesh. A study of an Android-based mHealth system in South Africa showed that the system was more cost-effective than pen and paper alternatives [16]. This finding matches our experience in the present study. An intervention program in India found that mobile phone messaging (eg, short messaging service) was an effective and acceptable method for the delivery of advice and support for lifestyle modification to prevent type 2 diabetes in men at high risk [17]. The results of our study suggest that literate subjects are at high risk of NCDs based on high BMI, blood pressure, blood glucose, and urine glucose results, and a mobile phone messaging system would be an effective approach to improving their health.

Results of the Health Checkup

We found a high rate of obesity based on a high waist/hip ratio (metabolic syndrome) and a high rate of hypertension at the

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first health checkup. A high carbohydrate and oil-rich diet may contribute to obesity in Bangladesh. In addition, the use of salt to preserve food where refrigeration is not widely available may increase the risk of hypertension. Conversely, despite the high prevalence of obesity, diabetes prevalence was not high, probably a result of high exercise levels. Many subjects were graded yellow based on the urine protein test. Chowdhury et al [18] have reported widespread arsenic contamination of drinking water in Bangladesh. We are currently investigating whether pollution with arsenic and heavy metals, such as cadmium, affects urine tests directly or causes kidney dysfunction.

At the first checkup, 472 of 16,741 subjects were graded red. This is potentially an important outcome of the study because we were able to initiate intervention for these high-risk subjects with health care guidance, teleconsultation, and encouragement to visit a clinic.

At the second checkup, there was a significant decrease in SBP for all color rankings ($P<.001$), even if the subjects were graded as green or yellow at the first checkup. This result indicates that the health of the subjects improved even with knowledge of the initial result and basic health guidance without intervention by a doctor.

Cost Evaluation

In this study, we performed all the available tests in all subjects. In our estimation, to enable sustainable operation and widespread implementation of the program, we need to reduce the total cost to <US$3 per subject. However, the cost of the blood glucose test is high, at approximately US$0.60 per measurement. We identified effective ways to reduce this cost by estimating the risk for diabetes using predictors and measuring blood glucose only in high-risk subjects.

In designing a predictor system, there has to be a tradeoff between true positive rate (TPR) and false positive rate (FPR) results. For example, we selected a threshold for Youden's index that minimized the balanced error rate (=1−TPR+FPR), and generated a predictor with a TPR of 87.6% and a FPR of 5.9%. That result indicates that we can skip 14,344 (15,243×94.1%) unnecessary tests if we accept 57 (462×12.4%) oversights. The predictor system would reduce the number of blood glucose tests from 15,705 to 1304; consequently, the measurement cost per subject would be reduced to one-tenth.

We need to design a predictor that maximizes TPR under existing budget constraints, to manage the health of a large group with acceptable FPRs. To be more precise, if we arrange the risk value in the descending order first and count the number by the limits of inspection, then we can choose the risk value as the threshold.

The cost of teleconsultation is also high because of the high salary paid to doctors. Reducing the workload of doctors reduces the cost of the medical program. We are currently analyzing eHealth records using the association rule to support the clinical decisions of medical staff [19]. This analysis can help doctors to add prescription data into the system faster because the system predicts what the doctors want to do and can show candidate inputs and instructions. Machine learning techniques could substitute formulaic, insignificant, and cumbersome work of doctors, enabling them to concentrate on more specific and important issues of patients.

In this study, we provided a health guidance booklet for subjects and a staff member explained the checkup results and health care guidelines orally for illiterate subjects. Because cost control is a serious concern of this project, we plan to make educational videos for health guidance and screen them on devices such as tablet PCs, etc, at the checkup sites. The videos could be useful not only for illiterate subjects but also for literate ones to increase their health awareness.

Limitations

Because we selected sites around Dhaka in the first year due to a logistic problem, we assessed the 1-year after-effects of the program only around Dhaka. However, because the first checkup results around Dhaka are similar to those of the second year site, except for the urine protein test, we consider that the program has a similar effect even other areas.

Conclusions

The present study findings suggest that our eHealth system, combining a health checkup and teleconsultation via the mobile network, is an effective tool in the social health care system in developing countries. It also suggests that the stratification rule is working effectively.

In the future, we plan to continue large-scale research into the results of our program, evaluating long-term outcomes to better assess the quality of the service. We will investigate changes in mortality and the frequency of clinic and hospital visits as well as changes in the basic health level and the total costs involved.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

AUC: area under curve
BAN: body area network
FPR: false positive rate
NCD: non-communicable diseases
PHC: portable health clinic
ROC: receiver operating characteristic
SBP: systolic blood pressure
TPR: true positive rate

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Original Paper

Virtual Patients on the Semantic Web: A Proof-of-Application Study

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Abstract

Background: Virtual patients are interactive computer simulations that are increasingly used as learning activities in modern health care education, especially in teaching clinical decision making. A key challenge is how to retrieve and repurpose virtual patients as unique types of educational resources between different platforms because of the lack of standardized content-retrieving and repurposing mechanisms. Semantic Web technologies provide the capability, through structured information, for easy retrieval, reuse, repurposing, and exchange of virtual patients between different systems.

Objective: An attempt to address this challenge has been made through the mEducator Best Practice Network, which provisioned frameworks for the discovery, retrieval, sharing, and reuse of medical educational resources. We have extended the OpenLabyrinth virtual patient authoring and deployment platform to facilitate the repurposing and retrieval of existing virtual patient material.

Methods: A standalone Web distribution and Web interface, which contains an extension for the OpenLabyrinth virtual patient authoring system, was implemented. This extension was designed to semantically annotate virtual patients to facilitate intelligent searches, complex queries, and easy exchange between institutions. The OpenLabyrinth extension enables OpenLabyrinth authors to integrate and share virtual patient case metadata within the mEducator3.0 network. Evaluation included 3 successive steps: (1) expert reviews; (2) evaluation of the ability of health care professionals and medical students to create, share, and exchange virtual patients through specific scenarios in extended OpenLabyrinth (OLabX); and (3) evaluation of the repurposed learning objects that emerged from the procedure.

Results: We evaluated 30 repurposed virtual patient cases. The evaluation, with a total of 98 participants, demonstrated the system's main strength: the core repurposing capacity. The extensive metadata schema presentation facilitated user exploration and filtering of resources. Usability weaknesses were primarily related to standard computer applications' ease of use provisions. Most evaluators provided positive feedback regarding educational experiences on both content and system usability. Evaluation results replicated across several independent evaluation events.

Conclusions: The OpenLabyrinth extension, as part of the semantic mEducator3.0 approach, is a virtual patient sharing approach that builds on a collection of Semantic Web services and federates existing sources of clinical and educational data. It is an effective sharing tool for virtual patients and has been merged into the next version of the app (OpenLabyrinth 3.3). Such tool extensions may enhance the medical education arsenal with capacities of creating simulation/game-based learning episodes, massive open online courses, curricular transformations, and a future robust infrastructure for enabling mobile learning.

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KEYWORDS

semantics; medical education; problem-based learning; data sharing; patient simulation; educational assessment

Introduction

Contemporary medical education has progressively extended into a wide variety of learning resources and domain-specific educational activities that have become more and more digitized [1]. The inherent driving force behind this is the need for worldwide access to clinical skills development, independent of time and place [2]. Much of this potential of information and communication technology (ICT) in medical education is due to the advancement of Web technology and the development of interactive learning environments with immediate, content-related feedback [3].

Modern medical education is largely based on case-based or problem-based learning (CBL/PBL) and other small-group instructional models [4,5]. Virtual patients, defined as "interactive computer simulations of real-life clinical scenarios for the purpose of health care and medical training, education or assessment" [6], have become one of the most commonly used CBL/PBL types in modern medical education [7] and have proved to be especially useful in teaching clinical decision making [8].

Moreover, Web-based virtual patients, unlike real patient practice, are inherently repeatable [9] and offer few limitations with respect to time, place, and failure-safe practice of clinical skills. Medical students have the opportunity to practice on any disease that may be encountered later in clinical practice, even rare or highly risky cases [10]. The reproducibility and capacity for standardized, validated assessments have made virtual patients an important and effective tool in modern medical education [11-13].

