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Developing a Disease Outbreak Event Corpus

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Abstract

Background: In recent years, there has been a growth in work on the use of information extraction technologies for tracking disease outbreaks from online news texts, yet publicly available evaluation standards (and associated resources) for this new area of research have been noticeably lacking.

Objective: This study seeks to create a “gold standard” data set against which to test how accurately disease outbreak information extraction systems can identify the semantics of disease outbreak events. Additionally, we hope that the provision of an annotation scheme (and associated corpus) to the community will encourage open evaluation in this new and growing application area.

Methods: We developed an annotation scheme for identifying infectious disease outbreak events in news texts. An event—in the context of our annotation scheme—consists minimally of geographical (eg, country and province) and disease name information. However, the scheme also allows for the rich encoding of other domain salient concepts (eg, international travel, species, and food contamination).

Results: The work resulted in a 200-document corpus of event-annotated disease outbreak reports that can be used to evaluate the accuracy of event detection algorithms (in this case, for the BioCaster biosurveillance online news information extraction system). In the 200 documents, 394 distinct events were identified (mean 1.97 events per document, range 0-25 events per document). We also provide a download script and graphical user interface (GUI)-based event browsing software to facilitate corpus exploration.

Conclusion: In summary, we present an annotation scheme and corpus that can be used in the evaluation of disease outbreak event extraction algorithms. The annotation scheme and corpus were designed both with the particular evaluation requirements of the BioCaster system in mind as well as the wider need for further evaluation resources in this growing research area.

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KEYWORDS

Biosurveillance; disease outbreaks; natural language processing; corpora; text mining; information extraction; public health informatics

Introduction

The need for computational tools for the tracking of emerging disease outbreaks from text has become increasingly important in recent years [1,2] leading to the development of various machine-aided surveillance systems (eg, Global Public Health Intelligence Network (GPHIN) [3], HealthMap [4], BioCaster [5], MedISys [6], Pattern-based Understanding and Learning System (PULS) [7], and EpiSPIDER[8]). One way to evaluate the semantics of such a system is to construct an event frame (ie, template), which is then associated with each outbreak event in a sample of news documents (the nature and scope of reportable events varies according to the case definition of each system). This paper reports on such a data set—an annotation scheme and corpus [9]—developed for disease outbreak event detection in the context of the BioCaster biosurvellance online news information extraction (IE) system [10,5].

We believe that a focus on event extraction offers additional advantages to methods based solely on information retrieval (IR). Traditional IR systems allow us to identify reports based on the presence or absence of disease terms whereas event-based IE approaches enable us to dig deep into a report's semantics. The mere presence of a disease term in a text should not necessarily lead us to the conclusion that the report contains pressing information about an outbreak. Indeed, Steinberger et al estimated that 63% of documents selected using traditional IR techniques do not contain outbreak events [11]. For example, vaccination campaigns, medical research results, and public health advice often occur in news texts and are likely to generate false positives if we rely solely on IR to identify documents of interest. An event-based strategy facilitates the exclusion of nonrelevant documents from further processing and could form the basis of more sophisticated text mining and visualization while providing richer outbreak data for end users. Note that the event-based approach suggested here requires antecedent document selection and named entity recognition (NER) modules (ie, a pipeline with a document selection module inputting relevant documents to an NER module before this output is piped to an event extraction module). In the case of the BioCaster system, the document selection module has a particularly important "gate-keeping" function as the system accepts input from over 1700 RSS feeds—far too many documents to subject to the computationally intensive NER and event extraction processes [10].

The event annotation scheme aims to identify each infectious disease outbreak event in a given text with its associated disease, time, location (at various levels of granularity), and other relevant information. An annotated corpus is necessary in order to evaluate the performance of the current BioCaster IE system and also serves as a test bed for the development of new biosurveillance-specific IE algorithms and techniques. Further, the provision of a reusable resource facilitates further work on disease event extraction and encourages the development of the field, as it has been shown that the provision of such resources (often in conjunction with organized "challenge evaluations" similar to, for instance, the Text Retrieval Conference (TREC) Genomics Track [12]) has increased research momentum for other IE tasks [13].

Previous work on evaluation for disease outbreak report IE systems has focused on disparate aspects of performance. For example, Blench [14] found that the GPHIN system identified 56% of the outbreaks verified by the World Health Organization (WHO) over a three-year period, while Freifeld et al [15] found that the HealthMap system successfully classified 84% of reports by disease and location over a one-month period. Kawazoe et al [16] reported that the BioCaster system's NER module achieved an F-score of 76.97, while for the PULS system (which is an event extraction system that relies on input from the MedISys IR system), it is estimated that approximately 72% of the extracted events are correct [11]. While this kind of evaluation work is important for system developers, the obvious difficulty in comparing reported results illustrates the need for a community-wide data set for algorithm testing.

The structure of the paper is as follows. First, we describe the event annotation scheme we developed, then, we set out agreement statistics before finally presenting a description of the corpus and associated software.

Annotation Scheme

Each document is associated with zero or more event frames reflecting the number of outbreak events described in the text (A full description of the annotation scheme, and all associated software can be downloaded from the project Google Code site [9]). The event frames are designed to capture the properties of outbreak reports that are of interest to public health experts and epidemiologists. Event frames are formatted in extensible markup language (XML) (see Figure 1) and consist of property names and their associated values derived from the document source (eg, HAS_DISEASE, "Ebola"). Reports have already been tagged for named entities such as person names, disease names, location names, and so on (twelve in total) using an ontology-based annotation scheme developed specifically for the disease outbreak domain [16]. Property names are of two types. First, entity properties are filled with appropriate entities derived directly from the text of interest (entity properties are conceptually similar to Message Understanding Conference (MUC) style "string fills"). For example, the HAS_DISEASE property could only have the value "polio" if "polio" is tagged as an entity in the document. Second, fixed slots (equivalent to MUC-style "set fills") take prespecified values of a restricted kind (normally simply Boolean true or false values), and, unlike entity values, are *inferred* from the document. For example, the INTERNATIONAL_TRAVEL property accepts only Boolean values.

The following are the entity properties (which are filled by named entities) and their definitions:

- HAS_DISEASE: disease that caused the outbreak (eg, Ebola)
- HAS_LOCATION.COUNTRY: country where the outbreak occurred (eg, United States, Indonesia)
- HAS_LOCATION.PROVINCE: province in which the outbreak occurred (eg, Kanagawa, New Hampshire)
- HAS_LOCATION.OTHER: other geographical location (eg, Balkans, New England)
- HAS_AGENT: agent (pathogen) of the disease (eg, HIV)

The following are the "fixed" slots (which are inferred from the text and take prespecified values) and their definitions:

- HAS_SPECIES: human or non_human
- TIME.relative: historical (more than three months ago), recent_past (between two weeks and three months ago), present (within the last two weeks), and hypothetical

- ZOONOSIS: has species transfer occurred? (Boolean)
- DRUG_RESISTANCE: is the disease drug resistant? (Boolean)
- NEW_TYPE_AGENT: is the disease a new strain? (Boolean)
- ACCIDENTAL_RELEASE: has the disease been released accidently? (Boolean)
- INTERNATIONAL_TRAVEL: is international travel involved? (Boolean)

- FOOD_CONTAMINATION: is the outbreak caused by contaminated food or water? (Boolean)
- HOSPITAL_WORKER: are any victims hospital workers? (Boolean)
- FARM_WORKER: are any victims farm workers? (Boolean)
- MALFORMED_PRODUCT: are contaminated blood products or vaccines implicated? (Boolean)

A working group consisting of the current paper’s authors developed the annotation scheme over a period of several months guided by the World Health Organization International Health Regulations [17] (see Textbox 1) and using advice provided by the National Institute of Infectious Diseases in Japan.

Figure 1. Worked example of event frame construction from raw text. Note that this paper focuses on the construction of event frames from documents already tagged for named entities. The named entity tagging process is described by Kawazoe et al [16].

Raw text report

```
                    BBC 2007/3/2
Cat  death prompts  bird flu  advice.   Cat owners  in countries hit by
bird flu  should keep their pets indoors, two agencies involved in co-
ordinating the fight against the virus have said.  The  World Health
Organization  and the  Food and Agriculture Organization's advice follows
the death of a  domestic cat  in  Germany  of the  H5N1  strain.   The death
is the  European Union's first known case of cross-species infection...
```

Named entity tagged

```
<DOC id="000700" source="BBC" domain="health" subdomain="disease"
date="2007/3/2" relevancy="publish">
<NAME cl="NONHUMAN" transmission="false">Cat</NAME> death prompts <NAME
cl="DISEASE">bird flu</NAME> advice.  <NAME cl="PERSON" case="false"
number="many">Cat owners</NAME> in countries hit by
<NAME cl="DISEASE">bird flu</NAME> should keep their pets indoors, two
agencies involved in co-ordinating the fight against the virus have said.
The <NAME cl="ORGANIZATION">World Health Organization</NAME> and the <NAME
cl="ORGANIZATION">Food and Agriculture Organization
</NAME>s advice follows the death of a
<NAME cl="NONHUMAN"transmission="false">domestic cat</NAME> in <NAME
cl="LOCATION">Germany</NAME> of the <NAME cl="VIRUS">H5N1</NAME> strain.
The death is the <NAME cl="LOCATION">European Union</NAME>s first known case
of cross-species infection...
</DOC>
```

Event frame

```
<EVENT name="OUTBREAK">
  <SLOT name="HAS_DISEASE" type="DISEASE" content="BIRD FLU|bird flu" />
  <SLOT name="HAS_LOCATION.COUNTRY" type="LOCATION" content="Germany" />
  <SLOT name="HAS_LOCATION.PROVINCE" type="LOCATION" content=""/>
  <SLOT name="HAS_LOCATION.OTHER" type="LOCATION" content="European Union"/>
  <SLOT name="HAS_AGENT" type="micro_organism" content="H5N1"/>
  <SLOT name="HAS_SPECIES" type="animal" content="non_human" alt=""/>
  <SLOT name="TIME.relative" type="string" content="Present"/>
  <SLOT name="INTERNATIONAL_TRAVEL" type="Boolean" content="false"/>
  <SLOT name="ACCIDENTAL_RELEASE" type="Boolean" content="false"/>
  <SLOT name="ZOONOSIS" type="Boolean" content="true"/>
  <SLOT name="DRUG_RESISTANCE" type="Boolean" content="false"/>
  <SLOT name="FOOD_CONTAMINATION" type="Boolean" content="false"/>
  <SLOT name="HOSPITAL_WORKER" type="Boolean" content="false"/>
  <SLOT name="FARM_WORKER" type="Boolean" content="false"/>
  <SLOT name="PRODUCT_MALFORMATION" type="Boolean" content="false"/>
  <SLOT name="NEW_TYPE_AGENT" type="Boolean" content="false"/>
  <SLOT name="COMMENT" type="string" content="Cat contracts H5N1"/>
</EVENT>
```

Textbox 1. Using the World Health Organization international health regulations (Annex 2 decision instrument) as the basis for an annotation scheme

World Health Organization International Health Regulations (Annex 2 Decision Instrument)

In developing our guidelines, we took inspiration from the World Health Organization's International Health Regulations Annex 2 decision instrument [17] for building our own decision tree. At the top level, this included general questions such as, "Is the topic of the article mainly about a current disease outbreak?" and "Are the victims of the disease mainly humans?" These questions were designed to guide annotators in the most obvious stages of selection. At lower levels, the decision tree we developed touched on issues more central to the Annex 2 decision tree such as known notifiable diseases (eg, SARS, Smallpox, Poliomyelitis, Cholera, West Nile Virus). The notion of “unusual” or “unexpected” is underspecified in Annex 2 but would be apparent to a public health expert familiar with the field. We tried to make the notion explicit for our annotators by encoding questions about the virulence and infectivity of the pathogen, the severity of the reported cases, the involvement of international travel, and drug resistance or accidental/deliberate release.

Agreement Study and Error Analysis

To gain insight into how consistently the scheme could be applied and to help pinpoint areas of systematic annotator error, we conducted a 100-document interannotator agreement study. We recruited and trained one annotator and compared that individual’s annotations with those of an annotator who was involved in the original annotation scheme design process.

Following the recommendations of Wilbur et al [18], we used percentage scores to assess agreement rather than the kappa statistic [19]. While some researchers in annotation scheme design refrain from the use of agreement studies entirely (eg, [20]), we felt that this exercise would help to draw out any systematic annotator difficulties and also facilitate the debugging of the annotation scheme and corpus.

We found that the two annotators agreed on the number of disease outbreak events 67% of the time. However, calculating agreement at the level of individual properties (eg, TIME.relative) was not as straightforward as calculating event number agreement for the following three reasons: (1) Annotators could identify a differing number of events for a document. (2) Unless both annotators produced just 1 (or zero) event frames, we were faced with the problem of aligning events. (3) The annotation scheme allowed for an arbitrary number of property values, reflecting synonymous or near synonymous terms in the source document. For example, it was not unusual to see a property/value pairing such as HAS_DISEASE=“bird flu|H5N1|avian influenza.”

Therefore, we concentrated our analysis on those 42 documents where only one event was identified per annotator, thus allowing for a direct comparison. These data are partially summarized in Table 1, where it can be seen that the annotators agreed 100% of the time on DRUG_RESISTANT, FARM_WORKER, INTERNATIONAL_TRAVEL, and PRODUCT_MALFORMATION. Agreement was worst for FOOD_CONTAMINATION and ZOONOSIS. Major sources of disagreement are summarized in Textbox 2.

The fixed slot properties, TIME.relative and SPECIES, are not Boolean and therefore are not represented in Table 1. TIME.relative had four values (historical, recent past, present, and hypothetical) and achieved an agreement score of 90.5% (with the most frequent value being “present”). SPECIES had two values (human and nonhuman) and achieved an agreement of 90.2%. More information about the annotation guidelines is available in [9].

The entity properties (eg, HAS_LOCATION.PROVINCE, HAS_DISEASE) were filled by tagged entities in the text. Agreement for HAS_DISEASE was 100% and for HAS_LOCATION.COUNTRY was 97.7%.

Table 1. Agreement for 42 documents with precisely one event per annotator (note that only Boolean fixed slot properties are shown)

	Agreement for Fixed Slot Properties in Each of 42 Documents				
Property	Annotator 1 (true)	Annotator 1 (false)	Annotator 2 (true)	Annotator 2 (false)	Agreement (%)
DRUG_RESISTANCE	0	42	0	42	100.0
FARM_WORKER	0	42	0	42	100.0
FOOD_CONTAMINATION	5	37	13	29	71.4
HOSPITAL_WORKER	0	42	1	41	97.6
INTERNATIONAL_TRAVEL	0	42	0	42	100.0
PRODUCT_MALFORMATION	0	42	0	42	100.0
ZOONOSIS	7	35	12	30	83.0

Textbox 2. Sources of disagreement

Event Agreement

On detailed examination of the data, a systematic problem concerning event granularity emerged accounting for the relatively low 67% event agreement rate. Our analysis showed that the issue of suspected zoonosis (ie, unconfirmed zoonosis or where zoonosis is presented as one possible explanation for a human disease) was central here. One annotator produced two events (one human, one non_human), while the other annotator only produced one event (human), ignoring the suspicion of, or speculation about, zoonosis.

Annotator Error

We can distinguish annotator agreement arising from ambiguity in the annotation guidelines from straightforward annotator mistakes. For instance, there are several examples where the temporal categories, present (within two weeks of the document time stamp) and recent_past (more than two weeks, but less than three months from the document time stamp), were confused.

Background Knowledge and Inference

For those properties that require an annotator to infer a category from the document (TIME.relative, ZOONOSIS, HAS_SPECIES, INTERNATIONAL_TRAVEL, DRUG_RESISTANCE, FOOD_CONTAMINATION, HOSPITAL_WORKER, FARM_WORKER, and PRODUCT_MALFORMATION), there is scope for incorrect inference. For example, several of the documents in the agreement study data set concern cholera. While cholera is spread primarily through water contamination (ie, FOOD_CONTAMINATION), this is not stated explicitly in the text. Only one of the annotators marked these documents as true for FOOD_CONTAMINATION, suggesting that the annotator who marked the property false was unaware of the primary transmission route for cholera.

Corpus Description

The corpus consists of 200 documents (all in English) and their associated event frames, with documents gathered from a variety of sources (see Table 2). The largest single source was ProMed-Mail [21], an expert-curated infectious disease reporting service. Additionally, documents were not randomly sampled, but rather selected to represent diseases and geographical areas of interest to the researchers. Major international news providers are also represented (eg, CBC, Reuters, BBC) in addition to primarily Asian or Asia-Pacific news services (eg, Vietnam-net, Thailand’s The Nation). Documents range from 45 to 1487 words long, with a mean of 305.9 words (without markup). Document selection was performed by author MC (see corpus documentation [9] for details).

Table 2. Corpus document sources (200 documents)

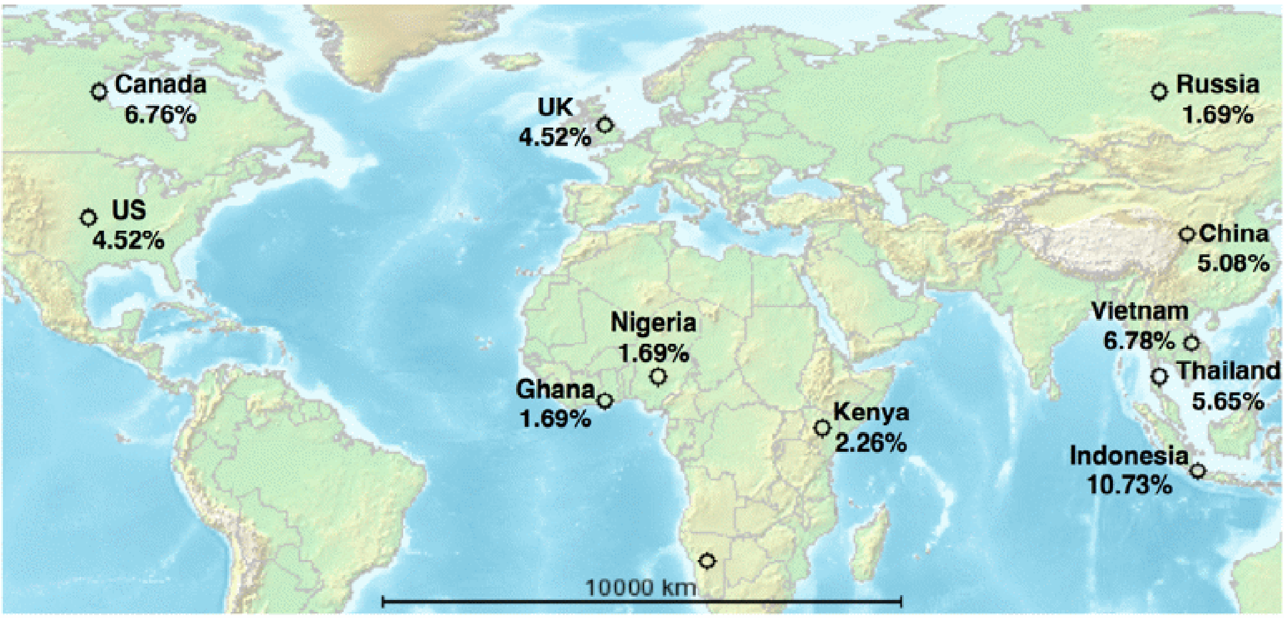
Document Source	Number of Documents	% of 200
ProMed-Mail	43	21.5
Reuters	16	8.0
BBC	16	8.0
WHO	41	20.5
CBS	13	6.5
CBC	17	8.5
Vietnam-net	12	6.0
Hindustan Times	18	9.0
The Nation (Thailand)	9	4.5
All Africa	5	2.5
Xinhua (China)	5	2.5
Antara (Indonesia)	5	2.5

Of the 394 annotated events in the corpus, 75.4% describe human (rather than animal) disease events (see Table 3). Most of the events identified (81.5%) have been classified as present outbreaks, although historical, recent past, and hypothetical events are also represented. To show the geographical range of the documents selected, the geographical distribution of events (by country) is shown in Figure 2. Note that the map does not show the actual distribution of disease events, but rather the geographical distribution of disease events in our corpus.

Table 3. Event statistics (total number of events is 394)

Type of Event	Number of Events	% of 394
Events involving humans	297	75.4
Events involving food contamination	35	8.9
Events involving hospital workers	3	0.8
Events involving malformed products	2	0.5
Events classified as present	321	81.5
Events classified as historical	49	12.4
Events classified as recent_past	11	2.8
Events classified as hypothetical	13	3.3

Figure 2. Distribution of disease events in our corpus by country (only countries with 2 or more events shown) (Map produced by GPS visualizer)



While we hope that the event frame may form part of the foundation for a future standard, we recognize that there are challenges in achieving this goal (see Textbox 3). Further, due to copyright restrictions, we are unable to distribute the corpus directly. Instead we have provided two methods for corpus access. First, a download script (a Perl script that downloads and cleans all the documents from their original source on the Web and then associates them with event frames) and a graphical user interface (GUI) based event browser (see Figure 3) [9]. Note that as of July 2009, only 176 of the original 200 documents were currently available online.