There is a worldwide trend to develop virtual patients and many academic institutions are working toward this goal [14]. However, some of their main disadvantages are that they are expensive and resource-intensive to develop [10]. Currently, few academic institutions can afford to dedicate resources for full-scale virtual patient development, thus facilitating the creation of online virtual communities where virtual patients can be shared as educational resources [6]. Open educational resource (OER) advances and innovative Web technologies have boosted content sharing and retrieval over the past few years. Web 2.0 encouraged a more human-centered approach to interactivity, with much support for group interaction, and fostered a greater sense of community in a potentially "cold" social (learning) environment [15].

To integrate the aforementioned evolutions toward a more sharable, searchable, and repurposable virtual patient paradigm, 3 aspects are being addressed: (1) the Semantic Web approach for annotating and consuming content, (2) the formulation of stable and standardized platforms for developing and deploying virtual patients, and (3) a cohort of proof-of-application studies in the form of formative and summative evaluation studies.

In the first aspect, the potential of Web 3.0, the Semantic Web, has added more dimensions beyond traditional Web services concerning education and research with a greater capacity for cognitive processing of information [16]. A primary feature of Web 3.0 is the use of metadata: "structured information that describes, explains, locates, or otherwise makes it easier to retrieve, use, or manage an information resource" [16].

Exploring this further with virtual patients, Semantic Web technology provides an opportunity to structure information within the virtual patients, so as to enable easy retrieval, reuse, and exchange of cases between different systems. Many European academic institutions use their own virtual patient authoring systems to deliver virtual patient cases for their own curricula; therefore, educational silos are formed because of this difficulty of sharing virtual patients across different platforms. The MedBiquitous Virtual Patient ANSI/MEDBIQ VP.10.1-2010 is a technical standard that enabled the development of global repositories of virtual patients [17]. Virtual patient cases in MedBiquitous standard format can be exchanged across systems or be exported in a MedBiquitous Virtual Patient package [17]. However, search and retrieval of specific content can be problematic when utilizing existing keyword-based searches. These often miss relevant cases or retrieve irrelevant information; for example, by contextual differences in the use of a keyword or where synonyms of the search term are employed. Moreover, with regard to the meaningful extraction of information, human browsing and reading is required to manually extract relevant information about medical resources. Without semantic metadata, virtual patients lack capacity to expose or consume meaningful information with other data consumers or providers. Semantic annotations allow context, structure, and content descriptions of virtual patients' data, providing completely new possibilities: robust and reliable searches, complex queries, and improved virtual patient exchange [18]. The mEducator Best Practice Network (BPN), funded by the European Commission within the eContentplus programme, is the first project globally to use Semantic Web services and linked open data [19] to not only federate different educational platforms, but also to publish educational resource descriptions on the Web of data. This project, after analyzing the use of existing standards and reference models in the e-learning field, aimed to develop mechanisms and best practices for discovering, retrieving, sharing, and reusing medical educational resources [20,21]. That overall goal incorporates the challenge of linking virtual patients with other resources available on the linked open data cloud and the Semantic Web, thereby paving new ways of using and exploiting virtual patients [22].

In the second aspect, that of standardized platforms for virtual patient creation and deployment, 1 of the most popular virtual patient authoring and delivering systems, OpenLabyrinth, is widely used across various academic institutions because it consists of an open source toolset that allows the creation and delivery of a wide range of pathway-based educational activities [23] with an easy-to-use, code-free interface [24]. The user-friendly interface, the level of Information Technology knowledge required for the case developers, and its compliance

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to the MedBiquitous standard have made OpenLabyrinth a popular virtual patient authoring tool for medical education [25]. However, despite its widespread use for virtual patient deployment, OpenLabyrinth offers a limited description of virtual patient resources and no resource search mechanisms. The core version of OpenLabyrinth does not offer a prominent, clear, and standards-based solution for the seamless sharing of virtual patients. The mEducator extended OpenLabyrinth module, OLabX, aimed to address these needs by applying the mEducator schema. OLabX has been developed to allow virtual patients to be described, shared, and semantically searched. OLabX offers easy virtual patient retrieval, sharing, and repurposing through a standards-based infrastructure that enables the sharing of this state-of-the-art digital medical educational content among medical educators and students of higher academic institutions.

In the final aspect, that of the evaluation and validation of virtual patients as efficient standalone learning tools and teaching aids in different modalities, things are recently picking up speed. Even though a lot of effort has been put in the area of virtual patients' development, description, and sharing, few studies are referred to a comprehensive evaluation of virtual patient authoring systems and efficacy of integration of electronic virtual patients in the medical curriculum. Medical students seem to embrace teaching and assessment through virtual patients and that is a prerequisite for virtual patients to be adopted widely [26]. The pilot evaluation of Web-SP, another Web-based virtual patient authoring tool, resulted in positive conclusions regarding the creation, management, and evaluation of Web-based virtual patient cases, but further studies looking at the learning outcomes, critical thinking, and patient management are required [27]. The trend of pilot evaluations of virtual patient-based learning episodes has been followed by a recent formal randomized controlled trial study [28] that aimed to investigate the efficacy of dynamic Web-based virtual patients in PBL sessions (dynamic PBL), the results were highly encouraging. Compared to a linear PBL group, the dynamic PBL groups' performance was better and this difference was statistically significant for all questions related to dynamic PBL.

This work is presented in 3 parts: (1) the rationale and basic principles that govern the transition to the Semantic Web, (2) a presentation of the architecture for extending OpenLabyrinth, a commonly used tool for virtual patients, introducing another free and open source distribution mechanism, and (3) an initial assessment of the feedback received from pilot evaluations of the tool.

Methods

Overview

The scope of this methodology section is twofold. On the technology front, we present a brief overview of how we extended the OpenLabyrinth platform using the mEducator metadata schema thereby creating OLabX. The mEducator OpenLabyrinth extension, OLabX, has been developed to allow virtual patients to be created, described, shared, searched, and easily repurposed. OLabX has enriched the global metadata describing a Labyrinth by applying the mEducator schema through the existing OpenLabyrinth global metadata editor. Therefore, a new database schema and interface has been proposed to implement the classes and properties defined by the mEducator schema. On the educational front, we describe the evaluation of the efficacy of the OLabX platform as a repurposing and authoring platform. This was done through a number of user scenarios and clinical tasks, as well as with formal system usability testing. The second part of the evaluation consists of assessing the repurposed content itself through previously verified and tested evaluation instruments [29].

The mEducator Metadata Schema

The mEducator schema defines the metadata accompanying an educational resource (eg, a virtual patient case) [20]. This metadata, often highly structured, is designed to support specific functions [30]. It also affords repurposing of educational resources [31]. The metadata schema is based on the established standard Health Care Learning Object Metadata [32], which is an extension of the Institute of Electrical and Electronics Engineers Learning Object Metadata, a more general standard [33]. The mEducator schema consists of 10 mandatory fields and a number of optional fields as demonstrated in Table 1.

A widget for searching SNOMED and Medical Subject Headings (MeSH) clinical terms via the National Center for Biomedical Ontology (NCBO) BioPortal platform [34] has also been implemented for coding consistency with the mEducator schema [35]. mEducator 3.0 implements open linked education functionality using Semantic Web services. As mentioned previously, an extension (OLabX) that builds on the mEducator schema has been developed for OpenLabyrinth. The extension is intended to make mEducator 3.0 more accessible to new and current users of this system and overcome the lack of standardized virtual patient sharing mechanisms [36].

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Table 1. Overview of the mEducator metadata schema.