Textbox 3. Barriers to general adoption of the event annotation scheme

Heterogeneous Systems and Requirements

The current event frames may not be suitable for all needs. For some users, the knowledge required by event frames may be superfluous (eg, a system that is solely concerned with identifying cholera outbreak has no need for zoonosis information). For other users, the event frame may not encode enough information (eg, an event's certainty or uncertainty—unrepresented in our event frame—may be important for system designers). Indeed, it is conceivable that some users may suffer from both these problems. Nevertheless, we believe that our event scheme provides a foundation for potential future standards developments.

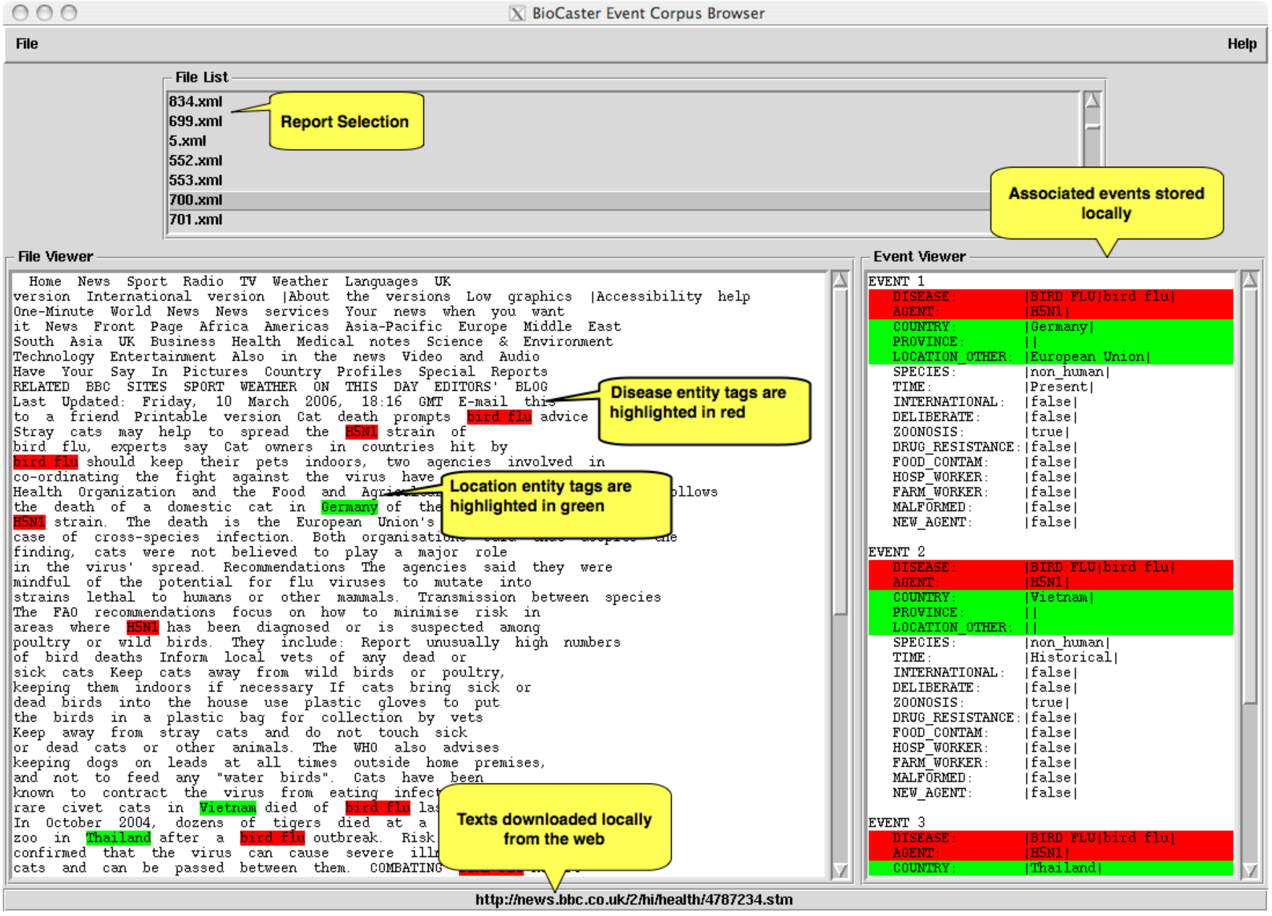
Agreement

The current agreement level for number of events (67%) is not high. However, this result masks the fact that agreement for important entity properties such as HAS_LOCATION.COUNTRY and HAS_DISEASE is almost perfect.

Extending to New Genres

The current scheme was designed for news text. It is not clear how well the scheme would extend to other, less formal genres that may contain information of interest (eg, blog postings and message boards).

Figure 3. Linux BioCaster corpus event frame browsing tool [9]



```
  Home  News  Sport  Radio  TV  Weather  Languages  UK
version  International  version  |About  the  versions  Low  graphics  |Accessibility  help
One-Minute  World  News  News  services  Your  news  when  you  want
it  News  Front  Page  Africa  Americas  Asia-Pacific  Europe  Middle  East
South  Asia  UK  Business  Health  Medical  notes  Science  &  Environment
Technology  Entertainment  Also  in  the  news  Video  and  Audio
Have  Your  Say  In  Pictures  Country  Profiles  Special  Reports
RELATED  BBC  SITES  SPORT  WEATHER  ON  THIS  DAY  EDITORS'  BLOG
Last  Updated:  Friday,  10  March  2006,  18:16  GMT  E-mail  this
to  a  friend  Printable  version  Cat  death  prompts  bird flu  advice
Stray  cats  may  help  to  spread  the  H5N1  strain  of
bird  flu,  experts  say  Cat  owners  in  countries  hit  by
bird flu  should  keep  their  pets  indoors,  two  agencies  involved  in
co-ordinating  the  fight  against  the  virus  have
Health  Organization  and  the  Food  and  Agri                           ollows
the  death  of  a  domestic  cat  in  Germany  of  the
H5N1  strain.  The  death  is  the  European  Union's
case  of  cross-species  infection.  Both  organisati
finding,  cats  were  not  believed  to  play  a  major  role
in  the  virus'  spread.  Recommendations  The  agencies  said  they  were
mindful  of  the  potential  for  flu  viruses  to  mutate  into
strains  lethal  to  humans  or  other  mammals.  Transmission  between  species
The  FAO  recommendations  focus  on  how  to  minimise  risk  in
areas  where  H5N1  has  been  diagnosed  or  is  suspected  among
poultry  or  wild  birds.  They  include:  Report  unusually  high  numbers
of  bird  deaths  Inform  local  vets  of  any  dead  or
sick  cats  Keep  cats  away  from  wild  birds  or  poultry,
keeping  them  indoors  if  necessary  If  cats  bring  sick  or
dead  birds  into  the  house  use  plastic  gloves  to  put
the  birds  in  a  plastic  bag  for  collection  by  vets
Keep  away  from  stray  cats  and  do  not  touch  sick
or  dead  cats  or  other  animals.  The  WHO  also  advises
keeping  dogs  on  leads  at  all  times  outside  home  premises,
and  not  to  feed  any  "water  birds".  Cats  have  been
known  to  contract  the  virus  from  eating  infect
rare  civet  cats  in  Vietnam  died  of  bird flu  las
In  October  2004,  dozens  of  tigers  died  at  a
zoo  in  Thailand  after  a  bird flu  outbreak.  Risk
confirmed  that  the  virus  can  cause  severe  ill
cats  and  can  be  passed  between  them.  COMBATING
```

```
EVENT 1
    DISEASE:           |BIRD FLU|bird flu|
    AGENT:             |H5N1|
    COUNTRY:           |Germany|
    PROVINCE:          ||
    LOCATION_OTHER:    |European Union|
    SPECIES:           |non_human|
    TIME:              |Present|
    INTERNATIONAL:     |false|
    DELIBERATE:        |false|
    ZOONOSIS:          |true|
    DRUG_RESISTANCE:   |false|
    FOOD_CONTAM:       |false|
    HOSP_WORKER:       |false|
    FARM_WORKER:       |false|
    MALFORMED:         |false|
    NEW_AGENT:         |false|

EVENT 2
    DISEASE:           |BIRD FLU|bird flu|
    AGENT:             |H5N1|
    COUNTRY:           |Vietnam|
    PROVINCE:          ||
    LOCATION_OTHER:    ||
    SPECIES:           |non_human|
    TIME:              |Historical|
    INTERNATIONAL:     |false|
    DELIBERATE:        |false|
    ZOONOSIS:          |true|
    DRUG_RESISTANCE:   |false|
    FOOD_CONTAM:       |false|
    HOSP_WORKER:       |false|
    FARM_WORKER:       |false|
    MALFORMED:         |false|
    NEW_AGENT:         |false|

EVENT 3
    DISEASE:           |BIRD FLU|bird flu|
    AGENT:             |H5N1|
    COUNTRY:           |Thailand|
```

In summary, we present an annotation scheme and corpus that can be used in the evaluation of disease outbreak event extraction algorithms. The annotation scheme and corpus are presented to the research community in the belief that such resources can help in the formation of an emerging standard for this rapidly growing research area.

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Conflicts of Interest

None declared

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Abbreviations

GPHIN: Global Public Health Intelligence Network
GUI: graphical user interface
IE: information extraction
IR: information retrieval
MUC: message understanding conference
NER: named entity recognition
PULS: Pattern-based Understanding and Learning System
TREC: Text Retrieval Conference
WHO: World Health Organization
XML: extensible markup language

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Viewpoint

Get Your Paws off of My Pixels: Personal Identity and Avatars as Self

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Abstract

There is an astounding silence in the peer-reviewed literature regarding what rights a person ought to expect to retain when being represented by an avatar rather than a biological body. Before one can have meaningful ethical discussions about informed consent in virtual worlds, avatar bodily integrity, and so on, the status of avatars vis-à-vis the self must first be decided. We argue that as another manifestation of the individual, an individual's avatar should have rights analogous to those of a biological body. Our strategy will be to show that (1) possessing a physical body is not a necessary condition for possessing rights; (2) rights are already extended to representations of a person to which no biological consciousness is attached; and (3) when imbued with intentionality, some prostheses become "self." We will then argue that avatars meet all of the conditions necessary to be protected by rights similar to those enjoyed by a biological body. The structure of our argument will take the form of a conditional. We will argue that *if* a user considers an avatar an extension of the self, *then* the avatar has rights analogous to the rights of the user. Finally, we will discuss and resolve some of the objections to our position including conflicts that may arise when more than one individual considers an avatar to be part of the self.

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KEYWORDS

Autonomy; rights; avatar; virtual world

Introduction

Medical ethics is a fluid field that is constantly evolving in response to new technological developments. One of the recent innovations to impact medical ethics is the Internet and the development of virtual worlds and interactions. Virtual interactions can be as mundane as a virtual business meeting or as provocative as the Red Light Center (www.redlightcenter.com) dedicated to sex. Some virtual worlds such as Second Life (secondlife.com) allow for a range of interactions between individuals similar to those in the nonvirtual world. Among these interactions are those relevant to bioethics, particularly the treatment of various psychological disorders including group therapy, patient education, medical education, research, and so on [1-6].

An individual navigates many of these virtual worlds as a construct known as an "avatar," named after the worldly incarnations of the Hindu gods. Avatars may or may not share physical similarities with the person they represent. Depending on the world, avatars can be individualized by "virtual plastic surgery" to emphasize the idealized characteristics of an individual.

If virtual sex is available, can virtual rape be far behind? In the first six months of 2003, the South Korean police received

22,000 reports of crimes committed by characters in online games [7]. In 2007, the Dutch police arrested a 17-year-old, accusing him of having stolen 4000 Euros worth of virtual furniture [8], and in 2007, Belgian police opened an investigation into a man accused of virtual rape and began patrolling Second Life to prevent crimes [9].

Accusations of virtual crime have forced governments to consider the legal status of virtual property. Given that virtual property often has value in the nonvirtual world, it comes as no surprise that theft of virtual property has been prosecuted as if it were theft of material property. What does come as a surprise is the astounding silence in the peer-reviewed ethics literature regarding what rights a person should expect to retain when being represented by an avatar rather than a biological body. This lack of peer-reviewed literature is particularly surprising given the claim in the existing literature that "[i]t appears likely that [online] gaming and its associated notions of play may become a metaphor for a range of human social interactions, with the potential for new freedoms and creativity as well as new oppressions and inequality" [10]. Before one can have meaningful ethical discussions about virtual assault, virtual rape, virtual consent, and so on, the status of avatars vis-à-vis the self must first be decided.

The ability to experience virtual worlds as an avatar, along with the ability of others to experience an individual as *nothing but* an avatar, requires an examination of the paradigm of what it means to be "self," or, to use the terminology of the philosophy literature, what it is that constitutes one's personal identity [11]. An individual can now have more than one manifestation of a single consciousness. As new "worlds" are defined, the definition of "self" must, and will, change. This article will defend the thesis that avatars can be thought of as part of the "self" and as such have rights analogous to the rights possessed by an individual's body in the nonvirtual world.

Our strategy will be to show that (1) possessing a body is not a necessary condition for possessing rights; (2) rights are already extended to representations of a person to which no biological consciousness is attached; and (3) when imbued with intentionality, some prostheses become "self." We will then argue that avatars meet all of the conditions necessary to be part of "self" and thus should be protected by similar rights as a biological body. Finally, we will discuss and resolve some of the objections to our position as well as conflicts that may arise when more than one individual considers an avatar to be part of the self.

We will argue that *if* a user considers an avatar an extension of the self, *then* their avatar has rights analogous to the rights of the user. It is not our intention to argue that the majority of individuals currently consider their avatar as part of the self. Even if this isn't currently the case, evidence suggests that with advances in virtual interface technology, more and more users will come to identify their avatar as an extension of themselves [12,13].

Throughout this paper we will use the term "nonvirtual world" to refer to our corporeal existence instead of the term "real world." The term "real world" connotes that other worlds are not "real." This creates a psychological bias minimizing the "realness" of virtual worlds.

Arguments

A Physical Body is Not Necessary for Legal Protection and Having Rights as a Person

The legal definition of psychological abuse provides evidence that one need not have a body in the usual sense to have legal rights. According to the US Department of Health and Human Services Children's Bureau, 48 US states have laws against the emotional abuse of a dependent child. They go on to say that the "[t]ypical language used in these definitions [of emotional abuse] is injury to the psychological capacity or emotional stability of a child" [14]. In Virginia, for example, emotional abuse can take the form of "ridicule, rejection, intimidation, ignoring a child, or indifference" [15]. Even though in the nonvirtual world a consciousness is always tied to a body, a physical presence (or body) is not necessary for any of these to take place. In fact, one can easily envision this type of crime occurring in a chat room, over the phone, via email or even in a particularly scathing viral video. Thus, while a consciousness is required for this crime to take place, a corporeal body is not.

If the previous example is not convincing, a will provides more direct evidence that having a physical body is not a necessary condition for possessing rights. A will provides instructions regarding a deceased individual's property. Having died, the author of the will no longer has a physical body nor any kind of mental activity. Even so, a person's wishes in regard to his or her property are binding; that is to say, individuals retain some amount of postmortem property rights.

In summary, a body is not a necessary condition to possess rights. And some rights continue even when a consciousness is no longer present. This does not imply that all inanimate objects qualify for rights. But in the proper circumstances, which we will discuss below, an avatar, which has neither a corporeal existence in the nonvirtual world nor inherent consciousness, can be a candidate for rights based on being part of the "self."

Rights are Already Afforded to Representations of an Individual

We already afford rights to some representations of an individual that are not connected in a biological sense to the individual's consciousness. Consider the case of an individual with prosthetic limbs. If these limbs are stolen from a house and destroyed, they are considered property: a burglary and destruction of property have occurred. Now consider two cases in which an individual is attacked. In the first attack (A1), the assailant misses the intended target entirely. This is unpleasant because of awareness of potential danger, but there is no bodily harm: the victim sustained no physical damage. In the second attack (A2), assume that the only damage that occurs during the assault is to the victim's prosthetic limbs while they are attached to the individual. Most readers will intuit that A2 reaches a different level of harm than A1 even though the prosthetic limbs are a nonbiological manifestation of the individual. Some moral/legal change occurs when the prosthetic limbs are attached to the victim of the assault. Imbuing the limbs with intentionality changes the moral status of the limbs from that of inanimate objects to extensions of the individual to whom they are attached.

Perhaps a more intuitive example comes from the transplantation of a biological "prosthesis" from one person to another. Take for example, a biological face, hand, or arm graft. These are prostheses, albeit of a sophisticated nature. Is it the case that these cannot be a part of the person because they are prostheses and do not contain the same DNA? Does being part of the "self" require a prosthesis to contain the same DNA as the user? We do not believe this to be the case. Rather, the person receiving the transplanted part gives it intentionality. Otherwise the part would simply be an inanimate object, unattached, and a candidate for burial or cremation.

We would argue that a biological prosthesis does not differ fundamentally from a sophisticated mechanical arm or a functional prosthetic mechanical eye. The difference between a biological prosthetic arm and a nonbiological prosthetic arm is one of degree and not of kind. Both are prostheses and devoid of rights (as a person) unless given intentionality. As future nonbiological prostheses become more sophisticated and integrated into the nervous system, this will become more self-evident. [16,17].

It does not appear that biological identity is necessary for something to be given intentionality and thus to become self. This does not imply that every object can be considered self. However, it allows for, although does not prove, that avatars can be "self." Avatars are analogous to prostheses in that they allow the user to manipulate the environment even though they have no direct biological connection to the consciousness of the individual. The individual thinks, moves a muscle, and the prosthesis moves. This is the same path taken by an avatar. The individual thinks, moves muscles (in this case controlling a keyboard or a mouse), and the avatar carries out an action. If, as we argue, we are going to assign "self" to one biological or nonbiological corporeal manifestation of an individual (prosthetic limbs) there should be no barrier to assigning similar rights to another nonbiological manifestations of an individual (the avatar).

Likewise, we already assign rights to the corporeal representation of an individual whether or not a biological consciousness is present *within* the representation. This is the case with rights afforded those in a permanent vegetative state. There are legal protections against assaulting and otherwise violating those in a persistent vegetative state. For our purposes, the reason for these rights is immaterial. Whether it is because there was once a consciousness present or because society finds violation of a biologically live body abhorrent is irrelevant. The point remains that consciousness need not be biologically present for the *representation* to have rights as a person. This is analogous to an avatar. It is a representation of an individual, and we will argue below that it is part of the self, even though there is no biological consciousness present within the representation.

Avatars are Appropriate Candidates for Rights as Part of the "Self"

The fact that having a physical body is not a necessary condition for an entity to possess rights does not show that avatars have rights. A young child's imaginary play friend does not have a physical body. It would be absurd to argue that it had rights as a person.

Our first argument showing that avatars are appropriate candidates for rights is a thought experiment. Let us imagine a "Matrix-like" world. Let us call this world MW_1. In this world, people are directly and permanently connected to a virtual world via brain-scanning hardware. The person thinks and their avatar in the virtual world moves. The nonvirtual world and virtual worlds are phenomenologically indistinguishable. All representations of the "self" in this world are via an avatar. What happens to the avatar is fed back into the brain scan system causing pain, pleasure, and other sensations. Higher emotions such as fear, greed, and love are also affected by the virtual world. It is unquestionably true that residents of this Matrix-like world can make legitimate rights claims on each other, the right to be free from torture, for example. Any rights claimed would be assigned to the avatar since it is the only manifestation of self that can act that exists in this world.

Now let us suppose that instead of being permanently hardwired into the virtual world, the residents of MW_1 can log in and out of the virtual world at will. Let us call this world MW_2. Does the ability to log in and out change legitimacy of rights claims in the virtual world? Nothing of moral (and presumably legal) importance has changed about an individual's relationship to the virtual world except that there are now two worlds in which an individual can make rights claims: a virtual world and a nonvirtual world.

Let us examine a third world, W. It is similar to MW_2 in all ways except that brain-scan technology has yet to be invented. People can only interact with the virtual world via a computer monitor and keyboard (one may note that W looks very much like the nonvirtual world we inhabit). There is an important difference between MW_2 and W. The behavior of, and toward, avatars can no longer cause certain phenomenological states such as physical pain or the sensations of touch, taste, and smell, for example (although hardware that allows some of these physical sensations has been developed). Other phenomenological states will still be affected by events in the virtual world such as joy, despair, anxiety, and annoyance.

The difference between MW_1 and W is one of degree and not of kind. If the difference is only in degree, people can still make legitimate rights claims for their avatars; all that changes is the degree of strength of said claims [18]. The use of keyboard and mouse certainly adds an additional barrier between a user and his or her avatar. Though the connection between user and avatar is less direct, the intentional relationship between user and virtual construct remains. The scope of rights claims is all that differs.

Degree of Identity and Rights

Given that an action that would cause physical pain to the user in MW_2 will cause no such pain for a user in W, some behavior that is not permissible in MW_2 will be permissible in W. Just as one has a right not to be assaulted, even when the assault causes no physical harm, avatars in W will have certain rights as part of the self. These may include bodily integrity and freedom from fear. The closer the identification between the avatar and the individual, the more complete the rights of the person-as-avatar. In the “Matrix-like” world, where phenomenologically the prosthetic is the person, the rights of the avatar are identical to those of the person

Starting with a paradigm that made the case for legitimate rights claims in MW_1, we made modifications that made MW_1 come to resemble W, which is in all relevant aspects similar to our own world. We further argued that each modification was only a change of degree, and not a change in kind. Given that avatars in MW_1 have rights, it follows that avatars in W also have rights.

Our final argument in favor of the rights of avatars is related to the previous argument, that is, avatars have rights by proxy of the rights of their users. For example, while my avatar is engaged in an online community I find myself facing unwelcome sexual advances. Things quickly escalate out of control. I find myself feeling extremely uncomfortable. Depending on the situation, my only recourse may be to disconnect my avatar. This looks like a violation of right to free access. One may now argue that “Aha, didn’t they just say the rights of an avatar are dependent on the proxy rights of the individual and not inherent to the avatar?” To this we would answer an emphatic yes. It shows the degree of identity between an avatar and the ”person.” Essentially, they are phenomenologically one and the same at this point. Changing the rights of the avatar changes the rights of the person. My avatar has certain rights and violating those rights is also a violation of my rights.

“Normal” Interactions and “Necessary Embeddedness”

The ability of a person to have interactions in more than one social milieu (virtual and nonvirtual) requires a redefinition of the “self.” One way we propose to redefine self is by using a principle we call “necessary embeddedness.” An object is “necessarily embedded” and has rights as part of the self to the extent that the object is necessary for “normal” interaction within some specific domain. Note that “normal interactions” change as the domain changes. What counts as a normal interaction in the nonvirtual world is not a paradigm of normal interaction in the virtual world. Additionally, what count as “normal” interactions in the virtual world can and do change as technology and programming evolve, allowing ever more phenomenologically complex interactions to occur. By basing the standard for rights possession by nonbiological extensions on “normal” interactions, necessary embeddedness captures the social nature of rights and manages to apply them to inanimate objects. For example, persons who are visually impaired may use haptic devices to provide tactile feedback in lieu of visual cues. In the case of the vitual world, haptic devices can substitute for vision allowing people who are visually impaired to locate other online individuals, navigate passageways, and so on [19]. Without such a device, the virtual world is essentially inaccessible to people who are visually impaired [20]. Thus, we argue that the haptic device would enjoy protection as part of the self should the user wish to deem it so. For any individual reliant on it, the haptic device is so fundamentally a part of the self within the virtual environment that removing it would change the “self” vis-à-vis that particular world. Likewise, although the avatar is not material, it is just as fundamental as a haptic device for interactions in virtual worlds.

We would also argue that applying the principle of necessary embeddedness may correct our mistaken intuitions on rights. In our Matrix thought experiment, it is not intuitively clear that avatars in W have rights; however, it is clear that avatars in MW_1 have rights. We posit that because avatars in MW_1 are more strongly “necessarily embedded” than those in W, our intuitions recognize the legitimacy of rights claims in MW_1 while they do not for avatars in W.

Response to Possible Objections

By this point the observant reader will have noticed a somewhat disconcerting trend with our argumentation. Any number of our arguments seem to lead to a question with an unacceptable answer: If an individual decides that a doll (or other object) is his representation in the nonvirtual world, should it have rights as “self?” By the argumentation expressed so far, it would appear that we must also accept the conclusion that a doll is an appropriate candidate for rights if an individual deems it so.

We have two responses to this conclusion. First, we intuitively assign rights to prosthetic limbs. As demonstrated above, we recognize on some level that prostheses are part of “self” when attached to an individual. Prostheses in the future will be more integrated with “self” as prostheses that interface directly with the brain and the biological body are developed [17,18]. Second, we would argue that the “self” is defined in a positive sense (at least in part) as that which allows an individual to interact with the world in a “normal” fashion. And, in a negative sense, if this “self” is disturbed somehow (prosthetic limbs are removed from the individual, or an avatar is attacked and disabled) its ability to interact in the world is hindered. Neither of these conditions is met by a doll.

This still begs the point about assigning “self” to a doll or a pair of glasses. We would suggest that if someone posits that “a doll is my representation in the world and part of my “self,”” it has to meet the “test of destruction,” that is, would destruction of this doll hinder my ability to function in the world in a fundamental sense (not just the depression suffered from the loss of an object)? Does the doll meet the test of necessary embeddedness? If the answer is no, it is not considered “self.” It is clearly separate from self in that its destruction does not fundamentally change the individual’s ability to function in the world. Similarly, one can raise the question about glasses, a wheelchair, or the white cane carried by visually impaired persons. We would argue that to the extent that individuals imbue these prostheses with intentionality and they are needed for “normal” interactions (necessarily embedded) with the world, they should be recognized as an extension of one’s self. Thus, they have a legitimate right to protection while in use; interfering with their active use would constitute assault and not a property crime. An analogy would be plucking out a functional prosthetic eye or a cochlear implant. As in the Matrix scenario, there is a difference in degree between interfering with someone's white cane and their prosthetic eye but not a difference in kind.

There may be a finite number of situations (eg, psychosis, delusions, or delirium) in which an individual does assign "self" to a doll, and the doll's destruction hinders or prevents the individual from interacting in the world (the doll is necessarily embedded in the individual's interactions). In this case, we would argue that the doll does have a right to bodily integrity as part of the self of the individual; attacking the doll has a fundamental consequence for the individual. However, this would apply to a very limited subset of individuals. Another caveat is that one obviously cannot define another individual as "self" even if the other "self" is being used as a prosthesis (for example, someone who is helping you cross the street). Nor can one claim as "self" a prosthesis to which someone already has a right. This is discussed further below.

Identity and Conflict

As we note above, rights require a social milieu. Thus, conflicts can arise which require rules. An interesting case occurs when more than one person claims a prosthesis as part of the self. For example, imagine a team of scientists who work with the Mars Rover. The Mars Rover is necessarily embedded for the scientists; it is the only way for them to interact with the surface of Mars. Some particular scientist (perhaps a bit deluded) comes to think about the Mars Rover as a part of himself. The Mars Rover then fulfills the two criteria for rights that we laid out previously: it is necessarily embedded and it is viewed as part of the self. Now imagine that not one but two (slightly deluded) scientists claim the Mars Rover as an extension of the self. Is the Mars Rover an extension of both scientists' selves? There are two caveats to add to the theory of necessary embeddedness. First, if an agent, A, is aware that some object, O, is possessed by another individual, A cannot extend rights to O. A's knowledge of the preexisting rights claim by some other person precludes A's making it a legitimate extension of the self. In the case of the Mars Rover, the scientists cannot extend their selves to the Rover because the Rover is known to be public property. Second, if two individuals make two competing, seemingly equal legitimate rights claims on an object at the same time, property law would come into play to resolve the conflict. If the claims are indeed equal, the claims would cancel each other out and neither scientist would be able to claim the object as self.

A more interesting scenario occurs when "borrowing" a prosthesis. Imagine a world similar to MW_1; call it MW_1* (recall that MW_1 is the "Matrix-like" world). In this world, two individuals share the same avatar. When one person goes to sleep, the other person wakes up and controls the avatar. In this case there does not seem to be any ownership claims that might undermine one individual's rights claims to the avatar as self. Nor is it the case that the rights claims overlap temporally; each individual makes his or her rights claim in turn *and with the agreement of the other.*

The concept of something serially being the "self" of two individuals seems at first counterintuitive. However, a real-world example would be a transplanted heart. The heart is serially part of the "self" of two individuals. In fact, if you remove it, the "self" of each individual will cease to exist (short of technological support). And, there is no inherent barrier to the heart being transplanted serially to others (once immunologic barriers are removed). Thus, the concept of something being the "self" of two individuals serially does not require a paradigm shift. In the case of the avatar, if there is an intention to deceive other people (for example identify theft) on the part of one party using the avatar, laws about personal identity come into play.

If the two individuals do not know each other and are not aware they are sharing an avatar, then there is a rights conflict (although from a practical perspective, by definition, it remains undiscovered). This would be similar to someone living in my vacation home without my knowledge. The fact that I am unaware of the occurrence does not mean that I do not have rights to my property.

The Right to Bodily Integrity

The right to bodily integrity is *one* of the most fundamental rights. Thus, it should be afforded to avatars in that they can be considered part of "self." The degree of rights assigned to an avatar as part of the self will depend on the degree of identity between the avatar and the person. In MW_1 (the "Matrix-like" world), the identity between the avatar and the self is complete. Thus, the avatar, as the only social and phenomenological manifestation of self, will be entitled to the full rights enjoyed by a person (sans rights to such things as health care that may not be not applicable).

We believe it is obvious a priori that the right to bodily integrity is one of the most fundamental rights. Before one can even contemplate higher rights (to free speech, to own property, etc), one needs to be free from fear of assault, rape (a particularly heinous type of assault), torture, murder, and so on. As noted above, certain states—such as joy, despair, anxiety, annoyance, and love—may be felt as direct consequences of *current* virtual interactions. Thus, assault or other violation of the self-as-avatar will have consequences in the nonvirtual world. The likelihood of this will increase in the future as more complex tactile feedback is given to the user (pain, pleasure, etc).

That avatars are candidates for rights also raises the question of informed consent within virtual worlds. We would argue that some type of informed consent should be required for virtual world research. Even a research questionnaire will have an impact on the individual whether the questionnaire is administered in the virtual or nonvirtual world. The virtual world inherently affords a degree of anonymity that may or may not exist in the nonvirtual world depending on the study design (eg, whether the questionnaire is administered in person). However, there will be some emotional impact on the individual in the study. Thus, consent, perhaps in a modified form, should be obtained in the virtual world as it is in the nonvirtual world.

Conclusion

We have outlined a case showing that avatars, as extensions of the self, are candidates for rights. The subset of rights one's avatar should enjoy will be dependent on the degree of phenomenological identity between the individual and his or her avatar. Drawing this line is difficult. Some people will have a stronger emotional reaction to a violation of their avatar than others. And, the situation in which the avatar is participating will obviously modify these rights. One would expect a greater degree of bodily integrity within virtual group therapy than in a combat simulation.

Areas of future research could focus on expanding the discussion of necessary embeddedness and it's application to virtual and nonvirtual worlds as well as further discussion of what elements of informed consent are necessary in a virtual world. A discussion of what might constitute the "inalienable" rights of an avatar should also be undertaken.

Conflicts of Interest

None declared

Authors' Contributions

Both authors contributed equally to this paper. The idea was conceived of and the paper written together.

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Viewpoint

A Multidimensional View of Personal Health Systems for Underserved Populations

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Abstract

The advent of electronic personal health records (PHR) provides a major opportunity to encourage positive health management practices, such as chronic disease management. Yet, to date there has been little attention toward the use of PHRs where advanced health information services are perhaps most needed, namely, in underserved communities. Drawing upon research conducted with safety net providers and patients, the authors propose a multi-level analytical framework for guiding actions aimed at fostering PHR adoption and utilization. The authors first outline distinctive user and technical requirements that need to be considered. Next, they assess organizational requirements necessary to implement PHRs within health systems bound by limited resources. Finally, the authors analyze the overriding health care policy context that can facilitate or thwart such efforts. The conclusion notes that heightened national attention toward health information technology and reform provides a significant opportunity for initiatives whose goal is to increase widepread access to PHRs.

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KEYWORDS

Medically underserved; chronically ill; personal health records

Introduction

The Need to Extend Public Health Record System Usage to Underserved Populations

There are important and pressing reasons for providing personal health information to underserved populations. Underserved groups are widespread within the United States and other industrialized countries [1,2] resulting in broad inequities in many communities. Such populations are typically diverse, low-income groups who lack adequate access to traditional care and are often referred to as living in the "safety net" [3]. Due to the fragmented nature of this population’s health care background and a general lack of preventive health measures, individuals in the safety net (including low income, uninsured, homeless, and other special needs groups [4]) are taxing general health and emergency health systems to their limits, resulting in adverse fiscal impacts on providers as well as private and governmental payers [5]. Outside of increasing medical staff and resources, one of the most promising ways to help alleviate the stress incurred by ever evolving patient needs and the health care systems that support them is to increase people’s ability to manage their own health.

Over the last few years, electronic and Web-based personal health record systems (PHRs) have entered the marketplace and have begun to demonstrate value for health care consumers. PHRs allow the patient to manage personal health information, to maintain provider and insurance services, to manage prescriptions, appointments, and medical procedures, and to receive data from the electronic medical record (EMR) systems used by providers to manage and process medical services provided to patients [6-9]. In addition, PHRs can help patients maintain a continuous health record for themselves and family members and also to communicate more extensively with physicians and other health care providers [9]. PHRs and the related health information technologies provide a new level of patient health management with the opportunity for an available, cumulative health management record. The success of large PHR implementations by Kaiser Permanente (My Health Manager) and the Veterans Health Administration (My Health*e*Vet), coupled with the recent entry of Web solution firms such as Microsoft and Google, leave little question as to the growing influence that PHRs will have on the future of health care transactions [8]. Our perspective is that the underserved should not be left out of these exciting advances in health technology, and conversely, there is value in extending the reach of PHRs in this direction.

While the emergence of PHRs provides an opportunity to address numerous challenges related to the personal management of health, this can only occur if such systems are usable by and accessible to a diverse array of health care consumers. To this end, a research-based, analytical framework has been designed that provides actionable guidelines for developing PHRs for the underserved. The framework described here focuses on the unique challenges of providing practical PHRs for underserved groups and outlines concurrent actions that need to be taken at the technology, provider, and policy levels. Prefacing this framework is an overview of the unique need for PHRs within the underserved groups, the research that has been conducted within these settings, and the overall findings that have informed what is being forwarded as a “framework for action” toward the timely design and adoption of PHRs within vulnerable populations.

Enhancing Health Self-Management: A High-Value Target

The US health care system struggles with an increasing burden brought about by an aging population, increasing numbers of underinsured populations, the high incidence of chronic health conditions, and an insufficient pool of incoming health care workers [10,11]. As a result, the burden of managing patient health, therapy, and medical transactions is shifting from overtaxed providers to patients and their families. In this environment, health management technologies such as PHRs can play a key role in aiding those requiring the most assistance.

Information technologies have gradually transformed many aspects of the health care service enterprise, yet scant attention has been paid to their use within provider settings that focus on diverse and vulnerable populations [3]. Much of the research on PHRs focuses on relatively educated health care consumers such as commercial health plan subscribers who are computer literate and have easy access to the Internet. Some of the most important health care system impacts, however, could be provided by efficient and effective solutions for implementing PHRs within populations not served by existing health care systems [9,12,13]. While it is clear that electronic record keeping and practices can decrease unnecessary medical encounters [14], such efficiencies can also be vital to resource-strapped providers who often care for the most vulnerable populations. Recently, there has been some attention to the need and potential for PHR adoption within one segment of the population: persons with disabilities [15]. A very similar but perhaps broader need for examination exists in the underserved population as well.

The term “underserved” refers to broad and diverse groups who are typically of low socioeconomic status. They are often uninsured or underinsured and are at risk of critical health problems due to gaps in health maintenance. The two most common measures of underserved are those without health insurance and those living in communities deemed by the federal government as medically underserved areas (MUAs) [16]. Recent estimates report that there are some 47 million uninsured Americans in the country, with a greater number of Americans (some 66 million living) in MUAs. In the state of California (where the bulk of this study’s field research was conducted), some 8.5 million Californians currently do not have health insurance, most of whom live in medically underserved areas [16-18]. The recently passed national health care reform legislation will make strides to address this problem, but it will take several years to unfold and does not erase the trying economic and health circumstances for many who have been underserved.

While the research presented here has focused on underserved groups in the United States, similar trends have been identified in many industrialized countries. In several European nations, for example, eHealth services are increasingly embraced among Internet users, while underserved groups in many parts of Europe have lower levels of such access [19-21]. For many, “only well-placed users (high education, high socioeconomic status)” are able to take advantage of eHealth services [22]. It is clear that developing nations in Asia, Africa, Middle East and elsewhere face even more daunting obstacles in providing such access.

Within the United States, many see a pressing need for practical solutions that can enable underserved populations to manage their own health care. In California, approximately 90% of adults who are uninsured do not qualify for public health care assistance; the largest proportion (32%) of this population is of Latino ethnicity [23]. Such individuals often engage in migratory work, lack stable residency, and are unlikely or simply unable to seek consistent preventive health services necessary to identify and address early indicators of health problems [24]. Moreover, fragmented care for chronic conditions such as diabetes can lead to life threatening situations that not only impact the individual but also place an extraordinary burden on the limited health care resources of both the individual and the health care system. Since these patients often lack an identifiable or familiar location to receive health care, there is little opportunity to create relationships with providers, thus decreasing the number of opportunities to receive preventive care [5]. In these situations, the emergency receiving department often becomes the primary care provider due to a lack of known choices, resulting in an expensive and excessive burden on hospital systems. Thus, convenient access to health information resources, appropriately adapted to the underserved patient, can have a positive impact on health and health resources [25]. Accordingly, provision of PHR resources focused on the needs of vulnerable populations deserves greater attention and is what the following research endeavors to accomplish.

As Senator Harkin said in his introduction to a 2009 congressional hearing on health care reform, “prevention and public health have been the missing pieces in the national conversation about health care reform. It’s time to make them the centerpiece of that conversation. Not an asterisk. Not a footnote. But the centerpiece of health care reform. And we need to guarantee that our most vulnerable high-risk populations have equal access to prevention services and public health [26].” The concepts below are offered as a means for PHRs to play a key role in an evolving health information technology (health IT) system.

A Multi-Phased Research Approach

This research aimed to outline several important ways in which PHRs can assist underserved populations. Also examined were several important obstacles inherent in the adoption of PHR in these communities. Between 2007 and 2008, with support from the Blue Shield Foundation, a series of structured and unstructured expert interviews were conducted. The first phase of interviews (n = 17) consisted of open-ended questions regarding general perceptions of the utility and feasibility of PHRs and included patients, outreach workers, care managers, and medical practitioners who function within the safety net. The second phase of interviews (n = 8) consisted of extensive structured interviews conducted with experienced leaders functioning within systems and policy-related levels [27].

This two-phased approach is consistent with grounded theory methodologies [28,29] and provided the opportunity to explore not only the hard realities of adopting personal health information systems within the safety net environment, but also the opportunity to devise systems that could assist in achieving health care goals. Participants were asked about their general perceptions and recommendations regarding the use of PHRs within the safety net and the inherent barriers and opportunities their use would entail. In addition, field visits were conducted within two underserved settings in California, one rural migrant field-worker environment in Sonoma, California, and one urban underserved setting in Los Angeles. The transcribed text of the interviews was categorically coded and iteratively categorized for thematic analysis by the researchers. The principal thematic outcome of this analysis (described in detail below) was the identification of personal, technical, organizational, and policy related dimensions for consideration when introducing PHRs into underserved settings. Findings and directions were then outlined within each of these dimensions.

As outlined below, key challenges identified through this and related research included user and technically centered challenges in accessing and using technologies, organizational challenges in the adoption and implementation of EMRs and PHRs, and a general lack of governmental policies and associated funding to provide the support for user and organizational adoption. The challenges, issues, and guidelines presented here were discussed and validated in a variety of settings, including PHR conferences and professional meetings [30,31]. Given the current spirit of enacting health care reform, the following elements and framework are presented as considerations for extending personal health management as part of broader health systems and health IT change.

Findings

The findings from this research have been organized into a deployment framework that synthesizes key issues identified across personal, technology, organizational, and policy related dimensions (Table 1). Based on findings from interviews, field visits, and literature review, each of these dimensions is advanced as requiring attention when considering and implementing PHRs in underserved populations. The following sections outline how these dimensions were defined and identified as central aspects for adoption and implementation of PHRs within underserved communities.

Challenges for Users: Usability Concerns

The PHR usability and functionality findings identified in this review suggest that some members of underserved populations are aware of tools such as PHRs, but efforts to encourage adoption often fall short due to the inability to engage patients in direct health management behaviors and enable transparent, patient-driven communications between patients and their care providers [32]. Health information is frequently presented in a manner that requires a higher literacy level than many other forms of information [33]; this presents obstacles for underserved subgroups, particularly ethnic minorities and undocumented workers who often lack sufficient formal education to become successful consumers of health information. Literacy shortfalls impact the ability to understand consent forms, to understand clinical instructions, to follow prescriptions, and to manage appointments [34,35]. In addition, this barrier is compounded when conveyed through an information system that people are not experienced in using.