Mandatory fields	Data type	Optional fields (nonexhaustive list)	Data type
Identifier	Number	Educational objectives	Free text
Title	Free text	Educational outcomes	Option from code list
Creator	Free text	Assessment methods	Free text
Intellectual property rights license	Option from code list	Educational context	Free text
Language of the resource	Option from code list	Technical description	Free text
Language of the metadata	Option from code list	Discipline	Free text
Creation date	Option from date picker	Discipline speciality	Free text
Metadata creation date	Option from date picker		
Keywords	Free text		
Description	Free text		

Architecture of the OLabX Application

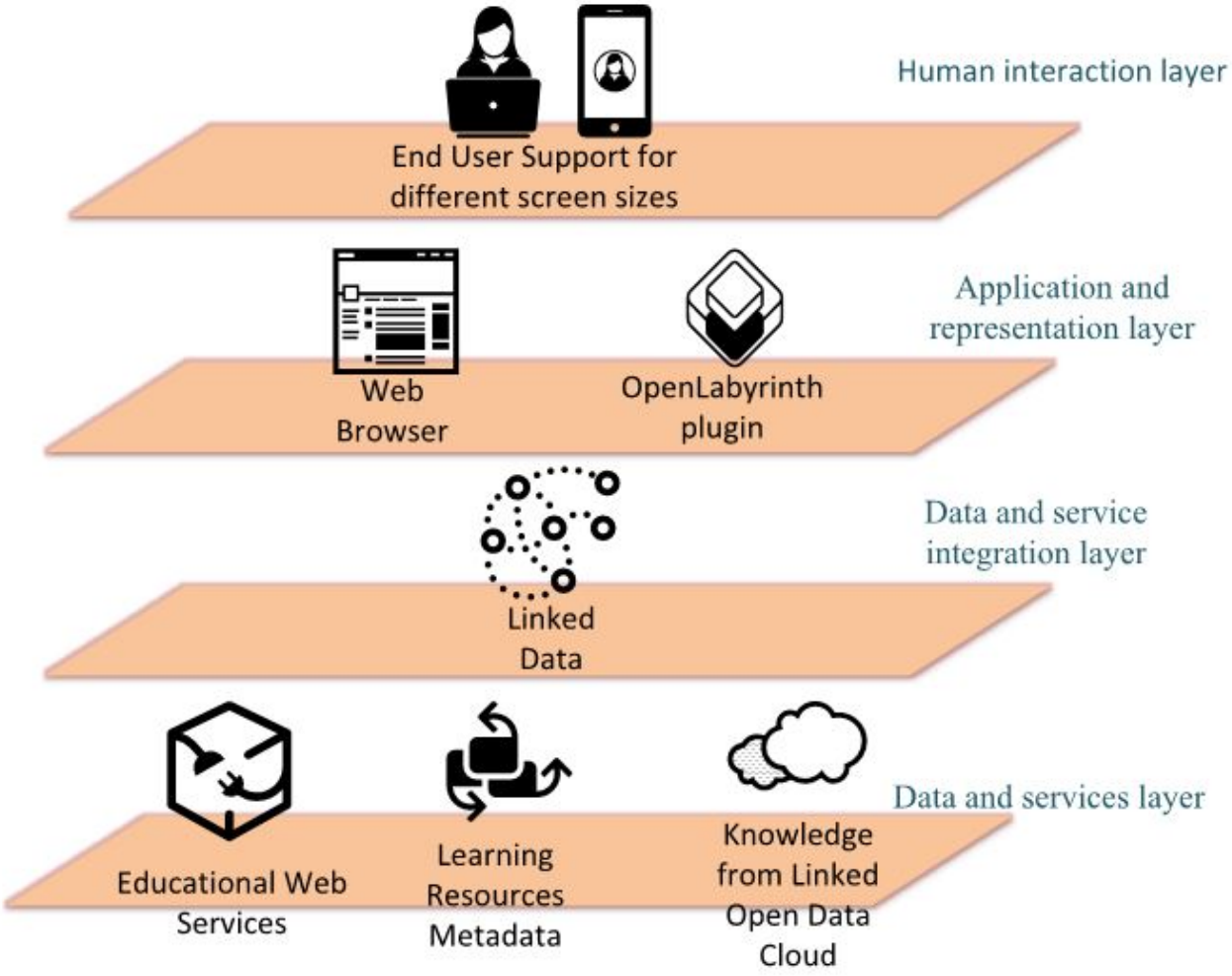
OpenLabyrinth is an open source, Web-based, activity modeling system that allows users to build interactive "game-informed" educational activities, such as virtual patients, simulations, games, mazes, and algorithms, and is used by various medical academic institutions [37]. OpenLabyrinth is a powerful platform for delivering game-based learning exercises, which have been shown to be effective for learners [38]. The Web-based nature of the tool means that it is platform-independent from the user's perspective, and easily accessible from any computer hardware through a browser, making it ideal for use in an educational environment [38]. Thus, it offers a convenient way for trialing new learner-centric pedagogic approaches such as those involving PBL paradigms.

Although the core version of OpenLabyrinth does not support advanced repository functionalities, OLabX, the mEducator OpenLabyrinth extension, enriches the metadata, describing a virtual patient by applying the mEducator schema on the existing metadata editor. This allows for enhanced learning scenarios to be facilitated, such as the following scenario: A medical student interested in acute myocardial infarction would like to access a relevant virtual patient case. Using her device, she would access the OLabX app through a Web browser. She would then use the app's search facility to submit a query for acute myocardial infarction. In the previous version of the app, only virtual patient cases with "acute," "myocardial," and/or "infarction" keywords would appear, whereas the app is now able to search through synonymous keywords and related medical areas. "Heart attack" and "cardiology" would also yield results when such a search was performed. Given a relatively large amount of available virtual patient cases, this saves the student from browsing the collection manually or entering the alternative keywords herself. Going a step further, OLabX is now able to store her preferences in content and intelligently suggest similar content coming in other formats within the mEducator-enabled network of resources. This capability stems from the network nature of the Resource Description Framework (RDF) metadata, which can be connected with existing medical vocabularies and other resources described as linked data. This architecture also considers future enabled scenarios in which search engines not only read the page-embedded RDF content, but also safely infer and index relationships between resources that are not otherwise explicitly linked.

That kind of scenario is supported by the overall interaction architecture that is demonstrated in Figure 1. This includes 3 layers [39]. The first (lowest), the (Web) data and service layer, consists of the available Learning Resource Metadata (LRM), Web services, and data sources (such as the linked data cloud). In the aforementioned example, at this level disambiguated, contextualized "bare bones" search terms from the previous layer would be consumed by the Web services to be compared against the linked open data cloud. Singular or multiple search terms, contextual synonyms, or contextual excluded terms formulate a complex search in the open data cloud. Then the relevant virtual patient cases would be discovered through their published resource metadata that the system is able to discover in this layer. The second (moving higher) is the data and service integration layer where the whole linked data infrastructure of OLabX is realized. The data and service integration layer is based on the linked services approach [40] using 2 repositories, iServe and SmartLink, and by exposing application program interfaces, which can be used to access the services programmatically. At this level, in the previous example, the "parsing," disambiguation, and contextualization of the search terms for acute myocardial infarction would occur to provide relevant data to the data and service layer for its search and retrieval facilities. The third layer, the app and representation layer, is a straightforward user interface front end and OpenLabyrinth plug-in that maintains the necessary provisions for seamless integration with the rest of the OpenLabyrinth platform. The search user interface and the process for invoking the OpenLabyrinth virtual patient Web player are all included in this layer, which is also what is visible to the end user through the device on which the virtual patient episode is run. The app can be accessed and used conveniently by any standards-compliant Web browser. This facet of the OpenLabyrinth extension, along with a template to allow other systems to embrace the mEducator schema, affords semantic description of medical educational resources.

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Figure 1. Overview of the mEducator interaction architecture.



OLabX Functionalities

The previously described architecture enables (1) resource queries across distributed and heterogeneous learning content management systems, whereas query results are automatically converted into the RDF, (2) storage of the metadata in an RDF store, and (3) metadata enrichment (eg, from SNOMED and PubMed) (Figure 2). The resulting mEducator metadata accompanying a virtual patient case are editable and searchable by all authorized users.