Conversely, there is a motivation among safety net patients to get some control over their health information. For example, in field visits to community clinics, it was identified that many members of underserved groups go to great lengths to keep track of small but important health information items and feel empowered by information resources such as ID cards issued by health providers because they know that having a document or card will increase their credibility with health care providers in future encounters [31].

In terms of overcoming these challenges, designers need to incorporate insights and findings related to human-computer interaction in underserved settings with best practices in health care to create a system that is secure, consumer-centric, and accessible [36]. While the ability of the underserved to access and use health information technology currently represents a barrier, the ability of these same populations to use a cell phone or an automated teller machine (ATM) is widely accepted, even though these tools are representative of complex information technologies. Accordingly, PHRs can be fashioned in such a way as to create equal access and understanding for all vulnerable populations. Designing systems that meet the needs of the most vulnerable users will ensure a wider adoption of health technology tools by the entire population [37].

In addition, there is value in understanding the communities in which the 66 million underserved Americans live and work. For example, interviewees noted that caretaker roles among migrant workers are often occupied by women, who may serve as health managers for multiple generations in a family group. Some families adapt by having a single member of the family obtain health insurance. This family member in turn serves as a channel of information and may even act as a conduit for services and medications for other members of the family. New PHR solutions should be adapted to work within these cultural practices. Moreover, there is a pressing need to connect personal health solutions with the community to address emerging public health issues. For example, asthma is on the rise in underserved communities, and there are currently inadequate means to engage families and thus facilitate the use of preventive measures [38]. There is a significant opportunity to address the complex epidemiology of health conditions in underserved communities through PHRs that address such specific needs.

Barriers to Access: Getting to the Technology

The value of having a primary medical home (a primary health provider or other resource who retains an individual's health information and serves as a coordinator for services) is now widely accepted [39]. For underserved populations, it is equally, if not more, important that patients have a "virtual medical home" due to the highly fragmented set of services in this population. However, a distinct obstacle that underserved communities will endure in trying to adopt PHRs is the lack of access to a computer either at home or at work and the related technical experience that comes with ownership. The well-documented "digital divide" still separates underserved communities from information technologies by a technology gap that results from low income, little or no education, misunderstanding of the value or purpose of information technologies, as well as many other limiting factors [40-43]. These conditions, coupled with the challenges of usability, literacy [44], and consistent health care, limit the potential adoption and use of PHRs [9,45,46].

It has been argued that technological diffusion will change this circumstance [47]. However, while overall computer ownership and use have increased at all levels of society, the elderly and populations of the lowest income levels still lag behind despite dramatic decreases in the cost of computer technologies [48,49]. Assuming that access to PHRs is not restricted by cost, other barriers must be considered. Compaine [50] suggested that a key factor in determining adoption of a technology is whether the skill level required to use a particular tool crosses a threshold where it is easy to use by the general population. Similarly, Salvador and Sherry [51] recommended creating technologies that include cultural adaptations for specific populations, especially when considering culturally diverse "low-tech" settings, both domestically and internationally.

The interviews and field visits conducted with safety net providers confirmed these findings and revealed several new issues and opportunities. For example, many experts and target community members emphasized that a prerequisite to access and PHR use was the development of trust, both in the privacy and usefulness of the technology, as well as in the health care system itself. While secure methods for accessing our health records is a widespread concern, such an issue is exacerbated for those who are reliant on accessing information from public resources. Others pointed to opportunities for access by designing systems that allowed for simple health information transactions and the ability to review information over more readily adopted mobile devices such as cell phones. This is of great significance for safety net populations, as they are often highly transient and in need of flexible and more secure methods for managing health information.

Encountering the Organization: Fragmented Systems

Attempts to implement PHR solutions for the underserved are challenged by a fragmented health care system in which there is limited communication between hospitals, clinics, practitioners, and community-oriented providers. Fragmentation leads to higher costs from duplicated services, as well as the potential health risk that arises from unnecessary medical procedures. In order for PHR systems to be effective for the underserved populations, broad-based participation and collaboration will be needed from all stakeholder and service provider groups. Consistent with this approach are projects such as the MiVIA program in Northern California, which is a PHR system for migrant farm worker populations that has diligently included consumers, health care leaders, and staff of community-oriented organizations in the development of the application with the aim of increasing communication opportunities across all aspects of the service chain [27].

Another challenge for PHR deployment within all populations, including underserved populations, is the high cost of implementing EMRs used by service providers. PHRs will be most valuable to patients if they are highly integrated with EMR systems, but not all health care providers use EMR systems as of yet, and the adoption of such systems has been slow. Despite the recent national push through the American Reinvestment and Recovery Act (ARRA) of 2009 to integrate EMRs into health service organizations, sufficient funding is often lacking for community health providers. The cost for the rollout of an EMR system per clinician can reach tens of thousands of dollars, an amount that does not include the costs of lost productivity as practitioners and health care personnel learn to operate and assimilate new systems into their practice [52]. Recent research findings by the Agency for Healthcare Research and Quality (AHRQ) support this need for understanding the use and value of a system, suggesting that the most effective PHRs will be integrated throughout a patient's care plan in a manner that informs patients of the health benefits that they will potentially experience through use of the PHR [10]. This, however, cannot happen until the community health providers that support the underserved are able to effectively adopt EMR systems for themselves.

Interviews and site visits to community clinics and safety net providers revealed that there is a reluctance to step forward in providing PHRs for their clientele. The principal reason is financial—these organizations are very hard-pressed for basic EMR resources. There is also reluctance given the diverse population that frequents the clinics. However, active involvement with health care is of great importance for safety net populations and suggests a pressing need to find innovative means for electronically delivering this information in ways that recognize the organizational limitations of the safety net setting. For example, as an outcome of this research, the researchers are actively field testing a PHR designed along the lines of an ATM [53]. The advantage of ATMs is that they are broadly accepted and widely used models of public information systems. There are undoubtedly countless other approaches that could be considered.

A Way Forward: Policies for Empowering Vulnerable Patients

Given the historic health reform changes presently underway in the US, the time is ripe to advance policies that assist in the implementation of a PHR model for underserved communities. The recently passed health reform legislation has placed near-universal coverage high on the policy agenda and, before that, the passage of ARRA unleashed a wave of national efforts to encourage the broad exchange of health information across local, regional and national healthcare entities. Efforts to increase health information sharing included opportunities for EMR adoption reimbursement, support for Regional (and Local) Extension Centers designed to aid providers in adoption and use of health IT and a host of Beacon Communities to be featured around the country that are composed of providers and their patients who can be models of effective use of health IT [54]. Bolstered by this wave, national and state-level entities, in collaboration with community-based providers, can take active steps to insure that provision of health IT is equally extended to those that serve and are a part of the health safety net.

A cornerstone for these activities is the concept of “meaningful use,” which provides an operational definition for the range of functionalities EMR systems must demonstrate in order to receive federal reimbursement from ARRA [54]. On July 13, 2010, the Centers for Medicaid and Medicare Services released its requirements for such meaningful use by 2011, with some attention to the role of PHRs (mainly as a conduit for providing patient office visit summaries) [55]. Looking past 2011, the Health and Human Services’ Federal Advisory Committee has made recommendations for enhanced patient engagement through meaningful use of PHRs [55]. While the thrust of the requirements and recommendations are incremental, the general direction is to encourage providers to increasingly engage patients through such means. Less clear is how such recommendations will play out within the underserved arena.

The point that is being advanced here is that there is both a clinical and societal rationale for ensuring that underserved populations have ready access to PHRs. From the clinical perspective, PHRs can lead to active engagement in health affairs for a segment of the population that has high rates of chronic disease. From a societal perspective, PHRs may aid in the public health goal of ensuring improved health and health conditions throughout the country. Indeed, the emerging domain of public health informatics has outlined several of the gains that can be made in terms of immunization registries, bio surveillance, and related public health monitoring [56]. These tools will be made that much more valuable by ensuring that the underserved are active participants in these new personal health technologies. That is, the widespread adoption of PHRs could provide an important and missing link toward connecting a population-level focus of public health to the individual circumstance of persons who could benefit from user-focused systems that help manage and potentially prevent chronic conditions. The current push for this in the United States, related to the ARRA of 2009, is in the right direction, but facilitating policy action needs to occur at the local level to weave together integrated service delivery systems and tools.

Interviews and field visits confirmed that the issue of privacy (and trust) is crucial to PHR utilization and is an issue that deserves much attention due to a potential lack of understanding within this population. In particular, there is limited understanding within underserved groups of the degree to which health information can be data mined and the consequences it entails. For example, individuals concerned about issues of residency status or family contact information may be particularly sensitive to information privacy and security due to fears (whether valid or not) of persecution or deportation. While interviewees from these populations had underlying concerns related to their status as noncitizens, the majority of them expressed minimal concerns about providing health information online. (It is perhaps debatable as to whether they truly had minimal concerns or if they did not fully understand the implications of entering health information online). In any case, as new provisions are enacted it will be important to analyze the specific implications for the underserved and how to best ensure that their rights are communicated and upheld. For example, ARRA of 2009 contains provisions that extend and strengthen the Health Insurance Portability and Accountability Act (HIPAA), including implications for PHR vendors [54]. Finding and ensuring that PHR resources targeting the underserved contain both privacy safeguards and affordable means of deployment that enhance trust and privacy will require significant consideration on the part of the community health organizations who seek to adopt these systems.

Directions

Framework for Action: PHRs in Underserved Communities

As outlined in the findings above, this research identified four critical layers to consider when devising PHRs for use in underserved populations: personal, technical, organizational, and policy-related dimensions [31]. Within this framework (Table 1) are examples of tangible health IT issues and requirements documented through recent research findings. The framework’s focus on underserved communities distinguishes it from broader, general agendas for electronic health records that have been previously proposed [57]. These findings should guide policy aimed at improving electronic access to personal health information by underserved communities and help to develop appropriate health IT standards and regulations.

Table 1. Framework for PHR systems in underserved populations

Conceptual Level	Constructs	Guidelines Relating to the Underserved
Personal	Health management	• PHR systems in underserved communities need to address integrated care challenges and bolster continuity of care with proper assessment and maintenance of health outcomes. • PHR systems in underserved communities need to include patient education and encouragement toward services needed to engender preventive health maintenance behaviors.
	Language and literacy	• PHR systems in underserved communities need to feature multi-lingual capabilities. • PHR systems in underserved communities need to be explicitly attuned to limited levels of literacy, computer skills, and health information knowledge.
	Privacy	• Privacy and security features need to not only address HIPAA requirements, but also allay concerns unique to underserved populations and provide education on its importance.
Technical	Infrastructure	• Low-cost standardized means for effectively importing and exporting patient data across community clinic environments are needed to allow for low-cost architectural approaches. • Underlying the adoption of software systems, there is a need for basic technological infrastructure improvements in community provider settings.
	User network	• Computer experience and access is limited for the underserved, and, therefore, very user-friendly and publicly accessible interfaces need to be provided. • User access requires a range of modalities depending on the type of fixed and mobile access needs and requirements that occur at both the provider and user level. • Critical user locations such as emergency rooms require appropriately adapted and efficient interfaces.
Organizational	Administration	• As a majority of community health patient data is still paper-based, providers will need incentives to adopt new technologies. • Community health organizations need to introduce new workflow and patient communication practices to facilitate PHR use as a health self-management tool.
	Adoption and integration	• Community health organizations need increased financial support in order to boost adoption of PHRs and their role in integrated service delivery. • Hastening of easy-to-adopt PHR-related standards and applications is needed to reduce administrative overhead and hesitance toward adoption for patient activation.
	Outreach	• Increased efforts are needed to provide outreach and education that address the unique personal health management and communication needs of the underserved. • Caregivers need to be equally educated so that they can become true ambassadors of health information technologies and their importance.
Policy	Funding and regulations	• Health care reform of 2010 provides a major opportunity to extend PHR systems to underserved communities. • Federal ARRA of 2009 and related policies need to advance significant PHR requirements and incentives that are inclusive of underserved populations. • Federal ARRA of 2009 and related policies need to ensure that the privacy and confidentiality concerns of underserved communities are addressed.

Beginning with the personal domain noted in Table 1, it is identified that users will require that PHRs be multi-lingual (according to primary populations serviced), easy to navigate and use, and inherently respectful of privacy and security issues that might otherwise deter this population. To date, a Spanish speaking person would have a difficult time finding a PHR with Spanish translations that is supported in the US health care system even though the Spanish language is the second most common language in the United States.

Moving to the technical domain of the framework, there are also pervasive technical issues that underscore these personal constraints. Largest among these is a lack of widely adopted standards for the exchange of health data. Finding flexible, light-weight PHR systems that can be worked into a provider's existing EMR system would be of invaluable assistance to having health information at the ready. Issues include provision of systems that can be effectively and inexpensively integrated with existing EMR systems while at the same time providing an interface that can clearly communicate health information to users. Furthermore, to reemphasize the aforementioned personal constraints, while a PHR technically provides the opportunity for extensive outreach abilities to patients, its effectiveness can be heavily undermined by not supporting the personal requirements (privacy, language, literacy, and access).

At the organizational domain level, the framework highlights how adoption of PHRs within public and private agencies, including community health organizations, may provide long-term financial benefits, but that in the short term it will necessitate extensive outreach and education efforts in order to influence not only the patients of these organizations, but their workers as well. It is possible that community health providers will have no choice but to adopt IT systems that can increase communications with their patients. A recent report by the California HealthCare Foundation noted that Medicare alone spends over US $12 billion per year for potentially preventable readmissions due to the inability to provide effective discharge and health education services [58]. Providers might be persuaded to adopt health information systems to help offset these enormous costs.

Finally, health care providers will only be able to adopt PHR systems if supported by policies that understand the unique issues encountered by community clinics and provide the funding needed to acquire the proper resources. This includes an understanding of how PHRs could be used to address public health issues and support inequities of Medicaid and Medicare systems. States are experiencing a continuing shortage of nurses for general care, decreases in the amount of doctors considering work in adult medicine and family practice, and declining provider participation in federal fee-for-service programs [59].

Exacerbating these issues are policies that have increased the number of restrictions on Medicaid reimbursement through federal laws and regulations. In relation to the PHR, if providers are unable to identify ways in which reimbursements can be obtained through PHR communications with patients, it is unlikely that their adoption will be seen as a feasible investment. Although there has been a national push toward adoption and integration of EMR systems as a whole, it is argued that the funding needed to allow community health organizations to do so in a manner that includes PHR capacity is yet to be adequate.

To sum up, this framework is meant to highlight considerations at the personal, technological, organizational, and policy levels that, if addressed, would facilitate the utilization of PHRs within underserved settings. While not a “recipe” for adoption, this framework does lay out general design guidelines for both technical design and broader organizational and policy design. Of course, achieving such adoption does not in and of itself translate into positive health outcomes. However, the emerging literature on PHRs does suggest that adoption has promise for health activation, communication, and improved health management [3,13,31,32]. For example, PHR pilot projects by organizations such as the Centers for Medicare and Medicaid Services [60] allow beneficiaries to choose from various PHRs (eg, Google Health, HealthTrio, NoMoreClipboard.com, and PassportMD) to assist in managing their care. The next wave of research would be to obtain a detailed understanding of the myriad health activity and health outcomes affected (or not) by active PHR use in underserved populations.

Limitations

A limitation that should be noted is that although the patients and experts interviewed for this study provided a varied and broadly representative sample of the available expertise on the topic of underserved groups, this research did not presume to fully represent all of the possible subcategories of underserved communities that can be defined by language, culture, age, disability status, economic status, and other factors. It is clear that additional research is required to refine our understanding of how PHRs can address specific subgroups within these populations. The premise of the research also represented the most significant challenge, namely, that there has not been systematic adoption of PHRs in safety net settings. This meant that there was not significant existing literature or diverse implementations to draw upon. Moreover, many community clinics are currently struggling with basic health IT systems and the notion of a PHR can seem as an “out year” consideration. This context represented both a challenge and an opportunity for the research.

Conclusion: Toward Positive Health Outcomes for All

ARRA of 2009 contained a major push for health IT, and this has been followed up by broader and historic health care reform. While this legislation has provided an unprecedented level of support for health IT, the act does not specifically target solutions for underserved populations. Yet, as discussed throughout this paper, there is a promising business, policy, and social case for using electronic services to enhance patient self-management among underserved populations. There are significant resources within ARRA of 2009 that can provide an important opportunity to extend electronic personal health records and services to underserved communities, such as through community health centers.

While the resources within ARRA of 2009 provide a general context for change, in and of themselves they are not sufficient to achieve the utilization that is warranted in underserved communities. As suggested by the framework, there are top-down, bottom-up, and midlevel needs that should be attended to in order to facilitate utilization. Self-empowerment through personal health technologies provides the opportunity to improve not only the health and welfare of the patient but also the fiscal and social health of society. Underserved groups are subject to what has been described as an “inverse information law” that limits access to information for those who need it most [61]. The multi-leveled set of actions outlined provides a means to create a level playing field for patient self-management through PHRs. The current wave of health IT support provides an important opportunity for leadership in designing and implementing PHR systems that can attend to the needs of all citizens in the United States and, in so doing, may offer insights for international efforts as well.

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Conflicts of Interest

The authors note current research and testing of an ATM-like PHR system in underserved communities; this application (HealthATM) may have commercial potential

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Abbreviations

AHRQ: Agency for Health care Research and Quality
AARA: American Reinvestment and Recovery Act
ATM: automated teller machine
EMR: electronic medical record
HIPAA: Health Insurance Portability and Accountability Act
health IT: health information technology
MUA: medically underserved area
PHR: personal health record

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Viewpoint

Public Health in an Era of Personal Health Records: Opportunities for Innovation and New Partnerships

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Abstract

In the near future, citizens will be able to control and manage their own health information through electronic personal health record systems and tools. The clinical benefits of this innovation, such as cost savings, error reduction, and improved communication, have been discussed in the literature and public forums, as have issues related to privacy and confidentiality. Receiving little attention are the benefits these will have for public health. The benefits and potential for innovation are broad and speak directly to core public health functions such as health monitoring, outbreak management, empowerment, linking to services, and research. Coupled with this is a new relationship with citizens as key partners in protecting and promoting the public's health.

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KEYWORDS

Personal health records; public health practice; informatics

Introduction

Personal health records (PHRs) have been a part of clinical care for decades. The most recognizable is a simple paper card that lists an individual's immunization history. During the last 10 to 15 years, with the increasing use of technologies in clinical care and growth in electronic medical records (EMR), the PHR too has gone electronic. More recently, the electronic PHR has garnered increasing attention as a potential agent for citizen-centric health systems transformation [1,2], as a new personal tool for promoting health and health engagement [3-5], as a means for increasing efficiencies in appointment scheduling and medication refills, and as a means of improving the doctor-patient relationship [6,7]. At the time of this writing, a PHR can take multiple forms, ranging from stand-alone software for one's computer to secure websites tethered to a specific practice or organization to general secure websites as platforms to integrate various kinds of health information. Each of these approaches supports different health needs such as tracking visits and costs, enabling secure email with physicians, scheduling appointments, refilling medications, and/or integrating clinical care. A subtle yet important difference in PHR offerings is the degree to which individuals have direct control over the data in their PHRs. Some PHRs offer "read only" access to one's medical record, while others allow individuals to control who gets to view what within their record. There is considerable debate regarding the degree to which individuals should be able to control access to their health information and the forms that control may take [8,9].

Like EMRs, PHRs may also enhance the quality of care, improve doctor-patient communications, reduce the risk of medical errors, prevent unnecessary repetition of medical tests and procedures, and improve quality of life and health outcomes [2]. In addition, PHRs are beginning to allow individuals to add information such as weight or glucose readings, care plans, and customized applications with data accessible by mobile devices. Soon PHRs and personal health platforms will be able to seamlessly integrate with more robust mobile health devices, services, applications, and Web-based social networks. These capabilities can help individuals understand the information contained in their health records and relate it to daily activities and their environment, which could allow health and healthy living to become more integrated into daily living [5,10-11].

From the above description of PHR capabilities, both current and future, the public health opportunities with PHR systems start to gain clarity. However, public health has yet to significantly engage with the growing momentum despite significant opportunities. Potential benefits of PHRs to public health include providing information and resources, promoting healthier living, strengthening the continuum of care, and being a source of health monitoring data to supplement traditional public health activities such as surveillance and surveys. Research has shown that 75% of the US population would share personal health information with public officials to speed outbreak investigations and other public health activities given proper security and confidentiality measures [12]. Now is the time to think critically about public health's role in the growing PHR movement: What potential do PHRs have in serving core public health functions?