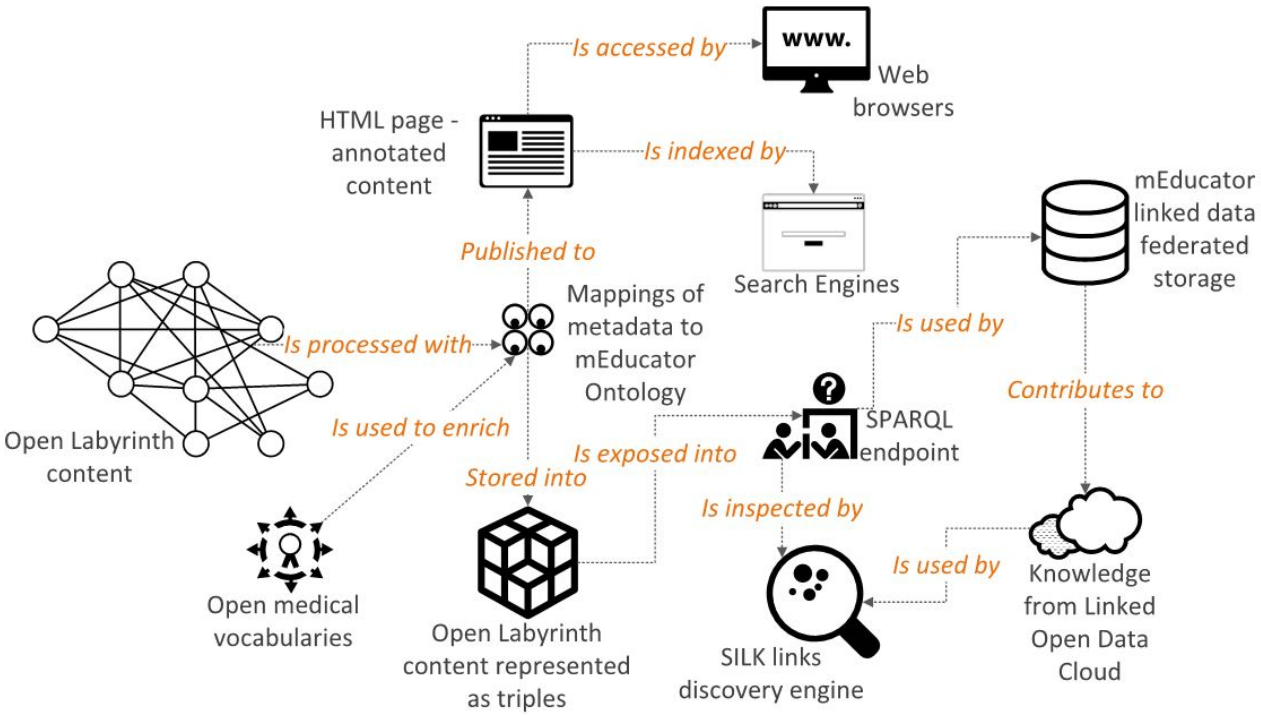
In the OpenLabyrinth case editor, a new field set was created including the mEducator metadata, namely "mEducator Metadata Entry." The original OpenLabyrinth metadata description schema was extended to be consistent with the mEducator metadata schema. This schema extension allowed the labyrinth authors to use existing, standardized medical taxonomies in a structured way. For instance, the mEducator ontology property named "subject" allowed the editor to select values from an autocomplete list that corresponds to terms from ontologies registered in the NCBO BioPortal platform [34]. This metadata annotation is important for searching among a large set of learning resources. The OpenLabyrinth database was extended, creating 2 kinds of tables: the first describing the mEducator classes and properties and the second linking the mEducator properties values for each virtual patient case. This change is nonintrusive, meaning it does not cause any administrative hassles and is reversible.

The mEducator schema also allows the repurposing of a case in a different educational context. A virtual patient can be repurposed to a different language, to a different culture, for a different pedagogical approach, for a different educational level, for a different discipline, to a different content type, and to a different educational technology [31,41]. Every medical educator is engaged with educational content transformation to some extent and repurposing becomes a necessary and common procedure in medical education. The semantic extension of OpenLabyrinth offers the opportunity of effective repurposing and reuse of a virtual patient case by medical educators and students as well. Furthermore, export-import and duplication functionalities have been extended according to the mEducator schema requirements. The original OpenLabyrinth exports the whole labyrinth in the MedBiquitous Virtual Patient data format [17]. In addition, a new feature has been implemented that allows exporting or importing the labyrinth's metadata in the mEducator metadata exchange format. It also adds support for duplicating a labyrinth together with its accompanying mEducator metadata, extending the original duplication

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functionality. Additionally, it facilitates the creation of a social hierarchy of linked repurposed resources in a parent-child approach, thereby allowing for a whole network of linked resources for which the resource creators are linked with repurposing actions (who is repurposed from whom).

Figure 2. Overview of the mEducator3.0 OpenLabyrinth module.



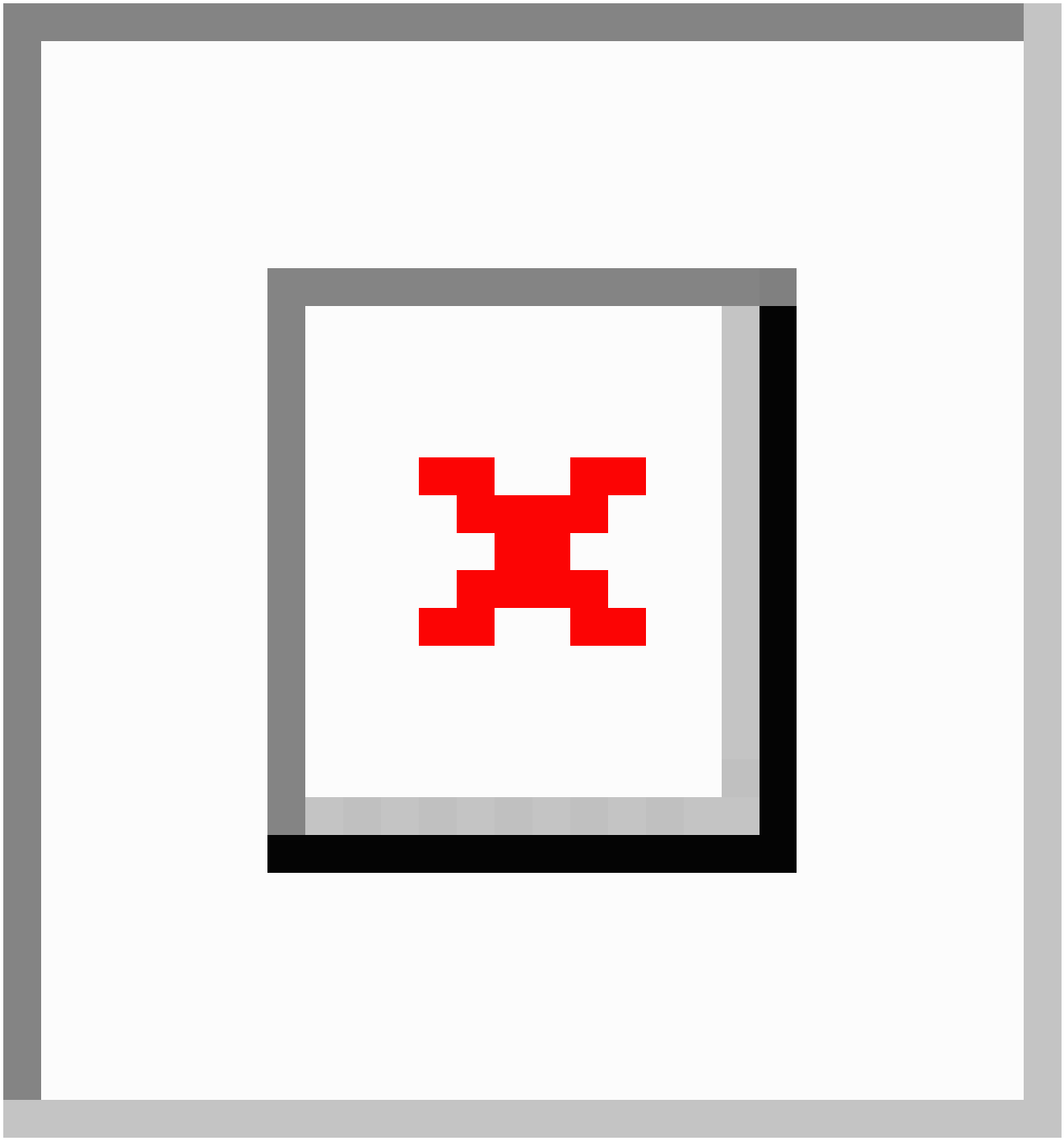
Evaluation Methodology

For evaluation of the OpenLabyrinth extension, a detailed test plan was designed. This included the identification of the overall objectives of the evaluation. The main point of the semantic extension, apart from virtual patient creation, was the sharing and repurposing of cases. Thus, it was important to evaluate system usability and efficacy as a repurposing tool. Moreover, an additional goal of this evaluation would be to provide an assessment of the output quality of the repurposed virtual patients created. Additionally, the overall evaluation was assessed by 2 expert reviewers whose sole aim was to provide meta-feedback for the whole process.

The evaluation methodology included formative assessment through user studies with testing scenarios and questionnaires, heuristic assessment through expert reviews, and summative assessment through the overall evaluation of the process. Formative assessment was used in the evaluation of the system usability and the quality of the output using formal instruments such as the System Usability Scale (SUS) questionnaire [42] and the student questionnaire from the previously validated electronic virtual patients (eViP) evaluation tool kit [43]. Expert reviews were used in all aspects of the evaluation and in the overall assessment of the process. The overall evaluation strategy is described in Figure 3.

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Figure 3. Methodology of the evaluation process.



Scenario-Based Evaluation Approach

The overall evaluation strategy was based on use case scenarios. Expert reviewers or formative assessment user groups acted as evaluators. User tests were performed according to the scenarios for sharing, searching, retrieving, and repurposing content. Testing groups included educators, health care professionals, and students.

The scenarios covered specific tasks: (1) virtual patient sharing, (2) virtual patient search and retrieval, and (3) virtual patient repurposing. The scenarios were initially presented to participants in a scheduled hands-on workshop organized in Vilnius, Lithuania, during the evaluation phase of the mEducator project. The purpose of that workshop was to familiarize participants with the creation, searching, and repurposing of resources within the environment of OLabX. The user sample consisted of approximately 12 health professionals from different specialties, including educators, students, and health care policy makers under the guidance of trained workshop facilitators.

The second part of the evaluation took place at the Medical School of the Aristotle University of Thessaloniki (AUTH), Thessaloniki, Greece, and was divided into 2 phases. The first phase included 2 categories of evaluators at the same time: (1) the team of medical educators that participated in the design and implementation process of virtual patient cases by OLabX after training workshops on the use of the platform and the rationale of Semantic Web annotations and (2) undergraduate

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medical students, randomly selected by a random student identification number generator from the final year cohort of the undergraduate curriculum, after suitable training in OpenLabX use. In total, 33 evaluators, 20 medical teachers, and 13 medical students of AUTH participated in this phase. The second phase included 48 undergraduate medical students randomly selected from a cohort of 120 students attending the undergraduate elective course on medical education. These students used the eViP questionnaire to assess the quality of repurposed virtual patients.

In both phases, the evaluation scenarios had a similar structure as the scenario used in the Užkrečiamųjų ligų ir AIDS centras (ULAC; Centre for Communicable Diseases and AIDS) workshop mentioned previously. Details of these scenarios are summarized in Table 2.

Table 2. Testing scenarios for the assessment of the OLabX virtual patient creation, search, retrieval, and repurposing platform.

User tests	Scenario 1	Scenario 2	Scenario 3
Aim	Familiarize users with the virtual patient creation process	Familiarize users with searching of resources	Familiarize users with virtual patient repurposing
Objectives	Show users how to log in; explain the basic functions involved in virtual patient creation; explain the notion of virtual patient metadata	Show users how to search for virtual patients, in comparison to simple search engines; explain the role of basic search attributes; explain how metadata enhances search functions	Show users the role of repurposing; explain intellectual property rights (IPR) metadata; demonstrate completion of assessment metadata
Expected learning outcomes	(1) Login to OLabX successfully, (2) understand the notion of metadata to trace it at a later stage, (3) enter the appropriate metadata using the system forms, (4) save the metadata in OLabX, and (5) visualize the entered metadata	(1) Specify the search attributes, (2) perform the search, and (3) appreciate and analyze the obtained results	(1) Perform case repurposing, (2) specify the IPR metadata for their own resources, (3) correctly enter repurposing metadata, (4) search for repurposed resources, and (5) appreciate and analyze the obtained results

For usability and efficacy testing by expert users, the same scenario-based approach was used. Experts were provided with a more open list of tasks:

1. Perform search(es)
2. Study and evaluate the results comparing to the search goals
3. Refine the search terms to perform new searches
4. Decide on which resources to inspect/download
5. Decide on the necessity of further searches
6. Decide on which resources to use later

The only deviation from this scenario-based approach was in the heuristic assessment that was performed by the overall evaluation expert reviewers. In their case, an observer's role was employed and they were allowed to express their feedback, in an open-ended qualitative manner, regarding the overall evaluation process.

System Usability Assessment

The first axis of system usability assessment consisted of a formative user-group usability survey and the standard SUS questionnaire.

The SUS questionnaire assesses the overall usability of the system. It is a 10-item questionnaire with 5 Likert-type response options ranging from the extreme positive (strongly agree) to the extreme negative (strongly disagree) and with half of the questions phrased in negative assertions to avoid bias [42]. It is a "quick and dirty" usability measurement instrument that produces a standardized score ranging from 0 to 100 that can be used to directly compare the usability between systems [44]. The results from both groups were collected and normalized into the standard percentile rank that facilitates comparisons between systems.

The second axis of system usability testing was conducted through an expert review of the system. The main directive that was provided to the reviewer was to assess the usability of the user interface and the overall look and feel of the platform within the scope of creating content in the OLabX platform. Specifically, the heuristic qualifiers that the reviewer was asked to check the system against, were the following:

1. The user interface is intuitive and facilitates content creation.
2. The system provides clear feedback to the user about her/his actions.
3. The system provides a level of accessibility and automation options that are expected of contemporary Web-based platforms.

Efficacy Assessment

The efficacy evaluation task was performed by 1 medical pedagogy specialist online and remotely. The reviewer explored the OLabX mEducator 3.0 instantiation freely, but trialed a selection of search terms from the following list: dermatology, cardiology, tumor, cancer, neoplasm, simulation, image, and clinical case. For search and retrieval, the expert was asked to perform the operations on the system previously mentioned. The expert's task was to comment on the use of the system using several heuristic qualifiers and an overall assessment of the strengths and weakness of the platform's efficacy along with open-ended recommendations and comments. The specific qualifiers used by the expert reviews for assessing the efficacy of the OLabX platform are listed in Textbox 1.

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Textbox 1. Specific qualifiers for assessing the OLabX platform.

Formulation (expressing the search):

1. User is provided access to appropriate resources in library and collections.
2. Structured fields for limiting the source are used (year, media, language, etc).
3. Entered phrases are recognized.
4. Variants such as differences in casing, partial matches, etc, are allowed.
5. The size of the result set is controlled.

Initiation of action (launching the search):

1. Explicit actions are included (consistently labeled, located, sized, and colored buttons).
2. Implicit actions are included (changing a parameter immediately produces new sets of results).

Review of results (reading messages and outcomes):

1. Explanatory messages are presented.
2. Overview of results and preview of items are viewed.
3. Visualizations can be manipulated.
4. The size of the result set and shown metadata fields can be adjusted.
5. Sequencing can be changed.
6. Clustering can be explored.
7. Selected items can be examined.

Refinement (formulating the next step):

1. Meaningful messages guiding the user in progressive refinement are provided.
2. Parameters are easy to change.
3. Feedback relevance is explored.

Use (compiling or disseminating insight):

1. Queries, settings, and results are allowed to be saved and annotated, emailed, or used as input for other tools.

Output Quality Assessment

Evaluating how medical students use repurposed virtual patients is crucial for the effective development and exploitation of repurposed educational resources [45]. For the output quality evaluation, an evaluation instrument developed and validated during the eViP European project for the creation and sharing of virtual patients was used [43].