Public Health and Personal Health Records

A useful frame for public health activities is the set of ten essential public health services [13], which are:

- Monitoring health status to identify community health problems
- Diagnosing and investigating health problems and hazards in the community
- Informing, educating, and empowering people about health issues
- Mobilizing community partnerships to identify and solve health problems
- Developing policies that support individual and community health efforts
- Enforcing laws and regulations that protect health and ensure safety
- Linking people to needed personal health services
- Assuring a competent public health and personal health care workforce
- Evaluating effectiveness, accessibility, and quality of personal and population-based health services
- Conducting research to develop new insights and innovative solutions to health problems

The range of services performed by a given public health organization will depend upon whether it operates at the local, state, or federal level. Through these services, public health agencies seek to protect health, prevent disease and injury, promote healthy lifestyles and behaviors, respond to disasters, and assure accessible, high-quality health services. The innovation potential of PHRs will allow public health organizations to enhance each essential service, thereby building a much stronger and more effective public health system. Here, we discuss PHRs in the context of five of the essential services in the hopes of adding clarity to the issues and energy to the dialogue. This discussion also seeks to provide pointers to how we think some of these envisioned functions could become reality.

Monitor Health

Monitoring population health status is a central public health activity. A variety of survey systems, such as the Center for Disease Control and Prevention's National Health and Nutrition Examination Survey (NHANES) and National Health Interview Survey (NHIS), as well as state and national reporting systems, such as the Behavioral Risk Factor Surveillance System (BRFSS), Pregnancy Risk Assessment Monitoring System (PRAMS), and the National Electronic Disease Surveillance System (NEDSS), provide public health with the ability to assess health trends, identify and respond to emerging threats (eg, salmonella and E. coli) and guide development of interventions and policies that address serious health conditions (eg, obesity, smoking, and tuberculosis). These tools and reporting systems have been in operation for many years and remain essential to assessing health status, measuring disparities, and protecting the public's health. However, PHRs hold the potential to improve health monitoring and may even foster entirely new approaches to this essential service. For example, through PHRs, individuals could easily, cheaply, and en masse share their health data anonymously with public health agencies, in essence creating "sentinel citizen" networks. Such networks could be both passive, where population data is anonymously analyzed in order to assess the prevalence of health issues, and active, where citizens elect to share targeted health information of interest to public health agencies. These approaches could enhance information gathering and reduce the resources necessary to support current health monitoring systems and further engage individuals as sentinels in protecting their own health and the health of their family, their community, and ultimately, the nation.

In a context where the public is actively and passively sharing health information with public health, this sharing also opens the door to a new kind of bidirectional relationship between individuals and public health, one not part of traditional public health monitoring activities. Currently, one of the few public health survey programs that has a bidirectional relationship with participants is NHANES. A routine part of the NHANES survey process is to synthesize survey findings and package them with a participant's own health information as a "report of findings," which is then sent through the mail to the NHANES participant. PHRs have the potential to streamline this process by offering to provide a participant's health information in electronic form for integration with their other personal health data. By digitizing this process, the potential is created to establish a bidirectional communication channel for information sharing, future opt-in survey involvement, and so forth. While this may not be applicable to most of public health's traditional survey activities, it does open a novel window on new ways to address public health's mission.

Finally, a central issue with all health-monitoring activities is data quality. Even with current health monitoring activities, considerable time is spent managing data (ie, cleaning, integrating, and linking) to ensure it is of the highest quality.

High quality data is the bedrock of evidence-based public health. PHRs have the ability to put some of these data management processes into the hands of individuals, allowing them to play a key role in maintaining the accuracy of their own personal health information. For example, individuals may identify and alert providers to gaps or inaccuracies in their personal health data ranging from personal characteristics, such as age, to past health events and current medications. Currently, health providers and administrators use such data primarily for administrative and reporting functions such as bill processing, service reimbursement, accreditation, and health monitoring. However, PHRs will allow individuals to monitor the quality of their health data/information and address data inaccuracies with their health providers, resulting in higher quality aggregated population health data reported at the local, state, and national levels. This example is not meant to address the validity or reliability of EMR or PHR data (an area in need of further research). Rather, we wish to highlight the effects that managing the quality of and controlling one's personal health information could have on the quality of reported data (eg, vital statistics registries and immunization registries). Because clinical data are essential to understanding and addressing population health issues, improving the quality of these data could likely lead to development of more effective public health policies and interventions. A case in point would be birth registries and health information collected on the mother and baby around the birth event. The type and quality of data captured by current registries vary by state. What if a PHR could be created for an infant at birth by the mother through the birth registration process? What if a mother's PHR could help provide information about her care and other data required at the birth registration (and if the mother did not have a PHR, offer her one through the auspices of the state health department)? These actions would not only strengthen birth registration content and information contained within PHRs, it would also impact the adoption of PHRs by tying them to birth registries. Further, mothers could provide data corrections back to the hospitals thereby compelling them to become more vigilant with regard to accuracy and the quality of health data in general as well as those data that are reported to public health.

Investigate Health Issues

A key public health objective is to shorten the time it takes to identify and control potential health threats, and PHRs hold the potential to increase the speed and improve the efficiency and effectiveness of outbreak investigations. Combining PHRs with current and anticipated tools (eg, location-tagged mobile phone pictures linked to personal health information) could make it much easier for individuals to assist public health with real-time reporting during and after outbreaks and disasters. Individuals could voluntarily share personally identifiable or anonymous health data and information for a time-delimited period to rapidly aid public health officials in identifying and controlling an event. This would provide a convenient and critical feedback loop where individuals could get back information of value in return for sharing their information with public health and contributing to improved population health. Another expanded option would allow individuals to proactively combine their PHR data with regularly available health surveillance data in exchange for receiving timely, personalized, and localized public health alerts and notifications.

Inform, Educate, and Empower

Driven by research and the changing incidence of health conditions, promotion of healthier behaviors is another of public health's core functions. PHRs offer the potential for deeply tailored health promotion opportunities that could go far beyond current strategies to improve health behaviors. Strategies include, for example, Web-based programs to improve self-management of diabetes or support tobacco use cessation. While such strategies are still relevant, new tools could be designed to use existing PHR data to allow individuals to monitor their data and benchmark their health against those in their zip code, county, state, and nation. Putting nationally representative health data to work in this context could provide the impetus to create healthier communities and homes. Consider the potential of using PHRs to provide individuals with profiles of their neighborhood (eg, parks, bike trails, sidewalks, air quality, and grocery and retail stores within walking distance), along with recommendations tailored to an individual's health characteristics. For example, could restaurant recommendations be made based on an individual's BMI, weight maintenance goals, current dietary needs, the day's level of physical activity, and geographical location?The potential benefits of converging personal health data with other information becomes a powerful tool for helping individuals incorporate healthy behavior into daily living.

Link People to Services

Through PHRs, the process of connecting citizens with needed health services and resources could become more streamlined and tailored to local circumstances [14]. Using influenza vaccination as an example, the Advisory Committee on Immunization Practices (ACIP) has recommended that individuals at high risk for serious complications receive an annual vaccination (eg, children 6 months to age 19, individuals over 50, those with chronic conditions, and those caring for individuals at high risk for complications) [15]. With PHRs, alerts could be sent directly to individuals who should receive a vaccination, along with a localized map of nearby clinics offering this service with information on hours, languages spoken, and costs. By sending this information via a mobile device, public health could harness the power of immediacy. In this way, individuals could be reached not just where they live or work, but where they happen to be at any given time during the day. Taking this a step further, PHRs could enable individuals to immediately report receipt of a vaccination (with date, time, and geographic location) to public health monitoring systems, allowing for a more nuanced picture of vaccination behavior trends. Flu vaccination represents only an example of the multitude of service connections enabled by PHRs; other examples include cancer screening, other immunizations, mental health counseling, well-baby services, support groups, and so forth.

Perform Research

Public health's research agenda addresses key areas of disease and injury burden. Currently this research is carried through extramural partnerships with educational institutions, research institutes, and intramural projects. The emergence of PHRs creates new research opportunities and new ways to partner with the public in the research enterprise. For example, PHRs could support the ability to build longitudinal research panels that could support public health research on the myriad connections between population health and health care (eg, clinical preventive service use) and greater insight into disease prevention and control efforts and outcomes. Additionally, individual self-report data and information could be of great value in refining public health research. For example, research has already suggested that under the right circumstances, blood pressure monitoring could be more accurate when taken at home by educated patients using an approved calibrated device and sent in to the physician's office as opposed to measurements taken in a clinical setting [16,17]. This example suggests an untapped continuum of qualitative to quantitative self-reported health information, which could be used to identify subtle aspects of contextual health behavior and develop more nuanced public health interventions, recommendations, and policies. Such innovation could result in a strengthened relationship with citizens as partners in the public health research process.

More on Data Quality

There are important questions as to the quality and reliability of the data shared from PHRs. For example, how reliable is data that is entered by an individual into their PHR? How useful is this data for clinical or public health purposes? Might there be a continuum of data reliability and usefulness? For public health, this is not a trivial issue. Data validity and reliability are the bedrock of public health's ability to create and recommend effective population-based policies and health interventions. As PHRs and other new health data sources become available, research will be needed to assess data quality, reliability, accuracy, and representativeness of each resource as it applies to the needs of public health [18].

Public Health's Role

There have been many cogent articulations and discussions of the significant challenges facing PHR adoption and use as well as policy levers to incent both individuals and organizations [2,19-23]. The challenges are not insignificant and at a minimum include being able to articulate the value of PHRs for individuals along the full wellness/sickness spectrum. The value and/or utility of PHRs outside of transaction-based functions (eg, appointment scheduling and medication refills), such as the potential benefits of PHRs for those managing chronic conditions [24], have not been sufficiently researched. However, as we work to increase our understanding of the uses and utility of PHRs, it would also serve the interests of public health to focus on issues related to data liquidity [25], personal health tools and platforms [5], general health literacy and education [26], and the ways in which these approaches and systems work to improve health outcomes and the quality of care as well as influence and streamline public health practice. Focusing energies and efforts in these areas should help prepare public health for what PHRs can become.

With these focal areas in mind, public health's role vis-à-vis influencing policy gains some clarity. Data liquidity and secondary use of electronic health information are of great importance to public health. Supporting these interests, public health has been involved in the standards-setting processes for health information exchange, data standards that support enhanced health monitoring and electronic laboratory reporting. While indirect, these activities move the dial on getting electronic health information into the hands of health professionals, individuals, and families, enabling all aspects of health care systems to work smarter to protect health. Regarding personal health tools and health literacy, Healthy People has been an important national framework supporting these activities [27]. Born of the 1979 Surgeon General's report, Healthy People [28] is now in its third decade of setting national health objectives that individuals, communities, organizations, and so on can use to develop programs to improve health. Components of *Healthy People 2010* included emphases on health literacy, health information quality, and improved general access to the Internet and Internet resources for all Americans. For *Healthy People 2020*, additional objectives have been proposed in the area of personalized health. Though still under development at the time of this writing, these include objectives such as increasing patient/provider interaction, increasing access to and use of personal health management tools, and increasing provider use of health information technology to improve population health. Each of these components plays a supporting role in the broader discussion of PHRs to build the systems and environmental variables tacked to improving personal health.

Lastly, there is significant room for public health's contribution in the area of how PHRs work to improve health outcomes, improve the quality of care, and support public health practice. The majority of this paper has focused on how PHRs and related tools can be understood to fit within the context of public health services. However, as has been noted recently [29], though personal health tools appear to have some promise to improve health outcomes and the quality of care, the state of the research in this field is sorely wanting. Public health agencies could be contributing more to research at this intersection specifically focusing on how these tools improve care for at risk populations. In addition to research, there are questions of workforce readiness and capacity to take advantage of such tools. In order for the public health workforce to take advantage of PHRs and related tools, a number of issues need to be further explored and addressed. Both the Institutes of Medicine [30] and the Associated Schools of Public Health have been calling attention to a significant US public health workforce shortage by 2020. With an increasing prevalence of chronic conditions in the population, PHRs and personal health tools could be framed as an additional burden to an already burdened system or understood as an opportunity to streamline and/or change public health practices. Innovation is sometimes born of stressed systems. Irrespective of how these capabilities are understood, there is an underlying need for a larger public health workforce and one that is attuned to possibilities and capabilities of PHRs and personal health tools.

Conclusion

We are witnessing the emergence and evolution of a health information economy the likes of which we have not seen before. Health information is increasingly updated and shared electronically, on a minute-by-minute basis. Investments made in the adoption of electronic medical records, most significantly supported through the American Recovery and Reinvestment Act, and increasing capabilities to securely exchange health information will only increase the speed at which this occurs. These trends and investments pave the way for new and innovative approaches and models for public health to extend its capabilities and achieve its mission. One of these will likely be PHRs. Here, we have highlighted the potential benefits of PHRs in terms of five essential public health services. Through PHRs and other sociotechnical innovations, public health has the opportunity to reimagine and reconsider the boundaries of traditional activities, such as health monitoring and threat investigations, and reconsider its traditional partnerships with individuals as public health information providers. PHRs also have the potential to provide tools to further strengthen other public health activities, such as educating and empowering people and linking them to needed health services. This is a fast-moving area, and policy considerations are currently being deliberated by national working groups such as the National Committee on Vital and Health Statistics [31]; data standards and models are being debated and proposed within national standards development organizations such as the Health Information Technology Standards Panel [32] and Health Level Seven; and applications are being rapidly developed to test these new waters—there are easily hundreds of health applications for the iPhone. For populations of particular concern for public health, PHR pilots are currently being conducted by the Centers for Medicare and Medicaid Services [33]. Data from these pilots will shed light on how these systems support the health needs of vulnerable and at risk populations. Further, with the potential increase in EMR adoption as stimulated through the American Recovery and Reinvestment Act of 2009, standardized health data will become readily available to populate PHRs [34]. There is much at stake in all of these activities and public health must have a direct and influential place at the table to ensure that these innovations will support core public health functions and benefit the protection and promotion of the population's health.

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Conflicts of Interest

None declared

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Abbreviations

BRFSS: Behavioral Risk Factor Surveillance System
EMR: electronic medical records
NEDSS: National Electronic Disease Surveillance System
NHANES: National Health and Nutrition Examination Survey
NHIS: National Health Interview Survey
PHR: personal health record
PRAMS: Pregnancy Risk Assessment Monitoring System

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Original Paper

Associations of Internet Website Use With Weight Change in a Long-term Weight Loss Maintenance Program

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Abstract

Background: The Weight Loss Maintenance Trial (WLM) compared two long-term weight-maintenance interventions, a personal contact arm and an Internet arm, with a no-treatment control after an initial six-month Phase I weight loss program. The Internet arm focused on use of an interactive website for support of long-term weight maintenance. There is limited information about patterns of website use and specific components of an interactive website that might help promote maintenance of weight loss.

Objective: This paper presents a secondary analysis of the subset of participants in the Internet arm and focuses on website use patterns and features associated with long-term weight maintenance.

Methods: Adults at risk for cardiovascular disease (CVD) who lost at least 4 kilograms in an initial 20-week group-based, behavioral weight-loss program were trained to use an interactive website for weight loss maintenance. Of the 348 participants, 37% were male and 38% were African American. Mean weight loss was 8.6 kilograms. Participants were encouraged to log in at least weekly and enter a current weight for the 30-month study period. The website contained features that encouraged setting short-term goals, creating action plans, and reinforcing self-management habits. The website also included motivational modules, daily tips, and tailored messages. Based on log-in and weight-entry frequency, we divided participants into three website use categories: consistent, some, and minimal.

Results: Participants in the consistent user group (n = 212) were more likely to be older ($P = .002$), other than African American ($P = .02$), and more educated ($P = .01$). While there was no significant difference between website use categories in the amount of Phase I change in body weight ($P = .45$) or income ($P = .78$), minimal website users (n = 75) were significantly more likely to have attended fewer Phase I sessions ($P = .001$) and had a higher initial body mass index (BMI) ($P < .001$). After adjusting for baseline characteristics including initial BMI, variables most associated with less weight regain included: number of log-ins ($P = .001$), minutes on the website ($P < .001$), number of weight entries ($P = .002$), number of exercise entries ($P < .001$), and sessions with additional use of website features after weight entry ($P = .002$).

Conclusion: Participants defined as consistent website users of an interactive behavioral website designed to promote maintenance of weight loss were more successful at maintaining long-term weight loss.

Trial Registration: NCT00054925; http://clinicaltrials.gov/ct2/show/NCT00054925 (Archived by WebCite at http://www.webcitation.org/5rC7523ue)

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KEYWORDS

Weight maintenance; Internet; intervention; weight loss; behavioral strategies

Introduction

Obesity is a significant public health problem [1]. Behavioral interventions are standard treatment for encouraging healthy weight loss [2]. Unfortunately, behavioral interventions are intensive, and access and adherence to them typically limited. A majority of American adults (74%) have used the Internet [3]. Among adults aged 50 to 64, 44% reported using the Internet as a source of fitness and exercise information, while 31% reported looking online for information about weight control [4]. These numbers and other recent studies suggest that the Internet could be a vehicle for delivering behavioral weight-loss treatments [5-7].

Despite a proliferation of Internet weight-loss programs, detailed information is lacking about which Web components are necessary to promote adherence and long-term success. Limited information has suggested that log-in frequency and use of interactive features are related to weight loss [8,9]. Hurling et al [10] compared the effect of a highly interactive website encouraging physical activity with one that was less interactive; participants using the more interactive website were more likely to continue logging in and logged in more frequently over the study period. However, associations between various website features and outcomes were not evaluated. We and other researchers have postulated that increasing frequency of website utilization and duration of website use are likely to improve weight loss and maintenance. Therefore, the development of attractive and engaging Internet-based weight-control programs should be a priority. However, to maximize effectiveness and minimize cost it is important to assess which components, if any, of a website encourage long-term engagement and best assist with weight-loss maintenance.

The Weight Loss Maintenance Trial (WLM) [11], one of the longest running and largest weight-maintenance trials to date, was designed to test the efficacy of different long-term intervention strategies for helping participants maintain weight loss. One of the treatment conditions, the Internet arm, involved an interactive website that encouraged self-management skills for weight maintenance that were established during an initial six months of face-to-face weekly group meetings. The Internet intervention enrolled 348 participants and presented a unique opportunity to evaluate the specific elements of website utilization, both patterns and features, in an intervention designed to maintain weight loss. Therefore, the aims of this investigation were to (1) describe participant website-use patterns and (2) evaluate which Web features were associated with weight-loss maintenance.

Methods

Sponsored by the National Heart, Lung, and Blood Institute (NHLBI), WLM was a 30-month, 4-center, randomized clinical trial testing the long-term efficacy of different strategies for maintaining weight loss. The study was approved by the institutional review board at each participating site and by an NHLBI-appointed protocol-review committee. All participants provided written informed consent.

In Phase I of the study, all participants enrolled in a six-month initial weight-loss program focusing on reducing caloric intake and increasing moderate-intensity physical activity [12]. Since weight loss of 4 kilograms (kg) is considered clinically significant for maintaining a health benefit [13,14], in Phase II, participants who lost 4 kg or more were randomly assigned to one of three maintenance conditions: a no-treatment self-directed control, a personal contact maintenance program involving monthly interaction with a health counselor, or an Internet maintenance program. The mean weight change (regain) at 30 months for each of the three conditions was 5.5 kg in the self-directed control group, 5.2 kg in the Internet maintenance program, and 4.0 kg in the personal contact maintenance program. The WLM study design and final results are published elsewhere [11,15]. This paper focuses on those randomized into the Internet condition (N = 348). The Internet arm involved use of an interactive website designed to facilitate and encourage behavioral skills initiated during Phase I and to aid in long-term weight-loss maintenance. The weight data used for final outcome analysis was collected in person at clinic visits for all three maintenance conditions. The final data-collection window began at 28 months. The study ended for an individual once his or her final weight had been collected. Therefore, to be consistent when comparing use of website features, this analysis compares website data for each Internet participant's first 28 months of use.

Participant Selection

Each participating institution recruited adults with a body mass index (BMI = weight in kg divided by height in m^2) of 25 or greater through 45 who were taking medication for either hypertension or hyperlipidemia. To be eligible, volunteers were required to demonstrate Internet and email access by responding to an email and logging on to a screening website.

The Internet Intervention

Participants randomized to the Internet group used an interactive website to self-monitor weight and enter information about diet, physical activity, and other weight-loss activities (eg, setting goals, making action plans, and getting support). The website provided unlimited access for 30 months to important behavioral intervention elements including a bulletin board, record-keeping tools, goal-setting modules, diet and exercise information, and tailored feedback. A description of the website design and implementation process has been published [16] as has the cost of developing the website [17]. The website was designed to support weight-loss maintenance using 5 key behavioral strategies: (1) reinforcing existing behavioral self-management, (2) encouraging new self-management skills, (3) improving self-efficacy, (4) encouraging long-term use of the website through providing innovative content, and (5) promoting social support.

Just after randomization, participants in the Internet group were oriented to the website at a one-time individual meeting with a weight-loss counselor. At the 45- to 60-minute orientation, participants set up a user account and established personal goals and plans for maintaining weight loss. They were instructed to log on to the website on their own within two days of the orientation and at least weekly for the duration of the 30-month study. At the orientation visit, the counselors encouraged participants to continue using specific lifestyle modifications similar to those used in Phase I of the study, including limiting calories, engaging in regular moderate-intensity exercise (goal of 225 minutes per week), and keeping food records. These targets were reiterated throughout the website.