This tool is for the evaluation of students' experience with virtual patients, focusing on the development of clinical reasoning skills. This questionnaire contains 7 subsets totaling 14 items. Likert scale questions were used in this questionnaire with their statements based on attitudes and cognitive activities. These questions play an important role in clinical reasoning skills. Additionally, a few open-ended questions were included. This instrument was administered to 48 undergraduate students after they encountered a group of repurposed virtual patients.

Overall Evaluation

Two observer expert review reports of the general performance were included in this evaluation process. The experts were familiar with the project, but they were not involved in the design or implementation tasks of OLabX. Their role was to act as observers in mEducator 3.0 OpenLabyrinth workshops and submit to the evaluation organizers an overall review for the workshops and the OLabX performance. Their feedback would provide a summative meta-evaluation of this diverse process of assessment to identify weaknesses and blind spots in the process itself. Given the scope and purpose of the required feedback, the reviewers were allowed to express this feedback in an open-ended fashion according to their overall experience and project-specific impressions.

Results

Usability Evaluation

The following are the OLabX testing results from the ULAC workshop. The raw SUS score from all 12 questionnaires was a 60.8 placing the OLabX application higher than approximately 30% of all products tested. The graph presented in Figure 4 shows the percentile rank associated with the SUS score and letter grades.

Next presented are the OLabX testing results from the AUTH workshop. The raw SUS score from all 33 questionnaires was a 65.83, placing the OLabX application higher than 40% of all

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products tested. Figure 5 shows the percentile rank associated with the SUS score and letter grades.

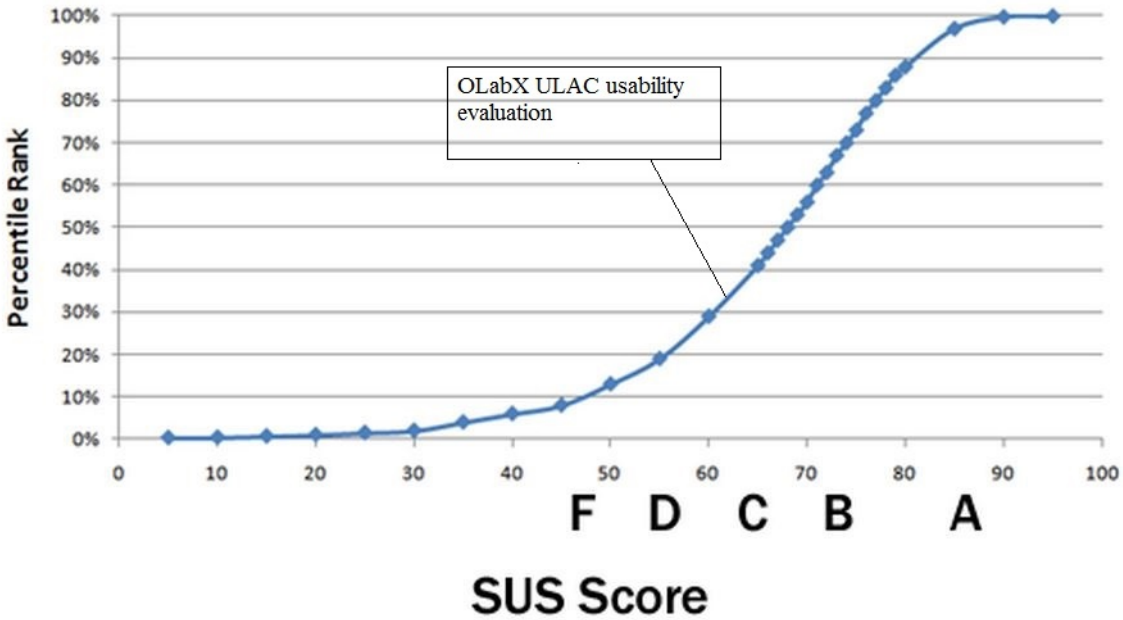
These scores were the trigger for the exploratory expert reviews to both verify the usability results from the SUS questionnaires, but primarily to identify areas of improvement required for placing the OLabX application in a competitive place in the overall SUS classification of products. Presented in Table 3 are the results of the heuristic evaluations of the 2 expert reviewers regarding the usability of the system.

From the feedback received from the expert reviewers, the main usability weaknesses were not related to the core OLabX functionality, but they were primarily attributed to standard computer applications' ease of use provisions. These provisions were indeed absent because the focus was on implementing core functionality extensions at this point in the development of the platform. This could be considered the main reason that the OLabX platform did not score competitively in the SUS hierarchy of products.

Table 3. Heuristic usability feedback from expert reviewers.

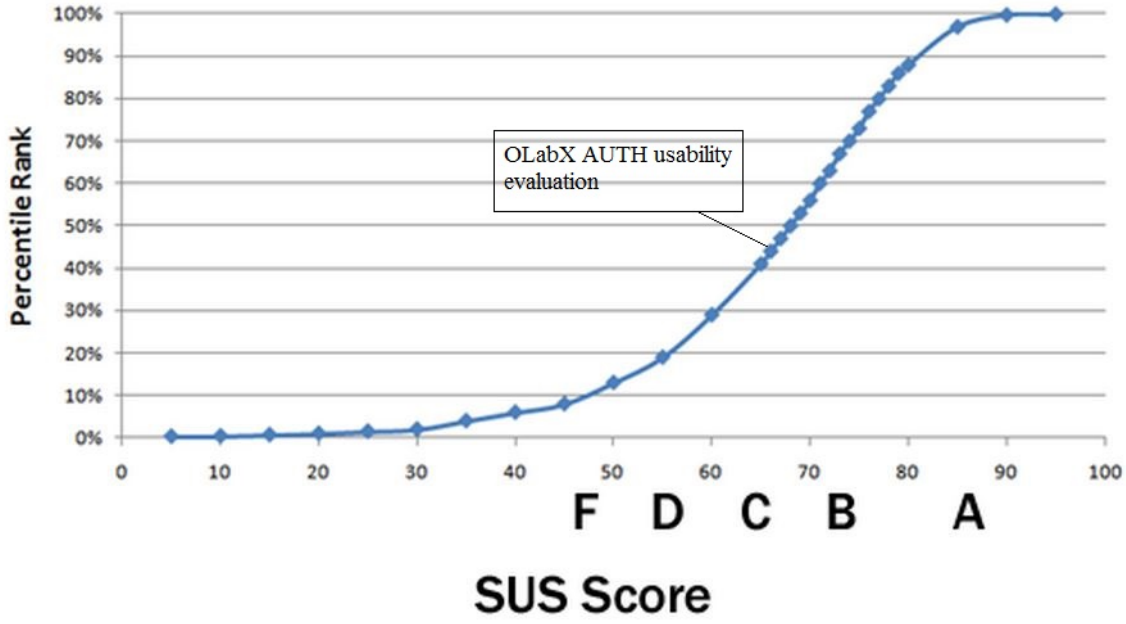
Feedback	Recommendations/Solutions
The user interface is intuitive and facilitates content creation.	
Links should perhaps be "link colored"	Use common interface conventions of Web services
All tabs should be visible by default	Provide an overview of the creation process steps at start
The system provides clear feedback to the user about her/his actions	
During the test the error messages after submitting a resource were not useful to common user	Ensure the readability and relevance of the error messages to the user
The system provides a level of accessibility and automation options that are expected of contemporary Web-based platforms	
Date should be automatically inserted	Use automatic calendar functionalities when possible
No provisions for multilingual keywords	Multilingual support should be implemented

Figure 4. Formative assessment results from the system usability evaluation from users (MD professionals), placing the OLabX higher than 30% of all products tested.



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Figure 5. Formative assessment results from the system usability evaluation from users (students and staff), placing the OLabX higher than 40% of all products tested.



Efficacy Evaluation

The results of the efficacy evaluation of the OLabX platform from the expert reviewers are summarized in Table 4.

Although most responses touched on usability, these concern core functionality issues that directly impact efficacy. Because no formative assessment has been conducted, these platform-specific notes, although touching on usability issues, are the best indicators for the efficacy of the platform for creating repurposed virtual patient content.