The website contained multiple interactive pathways intended to support participants' weight-management efforts, similar to in person group meetings. For example, just as participants might weigh in at the beginning of an in person group session, upon log-in, participants were immediately directed to the weight-entry screen. Participants could also check in by providing weekly progress updates (eg, enter weight, food records, and exercise minutes and select a date to return to the website). They could also revise goals, view their weight graph, and see a summary of progress compared with goals. Additional website features included a bulletin board for group interaction and discussion; a motivation center that provided tailored responses based on participants' answers to inquiries about progress; an information center that contained reliable resources related to diet and physical activity; and a homepage "hub" that displayed participant profiles, a weekly interactive poll, and tailored checklists with suggested website activities.

We hypothesized that using the website consistently to track weight was an important component of successful weight-loss maintenance. To encourage this self-monitoring tool, the website was programmed to require entry of weight at least weekly. The website calculated the number of days since the participant's last weight entry at each log-in; if more than seven days had elapsed since a weight entry, all areas of the website were disabled for that participant until a weight was entered. Once a weight was entered, links to the other features of the website were enabled. A series of automated email prompts and reminders encouraged regular log-ins. Participants who missed a weekly log-in date were sent an automated email reminder that was repeated after another week of no contact. After two weeks of no contact, participants received two weekly, automated telephone calls. If this did not result in a log-in, study staff contacted participants by telephone to encourage returning to the website; no behavioral weight-loss counseling was provided over the phone.

Website-use Categories

For this analysis, we categorized participants into three groups based on number of log-ins and number of weight entries. While participants were asked to visit the website weekly, our operational definition of "consistent use" was logging in and having at least one weight entry every month for 26 of the 28 study months. We defined "some use" as logging in and having at least one weight entry in 14 to 25 of the 28 study months. All other use was defined as "minimal use." We also defined the number of times a specific website feature was accessed for each of the participant-use categories. Website-use features analyzed were those related to behavioral self-management, including entry of weight and exercise, use of a social support component (ie, a bulletin board) and total time spent on the website. We defined one variable, "sessions with additional use after weight entry," to capture the number of sessions in which participants used the website beyond the weekly "required" weight entry. This included bulletin-board use as well as the numerous features accessible to participants once they had entered a weekly weight.

Weight Outcomes

We present several different weight outcome measures: (1) Phase II weight change (regain), (2) proportion of initial weight loss regained, and (3) proportion of participants at least 4 kg below initial weight. Final weights were collected for 323 of 348 (93%) Internet participants.

Statistical Methods

All analyses were conducted using SAS, version 9.1 (SAS Institute Inc, Cary, NC, USA). Tests at $P < .05$ were considered significant. Multiple imputation techniques to account for missing data are described elsewhere [15]. We used logistic and multiple linear regression analyses, as appropriate, to adjust selected weight outcomes for race, sex, education, income, age, and initial BMI. Suitably weighted point estimates, standard deviations, and P values were calculated using the MIANALYZE procedure in SAS.

Results

Participants and Website Use

Over 65% of the 348 Internet participants were still actively logging on to the website at 28 months after randomization. Table 1 shows characteristics for all individuals in the Internet group and each of the three subgroup categories.

Table 2 shows overall use of website features during the first 28 months for all Internet participants. In general, 50% of participants logged on at least 107 times and spent over 400 minutes on the website. Sessions lasted 3 to 5 minutes on average. During roughly 80% of log-ins, participants used website features in addition to the required weight entry. Participants read more bulletin board messages than they posted.

Table 1. Characteristics for all Internet participants and each subgroup category

	All (N = 348)	Consistent (n = 212)	Some (n = 61)	Minimal (n = 75)	*P* value[a]
Male	37%	42%	31%	28%	*P* = .07
African American	38%	33%	39%	51%	*P* = .02
Age, mean (SD)	55.7 (8.5)	57.0 (8.3)	54.1 (7.4)	53.3 (9.3)	*P* = .002
Initial weight, mean (SD), kg	97.2 (16.2)	95.7 (16.1)	96.2 (15.7)	102.3 (16.2)	*P* = .009
Initial BMI, mean (SD)	34.2 (4.9)	33.5 (5.0)	34.2 (4.5)	36.2 (4.4)	*P* < .001
Attended > 15 of 20 Phase I sessions	88%	93%	85%	76%	*P* = .001
Phase I change in body weight, mean (SD)	-8.6 (4.5)	-8.9 (4.5)	-8.1 (4.3)	-8.4 (4.4)	*P* = .45
College or post college degree	62%	67%	61%	48%	*P* = .01
Annual income ≥ $60,000[b]	61%	61%	57%	63%	*P* = .78

[a] Two-tailed *P* values based on Pearson chi-square test for categorical data and one-way ANOVA for continuous data

[b] Missing values = 7; n for each group: all = 341, consistent = 208, some = 58, minimal = 75

Table 2. Overall use of specific website features over the 28 study months (N = 348)

Website Feature[a]	Median (Interquartile Range)
Log-ins	107 (52, 143)
Minutes spent on website	433 (236, 792)
Weight entries	104 (51, 130)
Exercise entries	124 (32, 376)
Sessions with added use after weight entry	86 (44, 116)
Bulletin board messages read	54 (14, 152)
Bulletin board messages posted	1 (0, 4)

[a] Website features highly correlated with each other based on Spearman correlations

Consistent Use

Based on log-in and weight entry frequency described in the "Methods" section, 212 of 348 (61%) participants were defined as consistent users (Table 1). Relative to minimal users, consistent users were more likely to be older, male, other than African American, and more educated. Also, consistent users included participants who began Phase I at lower initial body weight and BMI and attended more Phase I weight-loss group sessions. With the exception of gender (*P* = .07), these differences were statistically significant. Participants in the "some use" group were generally intermediate to those in the "consistent use" and "minimal use" groups. No differences were observed between the website use categories for Phase I change in body weight or income.

Figure 1 shows that consistent users engaged with all features of the website more often and spent more time on the website than other users. The website features were highly correlated with each other (Table 3).

Figure 1. Use of various website features for consistent (n = 212), some (n = 61), and minimal (n = 75) use categories shown as median (square) with first (diamond) and third (triangle) quartiles

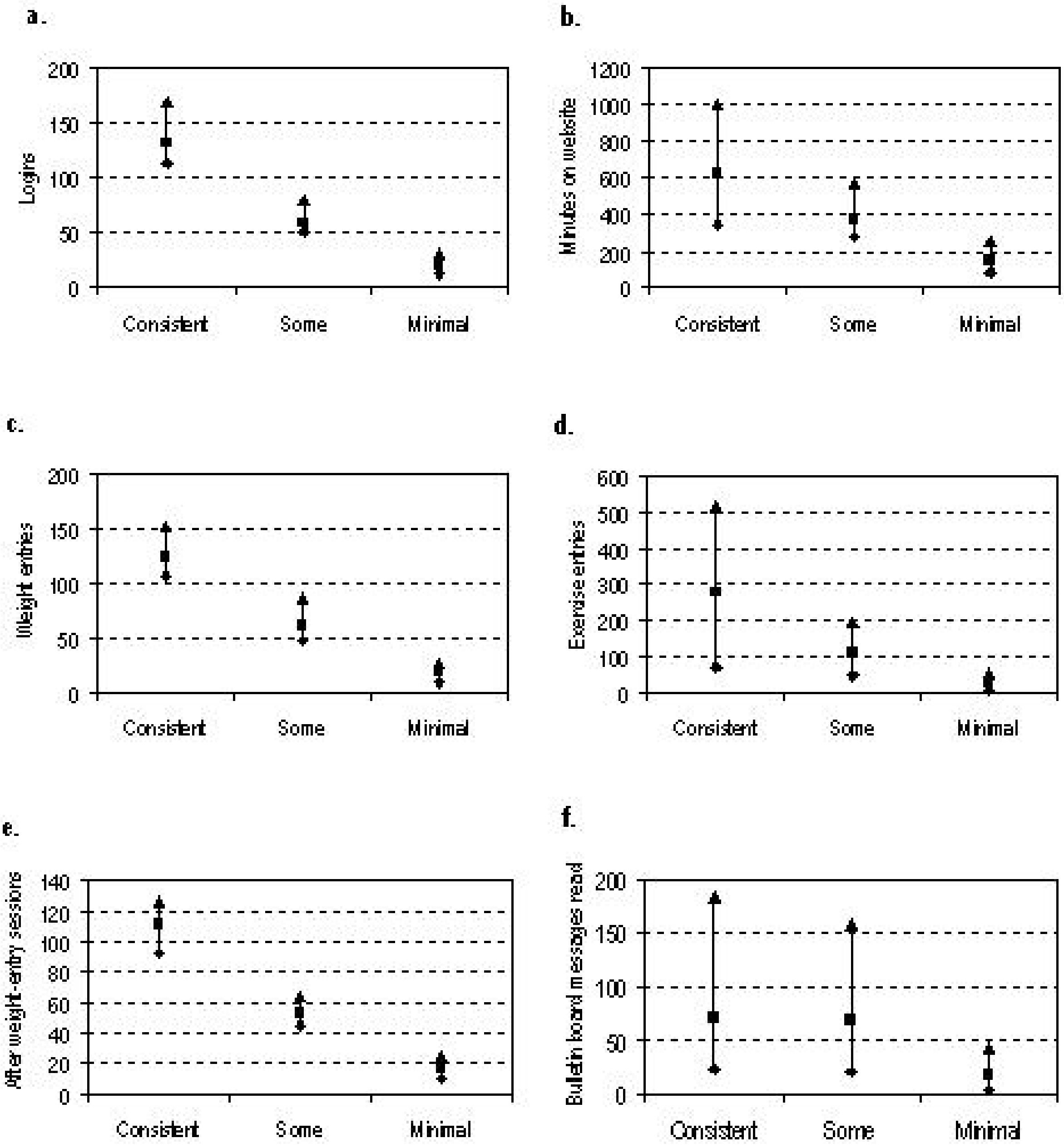

Table 3. Spearman correlations of website use features

	Minutes on Website[a]	Weight Entries[a]	Exercise Entries[a]	After Weight-Entry Session[a]	Bulletin Board Messages Read[a]	Bulletin Board Messages Posted[a]
Log-ins	0.72	0.82	0.53	0.97	0.46	0.28
Minutes on website		0.68	0.65	0.66	0.56	0.35
Weight entries			0.56	0.85	0.34	0.17[b]
Exercise entries				0.53	0.23	0.12[c]
After weight-entry sessions					0.38	0.20
Bulletin Board messages read						0.64

[a] All values *P* < .001 unless otherwise specified

[b] *P* = .001

[c] *P* = .02

Website Use Associated with Weight Loss Maintenance

Figures 2 through 4 show the associations between website-use categories (consistent, some, and minimal) and three different weight outcome measures. Regardless of outcome measure, those in the consistent category had better weight outcomes compared with the other categories. Mean weight change in Phase II, both absolute weight and proportion of initial weight loss regained, was significantly lower (less weight regained) in the consistent website-use category (*P* = .003 [Figure 2] and *P* = .001 [Figure 3]). Likewise, significantly more consistent users, 107 out of 212 (51%), maintained a clinically important weight loss of 4 kg compared with 16 out of 61 (27%) and 18 out of 75 (24%) in the other two categories (*P* = .002). Although not significant (*P* = .45), a higher proportion of participants in the consistent category experienced no weight regain compared with the some and minimal categories, 34 out of 212 (16%), 6 out of 61 (10%), and 6 out of 75 (9%), respectfully. When additionally adjusted for initial BMI due to the differences between groups, the results do not change.

Figure 2. Phase II weight regain (kg) for each website use category shown as 95% confidence interval for the mean (two-tail *P* value testing for differences based on linear regression analysis adjusted for race, sex, education, income and age, *P* = .003)

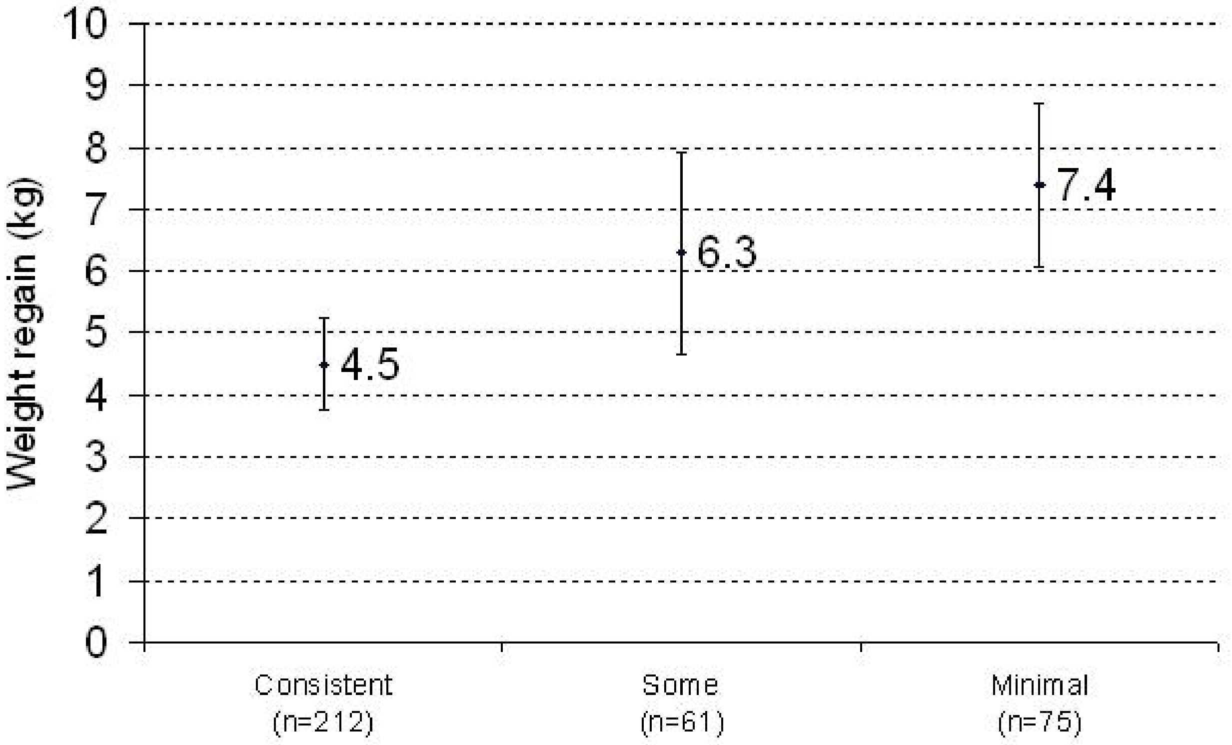

Figure 3. Proportion of initial weight loss regained for each website use category shown as 95% confidence interval for the mean (two-tail *P* value testing for any differences based on linear regression analysis adjusted for race, sex, education, income, and age, *P* = .001)

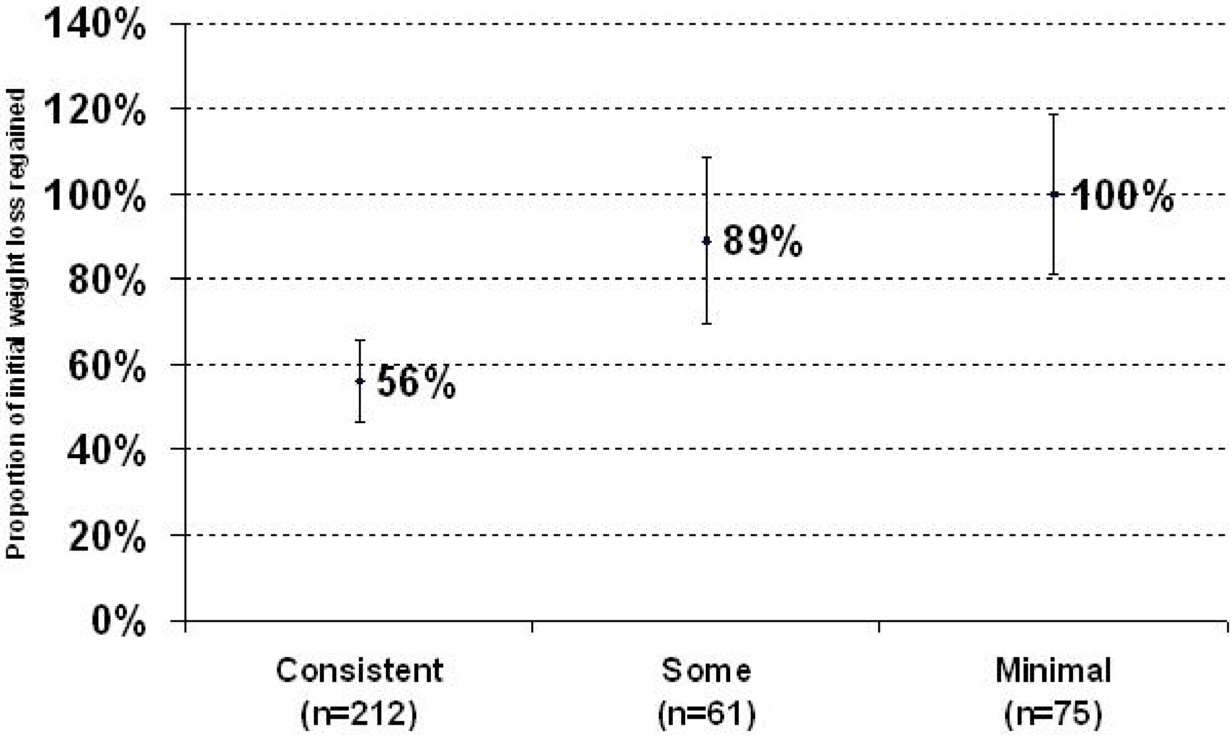

Figure 4. Proportion of participants at least 4 kg below initial weight for each website use category (two-tail *P* value testing for any differences based on logistic regression analysis adjusted for race, sex, education, income, and age, *P* = .002)

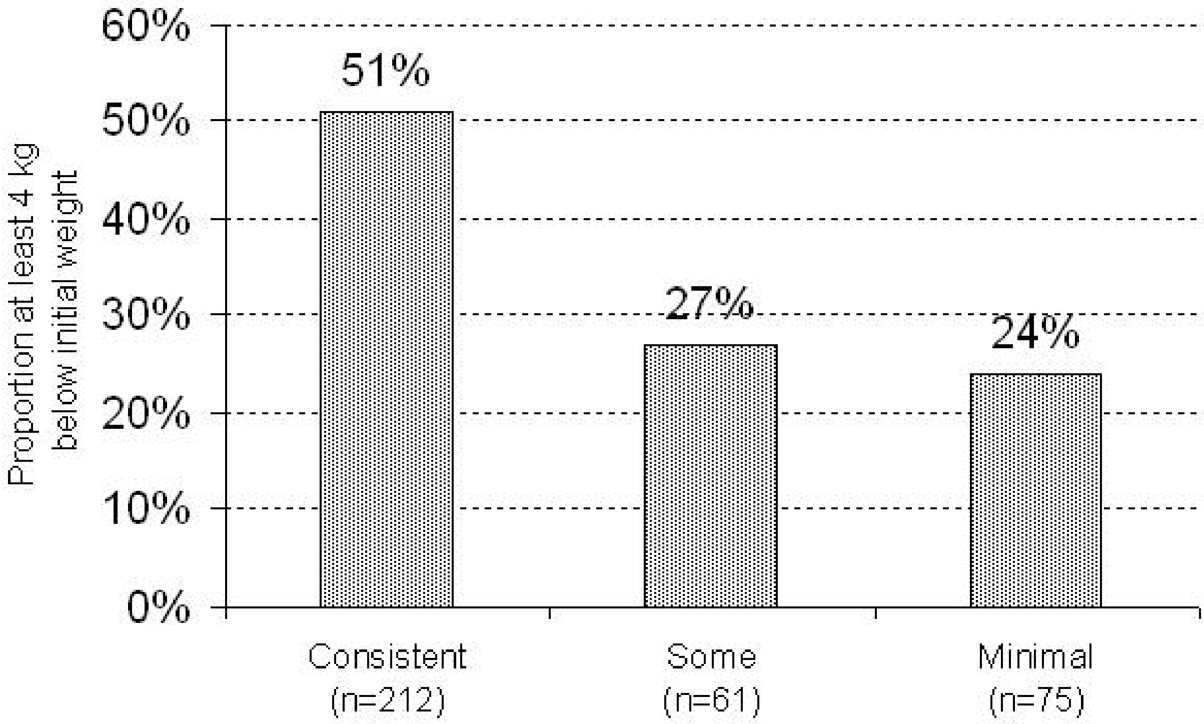

Table 4 shows top, middle, and bottom tertiles of use for specific website features and how frequency of use relates to weight loss maintenance. Greater numbers of log-ins, minutes, weight and exercise entries, and use of additional features after weight entry were associated with better weight outcomes for each weight outcome. Use of the bulletin board was associated with better weight outcome when that outcome was measured as either the proportion of initial weight regained or the proportion of participants at 4 kg below initial weight but was not significant when the outcome was measured as absolute weight regain. When the analysis was restricted to only consistent users (n = 212), the results were qualitatively similar (data not shown).