Table 4. Heuristic efficacy evaluation feedback from expert reviewers.

Phase of search process	Strengths	Weaknesses
Expressing the search	Letter casing and partial matches allowed; IPR and/or language can be used	No content overview; no real-time phrase recognition suggestions; no control over the size of results
Launching the search	Some implicit actions are included	Some explicit actions are missing (back to results, new search); a complete schema is problematic for locating key functions on the interface; sorting options should be visible by default
Reading messages and outcomes	Textual preview of results	No search progress info; no summary; no control over size of result set; no control over sequencing/order
Formulating the next step		System provides no automated feedback/support for refining the search
Compiling or disseminating insight		System provides no corresponding functionalities
Comments and recommendations	The extensive metadata schema presentation in the interface invites user to exploring the filtering of resources	The lack of support in terms of interface usability for user guidance needs to be corrected to fully exploit the richness of the schema

Output Quality Evaluation

Overview

From the preceding descriptions of the scenarios, quite a few repurposing attempts were conducted during the evaluation of OLabX. Overall, approximately 30 repurposed virtual patients were produced, with different aspects of repurposing applied during the process. More specifically, repurposing could refer to modifying at least the virtual patient node narrative and the media content of the virtual patient or the counter/timer measures. Figure 6 illustrates the overall output production of repurposed virtual patients during the evaluation scenarios.

A total of 48 undergraduate students were invited to choose approximately 5 from this pool of 30 repurposed virtual patient cases and then use the eViP questionnaire to provide feedback on the quality of the content. The following are the results from the repurposed virtual patient evaluation (Table 5). Most evaluators provided positive statements regarding the virtual patient content when the educational experiences with both the content and the system were considered. The eViP questionnaire

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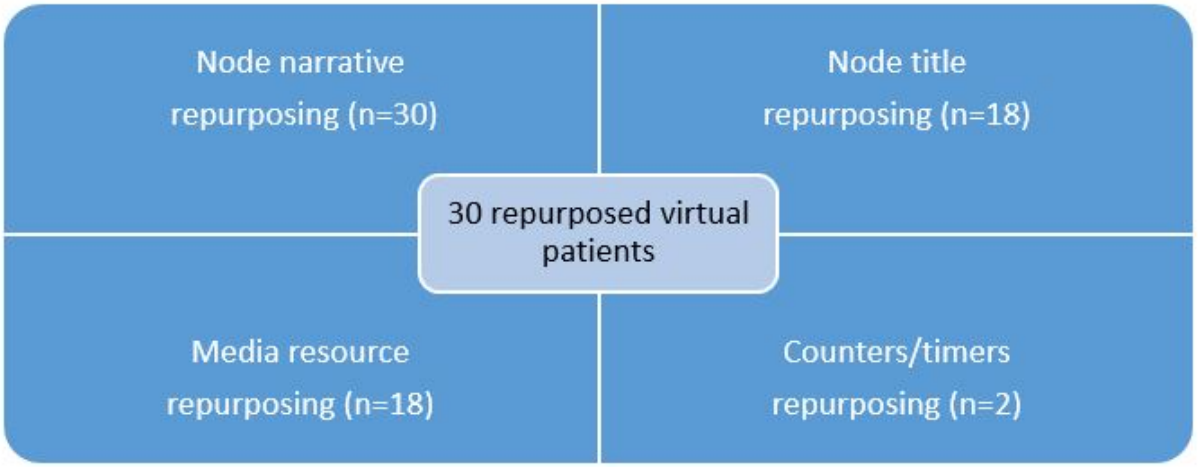
also contained several open-ended questions, which are summarized subsequently.

Table 5. Results from the evaluation of the output quality (repurposed virtual patients) from users as part of the formative assessment.

Questionnaire subset theme and questions	N	N/A	Rating,[a] n				
			1	2	3	4	5
1. Authenticity of patient encounter and the consultation							
Q1. While working on this case, I felt I had to make the same decisions a doctor would make in real life.	48	2	0	2	6	36	2
Q2. While working on this case, I felt I was the doctor caring for this patient.	48	2	0	3	12	25	6
2. Professional approach in the consultation							
Q3. While working through this case, I was actively engaged in gathering the information I needed (eg, history questions, physical exams, laboratory tests) to characterize the patient's problem.	48	2	2	5	11	16	12
Q4. While working through this case, I was actively engaged in revising my initial image of the patient's problem as new information became available.	48	3	0	3	10	27	5
Q5. While working through this case, I was actively engaged in creating a short summary of the patient's problem using medical terms.	48	2	0	4	11	25	6
Q6. While working through this case, I was actively engaged in thinking about which findings supported or refuted each diagnosis in my differential diagnosis.	48	3	0	2	9	24	10
3. Coaching during consultation							
Q7. I felt that the case was at the appropriate level of difficulty for my level of training.	48	5	5	15	10	10	3
Q8. The questions I was asked while working through this case were helpful in enhancing my diagnostic reasoning in this case.	48	2	0	1	11	23	11
Q9. The feedback I received was helpful in enhancing my diagnostic reasoning in this case.	48	3	1	6	16	15	7
4. Learning effect of consultation							
Q10. After completing this case, I feel better prepared to confirm a diagnosis and exclude differential diagnoses in a real-life patient with this complaint.	48	2	7	2	14	6	7
Q11. After completing this case, I feel better prepared to care for a real-life patient with this complaint.	48	3	1	4	9	21	10
5. Overall judgment of case workup							
Q12. Overall, working through this case was a worthwhile learning experience.	48	3	0	0	7	24	14

[a] 1=strongly disagree; 2=disagree; 3=neutral; 4=agree; 5=strongly agree.

Figure 6. Repurposing types of virtual patients produced during the evaluation scenarios of OLabX.



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What Are the Special Strengths of the Case?

Most participants pointed out that repurposed virtual patients were well constructed and delivered in ways that will elicit clinical reasoning skills in trainees. They allow for cognitive errors, through which the trainees learn without impact on a real patient. Training, development of critical thinking, and "virtual practice" before seeing real patients were the next popular features of repurposed virtual patients mentioned by the students. Better anxiety management in a safe environment was a popular answer, whereas a decision-making exercise and self-assessment were reported as advantages of great importance. They mentioned that these virtual patients contribute to the improvement of medical education and increase motivation for learning.

What Are the Special Weaknesses of the Case?

The most popular answer to this question was the statement that it is all about virtual patients and not real ones and virtual patients cannot replace the contact with real patients. Furthermore, stressful conditions that exist in real life are not fully reproduced with these virtual patients. Other comments sporadically mentioned were that questions had too few and too specific response answers.

Do You Have Additional Comments?

The additional comments conclusively included a summary of the students' evaluations. A common comment referred to the fact that OLabX offers, through repurposing, the opportunity of virtual patient adjustment to the student's level of knowledge. Almost all students commented that this effort should be supported, should be integrated into the curriculum, and expanded into other specialties. They would like a wide database of cases to be created in which each student will be able to choose a suitable virtual patient case because semantic markup will be available for easy retrieval and reuse of virtual patients.

Discussion

Context

Virtual patients cannot be considered a direct substitute for interpersonal experiential forms of learning, such as real clinical experience. However, their capacity for immediacy and safety has established them as standard learning tools in medical education [46]. There is ample literature available to cover details such as connecting specific clinical guidelines in the design of virtual patients [47] and providing quality control metrics for assessing them [48]. In fact, with the development of a formal MedBiquitous Virtual Patient international standard in 2010 [41,49], virtual patients are a widely available tool in the medical curriculum (lectures, exams, project PBL, synchronous or asynchronous e-learning sessions) [7]. This advent of virtual patients has triggered research for highly specialized, context-specific virtual patient design models for catering to specific medical specialties [50]. In this environment, the capacity of transferring and reusing virtual patient resources into different contexts, for different educational goals, across media and platforms becomes an attainable research goal.