Table 4. Associations of various website features by tertile of use with different weight outcomes at end of data collection

	Top Tertile	Middle Tertile	Bottom Tertile	*P* value[a]
Phase II weight change (regain) in kg, mean (SD)				
Log-ins	4.0 (10.1)	5.5 (9.4)	6.9 (9.6)	$P = .001$
Minutes	3.1 (6.1)	6.2 (9.6)	6.9 (8.6)	$P < .001$
Weight entries	4.8 (6.1)	4.3 (9.2)	7.2 (9.3)	$P = .002$
Exercise entries	3.6 (10.5)	5.7 (9.3)	7.0 (8.8)	$P < .001$
Added use after weight entry	4.3 (10.3)	4.9 (9.3)	7.1 (9.6)	$P = .002$
Bulletin board posts	4.8 (13.2)	6.5 (10.2)	5.3 (7.1)	$P = .10$
Bulletin board reads	4.7 (12.1)	6.2 (8.3)	5.4 (8.2)	$P = .16$
Proportion of initial weight loss regained, mean (SD)				
Log-ins	48.8% (127.5%)	68.2% (98.9%)	96.4% (134.7%)	$P < .001$
Minutes	36.3% (58.2%)	80.7% (137.5%)	95.7% (120.1%)	$P < .001$
Weight entries	55.4% (73.0%)	56.4% (107.1%)	101.0% (121.9%)	$P < .001$
Exercise entries	43.0% (108.6%)	78.5% (138.3%)	91.6% (113.5%)	$P < .001$
Added use after weight entry	54.1% (132.0%)	59.8% (96.1%)	99.3% (137.5%)	$P < .001$
Bulletin board posts	60.0% (159.0%)	88.4% (146.3%)	69.9% (90.9%)	$P = .02$
Bulletin board reads	55.6% (136.0%)	82.1% (106.6%)	75.3% (115.2%)	$P = .01$
Proportion of participants at least 4 kg below initial weight				
Log-ins	58.3%	39.5%	24.5%	$P < .001$
Minutes	59.7%	36.9%	26.0%	$P < .001$
Weight entries	49.1%	48.9%	24.6%	$P = .005$
Exercise entries	61.2%	35.0%	26.2%	$P < .001$
Added use after weight entry	54.8%	42.4%	25.2%	$P = .002$
Bulletin board posts	47.4%	30.3%	41.6%	$P = .05$
Bulletin board reads	53.9%	29.2%	39.5%	$P < .001$

[a] Two-tail *P* values based on logistic (binary) or linear (continuous) regressions analysis adjusted for race, sex, education, income, and age

Discussion

In this analysis, participants defined as consistent users of an interactive behavioral website designed to improve maintenance of weight loss had less long-term weight change (less regain). Consistent users were more likely to be older, other than African American and more educated, and used most features of the website more often when compared with other users. These results suggest that an Internet-based tool can provide some of the accountability and feedback assumed necessary for successful and long-term weight maintenance.

Website Use

Previous studies using websites designed to improve weight loss have shown mixed results. Some research has shown that using a weight-loss website is strongly associated with short-term weight-loss success, but few long-term analyses are available, and even fewer consider the possible benefits of specific website features [8,18,19]. In a study of overweight and obese adults using an Internet-based weight-control program for 12 months, feedback website features (ie, progress charts) were the best predictors of initial 6-month weight loss, while social-support features (ie, Web chats and participant profiles) were related to weight maintenance at 12 months [8]. In a 6-month study, participants in an interactive Internet-based, behavioral weight-loss program lost significantly more weight than those who simply received access to the study's website directory of selected weight-loss information [19]. Likewise, in a 12-month study, greater weight loss occurred in an Internet-plus-behavioral e-counseling intervention compared with those in just the basic Internet condition devoid of any email counseling [18]. On the other hand, no difference in weight regain was found at 12 months after a 4-month randomized behavioral weight-loss trial comparing a self-directed group with an Internet group that used a website with features like weight and exercise tracking, progress reports, and chat rooms [20]. This same study, however, found that in the Internet group use of the interactive diet-tracking features was related to weight change, a result similar to our findings.

Harvey-Berino et al [21] showed a clinically significant sustained weight loss 18 months after a 6-month behavioral weight-loss program for each of 3 intervention arms: frequent in person support, minimal in person support, and Internet-only support. The study concluded that the Internet was an effective vehicle for promoting clinically significant levels of weight loss, and that the Internet intervention was comparable to in person treatment up to 18 months. The WLM study showed promising weight-loss maintenance results for participants in the Internet group, compared with the self-directed control group at 18 months, but the effect was not sustained at 24 and 30 months [15]. This suggests that more research is needed to develop and promote a Web-based program that will produce sustainable long-term weight-loss maintenance.

Internet Engagement

Keeping participants engaged in long-term treatment of weight management is the key challenge for any weight-loss program and is reflected in high study dropout rates. In a review of nine randomized controlled trials published from 1996 through 2002, mean study dropout rate was 21.2% at 18 months following completion of a 6-month treatment program [22]. In a study comparing three 12-month weight-maintenance programs, one of which was an interactive Internet intervention, after a 6-month behavioral weight-control program, 32% of those in the Internet condition did not complete the 18-month visit [21]. While dropout rates are a concern, reported Internet intervention participation rates are even more concerning [23,24]. In one study, only 30% of participants remained active after a 12-week physical activity intervention [24], while in another study, only 23% of participants visited a personalized Web-based cardiovascular risk reduction program at least once in the first 4 months of the study [25].

The low dropout rate and high long-term Internet participation rate of this study are likely due to several factors. The WLM website continually changed and presented a tailored welcome message and homepage with a “to do” list for each participant. The tailoring was a result of sophisticated programming that took into account the length of time since the participant’s last visit and features that the participant might benefit from based on the data entered. Our system of automated email and telephone prompts also may have contributed to high participation rates since 86% of all initial automated email prompts resulted in a subsequent log-in. Continued participation was also probably a result of initial individual training provided at randomization.

Definition of Weight Loss Maintenance

Unfortunately, a standard definition for successful maintenance of weight loss does not exist [26]. We present our results using three different weight outcome measures to allow for thorough comparisons with other studies.

One way to define weight-loss maintenance is absolute weight change (regain) after initial weight loss. In this analysis, consistent website users regained less weight than those in other website-use categories. Also, those with higher counts of log-ins, minutes spent on the website, weight and exercise entries, and use after the weight entry regained less weight than those with lower counts. While absolute weight change during maintenance is an important outcome, it does not account for the total initial weight loss. Thus, the proportion of initial weight loss regained is a useful measurement. Using this second definition for weight-loss maintenance, the weight regain trend is similar to the absolute weight change results: consistent users regained 56% of initial weight lost compared with over 90% of initial weight regained among participants in the other categories.

We also present the proportion of participants whose weight is at least 4 kg below their initial weight. For adults, 4 kilograms of weight loss is generally accepted as clinically relevant [13,14]. This analysis demonstrated that significantly more consistent users and those in the highest tertiles of use for each website feature analyzed were more likely to be at least 4 kg below their initial weight.

This analysis has some limitations. Although, some subgroups in our population were more likely to be consistent users, our analysis did not include other factors that also may have contributed to being a consistent user. For instance, the screening process assured participants had regular access to the Internet; however, comfort level and familiarity with Internet-based tools, which were not assessed, also could have been a factor in consistency of use. This analysis did not assess the specifics of Internet access or how it may, or may not, have related to income and/or education. Internet access may have been from home, work, library, or somewhere else entirely, each of which may have some impact on consistency of use. Furthermore, the study design did not include integration of the interactive website into the initial Phase I weight-loss program. We speculate there may have been even greater use of the website in Phase II had this been done.

These observed Internet use associations do not prove causation. They are, however, consistent with our hypothesis that those who use a behaviorally based, interactive website more would be more successful at long-term weight maintenance. A major strength of this study is its long duration and large sample size, the diverse population (37% male, 38% African American), high follow-up data collection rate (93%), and high Internet participation rate (65% still logging on after 28 months) compared with other published Internet-use study results.

Participants defined as consistent users (based on regularity and frequency of use) of an interactive behavioral website designed to improve maintenance of weight loss had less long-term weight change (less regain), suggesting that Internet-based tools can provide some of the accountability and feedback assumed necessary for successful and long-term weight maintenance. The potential for widespread dissemination at relatively low cost per participant, even when the benefit is modest, makes further development of interactive-technology interventions worthwhile. Additional research is warranted of the relationship of long-term weight management with website-use patterns, use of specific behavior-change website features, and regularity of website usage.

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Conflicts of Interest

None declared

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Abbreviations

BMI: body mass index
CVD: cardiovascular disease
NHLBI: National Heart, Lung, and Blood Institute
WLM: Weight Loss Maintenance Trial

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Original Paper

Investigating Predictors of Visiting, Using, and Revisiting an Online Health-Communication Program: A Longitudinal Study

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Abstract

Background: Online health communication has the potential to reach large audiences, with the additional advantages that it can be operational at all times and that the costs per visitor are low. Furthermore, research shows that Internet-delivered interventions can be effective in changing health behaviors. However, exposure to Internet-delivered health-communication programs is generally low. Research investigating predictors of exposure is needed to be able to effectively disseminate online interventions.

Objective: In the present study, the authors used a longitudinal design with the aim of identifying demographic, psychological, and behavioral predictors of visiting, using, and revisiting an online program promoting physical activity in the general population.

Methods: A webpage was created providing the public with information about health and healthy behavior. The website included a “physical activity check,” which consisted of a physical activity computer-tailoring expert system where visitors could check whether their physical activity levels were in line with recommendations. Visitors who consented to participate in the present study (n = 489) filled in a questionnaire that assessed demographics, mode of recruitment, current physical activity levels, and health motivation. Immediately after, participants received tailored feedback concerning their current physical activity levels and completed a questionnaire assessing affective and cognitive user experience, attitude toward being sufficiently physically active, and intention to be sufficiently physically active. Three months later, participants received an email inviting them once more to check whether their physical activity level had changed.

Results: Analyses of visiting showed that more women (67.5%) than men (32.5%) visited the program. With regard to continued use, native Dutch participants (odds ratio [OR] = 2.81, 95% confidence interval [CI] = 1.16-6.81, *P* = .02) and participants with a strong motivation to be healthy (OR = 1.46, CI = 1.03-2.07, *P* = .03) were most likely to continue usage of the program. With regard to revisiting, older participants (OR = 1.04, CI = 1.01-1.06, *P* = .01) and highly educated participants (OR = 4.69, CI = 1.44-15.22, *P* = .01) were more likely to revisit the program after three months. In addition, positive affective user experience predicted revisiting (OR = 1.64, CI = 1.12-2.39, *P* = .01).

Conclusions: The results suggest that online interventions could specifically target men, young people, immigrant groups, people with a low education, and people with a weak health motivation to increase exposure to these interventions. Furthermore, eliciting positive feelings in visitors may contribute to higher usage rates.

(J Med Internet Res 2010;12(3):e37) doi:10.2196/jmir.1345

KEYWORDS

Health communication; Web-based interventions; research subject selection; Internet; exposure

Introduction

Background

Cardiovascular diseases and cancers are the main causes of mortality in many Western countries. Because these and many other diseases are largely the result of unhealthy behaviors [1-3], an important goal of health communication is to encourage and motivate people to engage in healthful and disease-preventive behaviors. But how can we most effectively reach a large part of the population? In high-income countries, most adults now have access to the Internet. Online health communication thus has the potential to reach large audiences, with the additional advantages that it can be operational at all times and that the costs per visitor are low [4-7]. Furthermore, research shows that Internet-delivered interventions can be effective in changing health behaviors such as physical activity [8,9].The Internet thus seems to offer vast opportunities for health communication. However, the public health impact of interventions is only in part determined by reach and efficacy. According to the RE-AIM Model, which offers a framework for the evaluation of the public health impact of health promoting interventions [10,11], other important factors are adoption, implementation, and maintenance. In this model, adoption refers to the extent to which the intervention is integrated in relevant settings and maintenance refers to the extent to which the intervention is sustained over time. Implementation refers to the extent to which the intervention is delivered and used as intended. In the present study we focused on exposure, which is closely related to implementation [12]. Exposure can be construed as consisting of (1) visiting the intervention website, (2) continued use (ie, staying on the intervention website long enough to use and process the information), and (3) revisiting the intervention website [13]. Whereas exposure in the colloquial sense suggests passive reception of incoming information, we see exposure in an online context as entailing a certain degree of user control [13]. Investigating exposure to Internet-delivered interventions is important because evidence from efficacy trials indicates that exposure rates are generally low, which limits the potential public health impact of these interventions [14-16]. In some cases, people may have low motivation to access the online intervention [17,18]. In addition, previous research has established that both online research and online health-communication interventions suffer from high attrition rates [15,19,20]. In fact, several authors have argued that the ease with which people may disengage from online interventions might pose a major problem, both for online research and for online therapeutic applications or health-communication programs [15,21]. Instead of regarding high attrition rates as an inevitable reality of online health communication efforts or as merely a study limitation, however, it has been argued that researchers should build a “science of attrition” [15]. Insight into the determinants of visiting, using, and revisiting of online health-communication interventions could enable us to increase exposure to online health communication. For this reason, the present study investigated several potential determinants of exposure to an online health-communication program.

Previous research has identified several factors that can influence exposure to Internet-delivered health-communication interventions. First, intervention factors such as ease of enrollment and ease of dropout have been shown to influence exposure rates [15]. Personal factors, such as participants’ expectations before use and participants’ level of education [15], might also be important. According to Rogers [22], users with less formal education are more likely to discontinue the adoption of innovations. Therefore, people with a low education level may be expected to be less likely to use online health-communication programs. In addition, because women have been found to be more likely to use the Internet for searching health-related information than men [23,24], it could be expected that women might also be more likely to use online health-communication interventions. Previous research at our department has indeed shown that visitors to established Dutch Internet interventions were more highly educated and were more likely to be female than average among the Dutch population [25]. In addition, age might influence exposure to an online health-communication program, older people being more likely to use the Internet for information about health than adolescents [20,26]. In line with this, a recent study found that women, older people and people living in census tracts associated with higher socioeconomic status were more likely to enroll in an online dietary intervention trial [16]. A dearth of literature exists, however, on the impact of other potentially important determinants of exposure to Internet-delivered health-communication interventions. One such factor might be participants’ motivation to pursue and maintain health [27]. Participants who are motivated to live a healthy lifestyle might be more inclined to visit, use and revisit online health-communication programs. Another potentially important factor is user experience, which refers to what a person thinks and feels during and after a visit [28]. A positive user experience during and after the first visit might be a prerequisite for staying long enough to complete the intervention and for revisiting.

Objectives

In the present study, we aimed to investigate demographic, behavioral and psychological determinants of exposure to an online program promoting physical activity. We assessed demographic variables, participants’ current physical activity level and their motivation to pursue and maintain health [27]. To investigate the role of user experience [28], we also assessed participants’ reactions toward the online content. Because previous research has shown that affective and cognitive beliefs are separate entities and can influence decision making differently (eg, [29,30]), we investigated both affective and cognitive components of user experience. We also assessed attitudes toward being sufficiently physically active and intentions to be sufficiently physically active. Attitudes and intentions have been shown to be closely related to actual health behavior [31] and have also been shown to be related to increased interest in health-promoting interventions in general [32,33] and online health-promoting interventions specifically [13]. In the present study, we investigated whether attitudes and intentions with regard to physical activity could lead to increased use of online activity-promoting interventions.

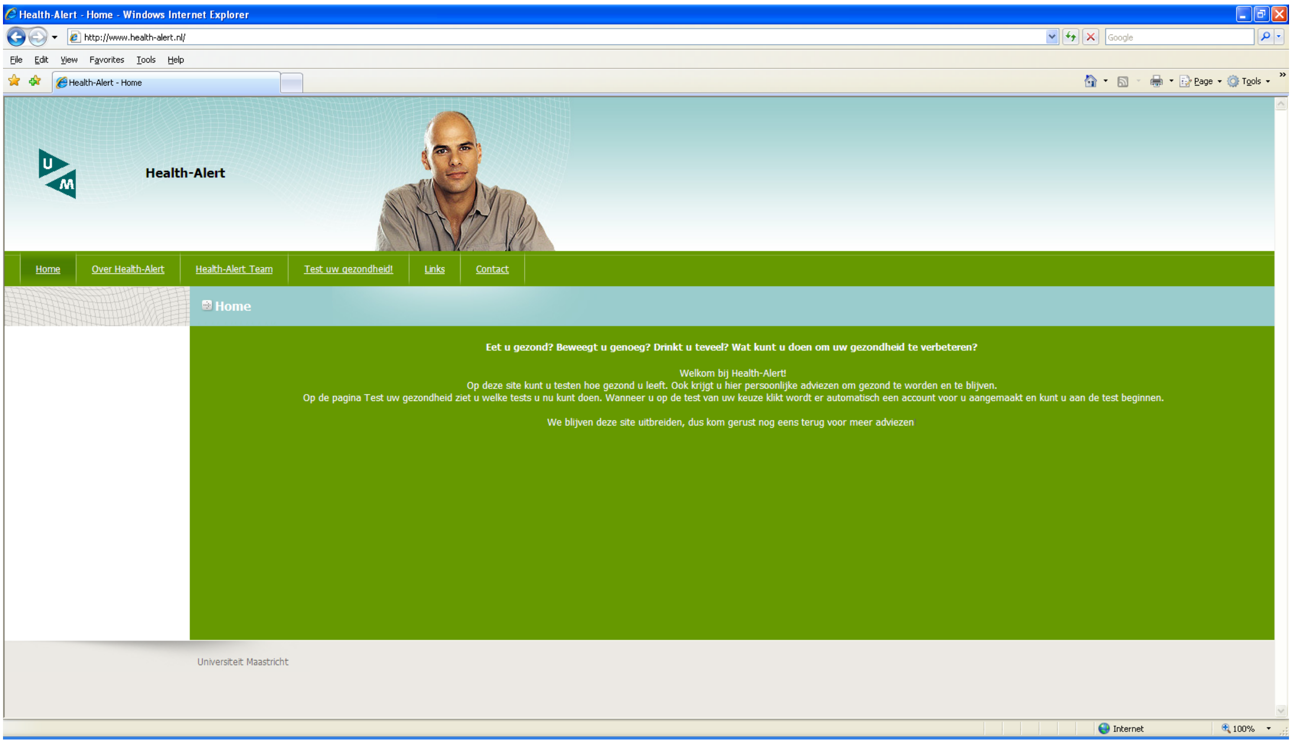
In sum, the Internet offers vast possibilities for health-communication efforts. Unfortunately, online health-communication interventions are characterized by low exposure rates. The present study sought to investigate predictors of visiting, using, and revisiting online interventions to increase our knowledge of exposure to these interventions.

Method

Recruitment

A webpage was created providing the public with information about health and healthy behaviour (www.health-alert.nl). (See Figure 1 for an impression of the visual impact of the website.) To recruit participants, we aimed to generate publicity for the website through local media. Two news items were broadcasted on local television and several articles appeared in local newspapers in the province of Limburg in The Netherlands. In addition, we approached webmasters of related Dutch websites (ie, websites about exercise, physical activity, weight control, or other health- or activity-related subjects) and asked them to link to our website. In total, we approached 16 webmasters, 7 of whom obliged. On our Health-Alert webpage, we created a hyperlink called “physical activity check” that led to a physical activity computer-tailoring expert system where visitors could check whether their physical activity levels were in line with recommendations. Dutch recommendations with regard to physical activity state that healthy adults should be physically active for at least thirty minutes on at least five days of the week [34]. Visitors were told that they would receive an invitation to again check their physical activity levels three months from the first assessment so that they could check whether their physical activity levels had changed in this period. Before entering the questionnaire, visitors were asked whether they consented to their answers being used for scientific research or whether they wanted to use the intervention but not participate in the research. Participants were also told that entering their email address was necessary for them to participate in the research. The minimum age required for participation was 18 years; participants younger than 18 could also use the intervention, but only adults were eligible to participate in the study. The majority of eligible participants (489/593 or 82.5%) consented to being included in the research.

Figure 1. Homepage of the Health-Alert website



Eet u gezond? Beweegt u genoeg? Drinkt u teveel? Wat kunt u doen om uw gezondheid te verbeteren?