The overall repurposing initiative of educational content has come of age for some time now [51]. With data standard infrastructure established as early as 2002 through the LOM standard [52] followed by the Sharable Content Object Reference Model (SCORM) [53] and the Healthcare LOM schema [54], an effort was initiated in the form of the mEducator project. Both Web 2.0 mash-up technologies and federated, semantic, Web service-based learning content management systems were explored as possible avenues of standardizing the repurposing of medical education content [55]. The overarching purpose was to make educational content discoverable and context-independent to facilitate its reusability and repurposing for different educational goals and across different educational environments [51].

Contribution of This Work

This work, initially named LinkedLabyrinth during the mEducator project [56], is an extension of the OpenLabyrinth Virtual Patient creation and deployment platform. This extension added semantic annotations and repurposing capacities to the OpenLabyrinth platform [22]. Post-mEducator project activities were focused on aligning efforts with the MedBiquitous Consortium (an organization producing standards for digital health education) [41]. MedBiquitous has adopted the previously described mEducator proposal for the semantic extension of its current standards as evidenced by ongoing technical discussion taking place in its Technical Committees and Working Groups [57]. These developments together with the extension for OpenLabyrinth makes mEducator 3.0 accessible to a completely new user base, that of the OpenLabyrinth platform, and overcomes the lack of standardized sharing mechanisms.

The results presented in this work from the multifaceted assessment of the OLabX provide some insights into the system's characteristics. First among the system's strengths is the core repurposing capacity. By using semantic annotation of virtual patient content through the mEducator 3.0 metadata schema in combination with the specifications of the MedBiquitous Virtual Patient standard, OLabX provides a systematic and organized capacity for content repurposing across several axes (context, educational objectives, and platforms).

This assessment also demonstrated this prototype's weaknesses. At present, the project has built a semantic infrastructure for enabling mEducator 3.0 capabilities. The lack of uptake of this semantic infrastructure is recognized, as demonstrated by weaknesses referred in the results of the experts' evaluation. The concerns regarding usability are expected because this is a rather unpolished prototype product. Users of the platform would make better use of semantic annotation when more clearly informed of the underlying semantic annotation process and functionality. This interesting anecdotal result touches on the expectations of users that are starting to become semantically aware in the Web 3.0 environment. On the main exploratory track, however, this lack of uptake for the provided services is not unexpected because of the prototype nature of the development of the OpenLabyrinth extensions. These are important follow-up steps to the core effort, which is the implementation of the mEducator semantic infrastructure within the OpenLabyrinth platform.

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Furthermore, the evaluation consisted of a series of evaluation episodes performed during various workshops that were held as part of the mEducator project and was not fully designed from the beginning of the assessment procedure. That could be mentioned as a limitation of our study protocol, although it ended up providing us with valuable feedback for the OLabX performance in virtual patient retrieval, discovery, and repurposing. Regarding usability, the 2 trial and evaluation episodes, although they were not preplanned, provided similar SUS scores with only a 10% difference (30% and 40%, see Figures 4 and 5). Additionally, qualitative results appeared to converge across evaluation episodes. Both expert reviewers and evaluating students provided positive feedback for the capacity of OLabX to facilitate meaningful exploration and filtering of virtual patient resources through semantic annotation. They both noted the intuitiveness of the search process and the contribution to it of the extensive metadata scheme that was incorporated in this extension of the OpenLabyrinth platform. The results obtained match those that have arisen from previously published studies as far as fostering of clinical reasoning and students' virtual patient adoption into the curriculum are concerned [26-28].

The input from the evaluation has already led to a more powerful annotation subsystem for the next version of OpenLabyrinth v3.3 [58]. This new extension is not monolithic. Rather, it is composed of many smaller and flexible submodules, allowing system administrators to enable functionality depending on their institution's needs. The new functionality includes out-of-the-box custom semantic metadata fields, support for any classification represented in the RDF format, and visual reports with iterative development pending the results of follow-up assessment [59,60].

Future Directions

Semantic Web technology provides a powerful opportunity to structure and annotate information about virtual patients to allow for easy retrieval, reuse, and exchange of virtual patients' content between different systems. The current work directly addresses the needs for sharing, exchanging, searching, and cataloging these resources through the mEducator approach [51]. Beyond the resource-level annotation, Semantic Web technology can also be facilitated in the included content element level, indexing the resources in a finer manner. A more sophisticated approach could include metadata about the real-time interaction of students with the content.

Extending this view, there are initiatives that are using this kind of annotation to facilitate the creation of massive open online courses and small OERs [61]. In medical education, the virtual patient space has become quite prolific [46]; therefore, semantic annotation can be an asset in repurposing content and also context or platform [41]. Research in open education has identified that resource and system interoperability are significant aspects for successful endeavors in open education initiatives [62]. The repurposing of virtual patients becomes a significant contributor to open access medical education. On enhancing the efficacy of the latter, the use of virtual patients and PBL in teaching clinical decision making is currently considered a substantially effective instructional approach [46]. The availability of systems such as the one presented in this paper is important especially when one considers curricula adaptations/transformations such as those under development in 6 institutions of the ePBLnet consortium, a European Commission-funded program [63].

Game-based medical education content that allows for more exploratory freedom to the learner provides a different field for case-based content repurposing. Such efforts include the dynamic patient simulator [64], a more open-ended virtual case software; the virtual standardized patient, a more psychologically realistic approach to doctor-patient encounters [65]; or multi-user virtual environment-deployed virtual patients [41,66] for providing a more graphically rich experience for learners. These efforts point to a clear direction of emergent, experiential, dynamically created content in which repurposing capacities enabled by semantic annotations such as those offered through the OLabX platform can provide a method for rapid and even automated content creation and customization.

There are already documented efforts for providing educational resources to medical students through nonconventional hardware (eg, personal data assistants, mobile phones) with encouraging results from the assessment [67]. A repurposing platform that could aggregate and push frequently accessed content from virtual patient usage, along with "tweetations" [68] that reference or push useful resources to mobile devices could allow for a migration of "educemiology" (an educational content proliferation patterns study) [69,70] to the virtual patient space to assess and promote educational content relevant to the specific needs of a learner or group. This emergent semantification of resources through social tagging is not new. The term FolksOntology was coined as early as 2007 [71] to describe the emergence of informal ontologies through social tagging (folksonomies). Efforts for promotion of trending educational resources that are rapidly repurposed for context by the learners themselves would enable this next synergy of Web 2.0′s folksonomies [72] and Web 3.0′s semantics [73] and this could evolve into a custom, localized, and emergent educational content commons. In that context, virtual patients that facilitate experiential anchoring of previously acquired formal knowledge through game-based scenarios could find uses through push notifications. These trending tweetations could be accessed from self-directed learning endeavors instead of authoritative suggested cases. For that purpose, the capacity to rapidly develop virtual patient content by repurposing existing cases, even by allowing learners to customize context according to their special needs instead of just expecting authors to create new cases, could contribute far greater value than that of an ease-of-life tool for virtual patient authors. It would provide an infrastructure for enabling learners and educators to create and consume educational content on a "just-in-time" basis [74], enabling rapid and ubiquitous dissemination of medical knowledge.

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Authors' Contributions

E Dafli: concept; literature review; technical development contribution; evaluation of methodology design and implementation; Introduction, Methods, Results, and Discussion writing contribution. PE Antoniou: literature review; evaluation methodology design; Methods, Results, and Discussion writing contribution. L Ioannidis: technical development; Methods and Discussion writing contribution. N Dombros: literature review; critical manuscript revision; feedback and suggestions; Introduction writing contribution. D Topps: design of extended implementation; feedback and suggestions; critical manuscript revision. PD Bamidis: conception of idea; overall development and evaluation coordination; literature review; editing; Introduction, Methods, Results, and Discussion writing contribution; critical manuscript revision.

Conflicts of Interest

None declared.

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Abbreviations

AUTH: Aristotle University of Thessaloniki
BPN: Best Practice Network
ICT: information and communication technology
IPR: Intellectual Property Rights
LRM: Learning Resource Metadata
MeSH: Medical Subject Headings
NCBO: National Center for Biomedical Ontology
OER: open educational resource
RDF: Resource Description Framework
SUS: System Usability Scale

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