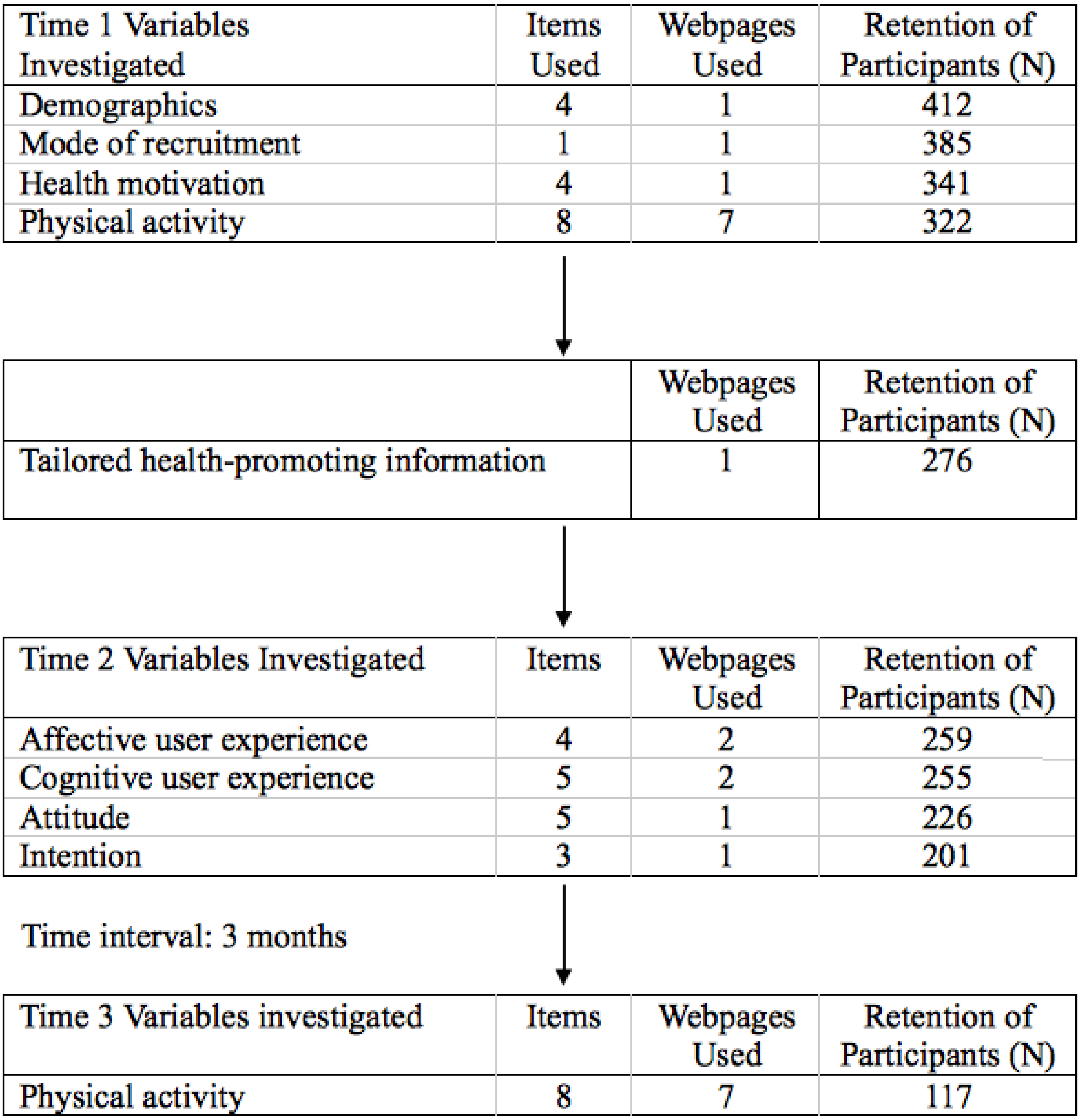
Welkom bij Health-Alert!
Op deze site kunt u testen hoe gezond u leeft. Ook krijgt u hier persoonlijke adviezen om gezond te worden en te blijven.
Op de pagina Test uw gezondheid ziet u welke tests u nu kunt doen. Wanneer u op de test van uw keuze klikt wordt er automatisch een account voor u aangemaakt en kunt u aan de test beginnen.

We blijven deze site uitbreiden, dus kom gerust nog eens terug voor meer adviezen

Design and Procedure

The present study used an observational longitudinal design. After giving informed consent to participate, participants were invited to complete a questionnaire that assessed participants’ demographics, mode of recruitment, health motivation, and current physical activity levels (Time 1). Immediately after, participants were provided with a short message about the Dutch recommendations for physical activity. After participants were informed about these recommendations, they received tailored feedback concerning their current physical activity level. This tailored feedback informed them whether or not they met the recommendations for physical activity and offered tips on how to increase their physical activity or maintain their (already sufficient) current level of physical activity. The feedback was tailored solely to current physical activity levels and was not tailored to demographic or psychosocial variables. After reading the tailored feedback, participants completed an additional questionnaire assessing affective and cognitive user experience, attitude, and intention (Time 2). Three months later, participants received an email inviting them to participate in an assessment of whether their physical activity level had changed (Time 3). Figure 2 depicts a flowchart of the study, showing the assessed constructs, the number of items that were used for each construct, the number of webpages that were used for each construct, and the number of participants that completed all measures for each construct. Completion of the study at Time 1 and Time 2 took 30 minutes on average, whereas completion of the Time 3 measures took only 5 minutes on average. All 489 participants who entered the study were invited to complete the three-month follow-up questionnaire. In case of nonresponse, participants were sent one reminder email one week later. The study was conducted from November 2007 through March 2008 and was approved by the Medical Ethical Committee of Maastricht University.

Figure 2. Flowchart of the study



Time 1 Variables Investigated	Items Used	Webpages Used	Retention of Participants (N)
Demographics	4	1	412
Mode of recruitment	1	1	385
Health motivation	4	1	341
Physical activity	8	7	322

	Webpages Used	Retention of Participants (N)
Tailored health-promoting information	1	276

Time 2 Variables Investigated	Items	Webpages Used	Retention of Participants (N)
Affective user experience	4	2	259
Cognitive user experience	5	2	255
Attitude	5	1	226
Intention	3	1	201

Time interval: 3 months

Time 3 Variables investigated	Items	Webpages Used	Retention of Participants (N)
Physical activity	8	7	117

Questionnaire at Time 1

Demographics and Mode of Recruitment

We assessed gender, age, ethnicity (1 = native Dutch; 2 = nonnative Dutch) and education (1 = low education; 2 = medium education; 3 = high education). In the complex schooling system in the Netherlands, a low education level refers to primary or basic vocational school, a medium education level refers to secondary vocational school or high school, and a high education level refers to advanced vocational school or university. In addition, we asked participants to indicate how they learned about the physical activity check (1 = through a search engine, eg, Google; 2 = through a link on another website; 3 = through a newspaper; 4 = through family, friends or co-workers; 5 = through local television).

Health Motivation

To measure participants’ health motivation, a 4-item questionnaire was used (based on [27]). Participants indicated their agreement with the following items on a 7-point scale (1 = I do not agree at all to 7 = I totally agree): “I often think about making sure that I am healthy.” “I often think about staying healthy," "In general, I aim to prevent poor health," and "I often think about preventing poor health." These items were averaged to create a general health motivation score (Cronbach alpha = .80). In a pilot study among 171 university students aimed at testing the health motivation scale, it was found to have acceptable test-retest stability over a one-week period ($r = .65$) and to have small to medium-sized correlations with a number of health behaviors such as vegetable and fruit consumption and exercise.

Assessment of Baseline Physical Activity

Physical activity levels were assessed using the short version of the International Physical Activity Questionnaire (IPAQ) [35]. Two questions were asked to assess vigorous physical activity, The first question asked participants to indicate on how many days during the past week they had engaged in vigorous physical activity (eg, exercising). The second question assessed the time participants typically spend being vigorously physically active on such a day (in minutes). The two measures were multiplied to arrive at a total score of vigorous physical activity per week. In addition, two questions were asked to assess moderate physical activity. The first of these asked participants to indicate on how many days during the past week they had engaged in moderate physical activity (eg, gardening or cycling). The second assessed the time participants typically spend being moderately physically active on such a day (in minutes). The two measures were multiplied to arrive at a total score of moderate physical activity per week. Finally, vigorous and moderate physical activity were added up to arrive at a total score of physical activity during the past week and divided by seven to obtain a score of physical activity per day [35]. Because the Dutch recommendations for physical activity do not include walking [34], the walking-items of the IPAQ were not used to calculate the total physical activity score. We found that scores for 4 respondents indicated they had been physically active for more than eight hours a day on all days of the week, a physical activity level that we judged highly unlikely. Thus, we truncated the physical activity variable to a maximum of eight hours a day. Not truncating the physical activity variable or omitting these cases from the analyses yielded similar results and identical conclusions.

Questionnaire at Time 2

Affective User Experience

Two items assessed positive affective reactions to the online content (ie, positive affective user experience); these items assessed the extent to which participants thought the content made them feel happy (1 = very happy to 7 = not at all happy) and relieved (1 = very relieved to 7 = not at all relieved). Scores were reversed and combined to create an average score. (Cronbach alpha = .75). Two items assessed negative affective reactions to the online content (ie, negative affective user experience) and assessing the extent to which participants thought the content made them feel sad (1 = very sad to 7 = not at all sad) and afraid (1 = very afraid to 7 = not at all afraid). Scores were reversed and combined to create an average score (Cronbach alpha = .83).

Cognitive User Experience

Five items assessed cognitive user experience by asking participants to indicate the extent to which they thought the online content was relevant (1 = very relevant to 7 = not at all relevant), interesting (1 = very interesting to 7 = not at all interesting), objective (1 = very objective to 7 = not at all objective), and exaggerated (1 = very exaggerated to 7 = not at all exaggerated). Furthermore, one item asked participants to indicate the extent to which participants agreed with the content (1 = I totally agree to 7 = I totally disagree). After we reversed the scores of all items except the exaggerated item, the scores on the five items were averaged (Cronbach alpha = .75).

Attitude

Five items were used to assess attitude toward physical activity asking participants to indicate on semantic differentials the extent to which they rated engaging in at least thirty minutes of physical activity for at least five days of the week as: 1 = very good to 7 = very bad; 1 = very important to 7 = very unimportant; 1 = very sensible to 7 = not sensible at all; 1 = very nice to 7 = not at all nice; 1 = a lot of fun to 7 = no fun at all. After scores on the attitude items were reversed an average score was created (Cronbach alpha = .90).

Intention

Three items were used to assess intention to be physically active. Two items asked participants to indicate whether they planned to be physically active for at least thirty minutes a day on at least five days of the week and whether they considered being physically active for at least thirty minutes a day on at least five days of the week (1 = definitely not to 7 = definitely). One item asked participants: "How likely is it that you will be physically active for at least thirty minutes a day on at least five days of the week in the coming six months?" (1 = very unlikely to 7 = very likely). An average intention score was calculated (Cronbach alpha = .89).

Questionnaire at Time 3: Physical Activity

During the three-month follow-up, physical activity levels were assessed using the same procedure as in the pretest questionnaire (ie, using the IPAQ).

Outcome Measures

The present study had three main outcome measures: visiting the website at Time 1, using the website at Time 1, and revisiting the website at Time 3. Determinants of visiting were investigated by comparing the demographics of the study sample with those of the general Dutch population. To assess continued use, we recorded which webpages were accessed by participants. A dichotomous variable was created that indicated whether participants had continued in the program up to the point of being exposed to the tailored health-promoting information (0 = dropped out before exposure to the information; 1 = continued use up to exposure to the information). Revisiting at Time 3 was assessed by means of a dichotomous variable indicating participation at Time 3 (0 = did not revisit at Time 3; 1 = did revisit at Time 3).

Statistical Analysis

First, we investigated the demographic profile of the sample and the prevalence of the different modes of recruitment by means of descriptive analyses. Second, logistic regression analyses were performed to investigate whether continued use of the study could be predicted by gender, age, ethnicity, education (we created two dummy variables to be able to estimate the contribution of the three education groups), mode of recruitment (we created four dummy variables to be able to estimate the contribution of the five modes of recruitment groups), health motivation, and baseline physical activity. Third, logistic regression analyses were performed to investigate which variables could predict participation at Time 3. In step 1 of the logistic regression analyses, the Time 1 variables were entered (demographic variables, mode of recruitment, health motivation, physical activity), and in step 2, the Time 2 variables were entered in addition (affective user experience, cognitive user experience, attitude and intention). We used the statistical package SPSS 15.0 (SPSS Inc, Chicago, IL, USA) for the analyses. To calculate the statistical power of this study to reject false null hypotheses, we conducted a post-hoc statistical power test [36,37]. With 16 predictors in the regression analysis, an observed R^2 of 0.22 (see Table 5), a sample size of 489 and alpha = .05, the test results indicated an observed power of 1.0.

Results

Participants

In total, 489 people participated in the study. The sample consisted of more women (n = 336; 67.5%) than men (n = 162; 32.5%). Age ranged from 18 to 86 years, with a mean age of 38.6 years (SD 15.0). Reflecting the general Dutch population, most of the participants were native Dutch. Approximately one-third of participants (n = 186) had a high education level, 48.6% (n = 242) had a medium education level, and 14.1% (n = 70) had a low education level. In the general population these percentages are 29.0%, 42.3%, and 28.6% respectively [38].

Table 1. Demographic profile of participants

Variable	Percentage
Sex	
Male	32.5
Female	67.5
Ethnicity	
Native	81.5
Nonnative	18.5
Education	
Low	14.1
Medium	48.6
High	37.3
Recruitment	
Search engine	28.6
Hyperlink on related website	48.7
Advertisement in newspaper	3.5
Through family, friends, coworkers	2.2
Local television	17.0
Physical activity (minutes/day)	
0-15	21.3
16-30	16.9
31-45	15.7
46-60	12.0
61 or more	34.1

Recruitment

The majority of participants indicated that they had learned about the physical activity check on related websites. Percentages for mode of recruitment, as well as additional demographics and physical activity levels, are presented in Table 1.

Analyses of Continued Use

Of the 489 participants who enrolled in the study, 276 (55.4%) continued in the study up to the point of being exposed to the tailored information. We conducted a logistic regression analysis to investigate whether demographics, mode of recruitment, or physical activity levels could predict continued use at the first measurement. Results of the logistic regression analyses showed that native Dutch participants completed more pages than nonnative participants. Furthermore, participants with a strong health motivation completed more pages than those with a weak health motivation (Table 2). Combined, all variables accounted for 8% of the variance in continued use (Nagelkerke R^2 = .08).

Table 2. Results of the logistic regression analysis with continued use as the dependent variable

	Odds Ratio (OR)	95% Confidence Interval (CI)	Wald χ^2	*P* Value[a]
Gender	1.22	0.67-2.39	0.51	.48
Age	1.02	1.00-1.04	2.29	.13
Medium education[b]	0.97	0.40-2.35	0.01	.94
High education[b]	1.44	0.56-3.66	0.57	.45
Ethnicity (0 = nonnative Dutch; 1 = native Dutch)	*2.81*	*1.16-6.81*	*5.23*	*.02*
Recruitment through other website[c]	1.43	0.73-2.83	1.08	.30
Recruitment through newspaper[c]	0.79	0.14-4.33	0.07	.79
Recruitment through family, friends, coworkers[c]	1.03	0.18-5.75	0.00	.98
Recruitment through television[c]	0.92	0.40-2.13	0.04	.85
Health motivation	*1.46*	*1.03-2.07*	*4.51*	*.03*
Physical activity	1.00	1.00-1.00	0.02	.88

[a] Significant effects (*P* < .05) are indicated by italics.

[b] "Low education" as reference group

[c] "Search engine" as reference group

Analyses of Revisiting at Time 3

Of all 489 participants, 126 (25.3%) participated in the three-month follow-up assessment (Time 3), of which 117 (23.5%) completed all measures. We first conducted correlation analyses to investigate whether revisiting was associated with physical activity, health motivation, positive affective user experience, negative affective user experience, cognitive user experience, attitude, intention, and continued use. (We used Spearman's ρ as a measure of all correlations involving continued use and revisiting and Pearson's *r* for all other correlations.) These analyses showed that revisiting was positively correlated with health motivation, positive affect, cognitive user experience, and continued use, and negatively with negative affect (see Table 3).

Furthermore, we conducted a logistic regression analysis to investigate which variables could predict revisiting at Time 3. Results of step 1 of the logistic regression analyses showed that older participants were more likely to participate at Time 3. In addition, highly educated participants were more likely to participate than participants with a low education level (Table 4). Nagelkerke R^2 for this analysis was .18. In step 2 of the analyses (Table 5), age and education were still significant predictors of participation at Time 3, but in addition, positive affective user experience contributed significantly to the prediction of revisiting at Time 3. The more participants indicated that the computer-tailored feedback had made them feel good, the more likely they were to participate in the study at Time 3. Negative affective user experience, cognitive user experience, attitude, and intention did not have significant effects on revisiting at Time 3. Nagelkerke R^2 for this analysis was .22.

Table 3. Correlations, means, and standard deviations for continued use, revisiting, and other variables

Variables[a]	1	2	3	4	5	6	7	8	Mean	SD
(1) Physical activity									68.71	85.06
(2) Health motivation	.04								5.96	0.77
P value	.49									
(3) Positive affect	*.22*	*.23*							4.40	1.09
P value	< .01	< .01								
(4) Negative affect	-.10	-.07	-*.39*						2.43	1.34
P value	.10	.23	< .01							
(5) Cognitive user experience	.03	.10	*.36*	-*.16*					5.18	0.88
P value	.61	.14	< .01	.02						
(6) Attitude	*.21*	*.37*	*.32*	-*.16*	*.26*				5.92	0.85
P value	< .01	< .01	< .01	.01	< .01					
(7) Intention	*.27*	*.21*	*.27*	-*.25*	*.15*	*.67*			5.49	1.34
P value	< .01	< .01	< .01	< .01	.02	< .01				
(8) Continued use	.00	.04	-	-	-	-	-		0.55	0.50
P value	.97	.43								
(9) Revisiting	.08	*.10*	*.18*	-*.18*	*.13*	.03	.09	*.19*	0.25	0.44
P value	.13	.04	< .01	< .01	.049	.60	.16	< .01		

[a] Significant correlations ($P < .05$) are indicated by italics.

Table 4. Results of step 1 of the logistic regression analysis with participation at Time 3 as the dependent variable

Variables[a]	OR	95% CI	Wald χ^2	*P* Value
Gender	1.03	0.58-1.85	0.01	.91
Age	*1.05*	*1.03-1.07*	*18.64*	*.00*
Medium education[b]	2.15	0.85-5.44	2.61	.11
High education[b]	*3.54*	*1.39-9.00*	*7.03*	*.01*
Ethnicity (0 = nonnative Dutch; 1 = native Dutch)	1.14	0.58-2.21	0.14	.71
Recruitment through other website[c]	1.33	0.69-2.59	0.72	.40
Recruitment through newspaper[c]	1.36	0.38-4.93	0.22	.64
Recruitment through family, friends, coworkers[c]	1.37	0.23-8.27	0.12	.73
Recruitment through television[c]	2.09	0.95-4.62	3.34	.07
Health motivation	1.24	0.86-1.77	1.33	.25
Physical activity	1.00	1.00-1.01	0.98	.32

[a] Significant effects ($P < .05$) are indicated by italics.

[b] “Low education” as reference group

[c] “Search engine” as reference group

Table 5. Results of step 2 of the logistic regression analysis with participation at Time 3 as the dependent variable

Variables[a]	OR	95% CI	Wald χ^2	*P* Value
Gender	0.90	0.44-1.83	0.09	.77
Age	*1.04*	*1.01-1.06*	*7.99*	*.01*
Medium education[b]	2.84	0.92-8.78	3.28	.07
High education[b]	*4.69*	*1.44-15.22*	*6.61*	*.01*
Ethnicity (0 = non-native Dutch; 1 = native Dutch)	0.96	0.45-2.05	0.01	.92
Recruitment through other website[c]	1.07	0.46-2.48	0.03	.87
Recruitment through newspaper[c]	1.66	0.34-8.22	0.39	.53
Recruitment through family, friends, co-workers[c]	1.44	0.19-11.20	0.12	.73
Recruitment through television[c]	1.49	0.55-4.00	0.62	.43
Health motivation	1.13	0.69-1.85	0.22	.64
Physical activity	1.00	1.00-1.01	0.25	.62
Positive affective user experience	*1.64*	*1.12-2.39*	*6.56*	*.01*
Negative affective user experience	0.88	0.67-1.15	0.91	.34
Cognitive user experience	1.06	0.71-1.59	0.09	.77
Attitude	0.90	0.54-1.52	0.15	.70
Intention	0.97	0.70-1.34	0.03	.86

[a] Significant effects (*P* < .05) are indicated by italics.

[b] “Low education” as reference group

[c] “Other” as reference group

Discussion

The aim of the present study was to identify demographic, psychological and behavioral determinants of exposure to an online health-communication program advocating physical activity.

Visiting

The results concerning visiting the website revealed that most participants were women and that, in comparison to the total Dutch population, our sample was highly educated. Almost half of our participants were recruited through links on related websites, suggesting that for online health-communication interventions, the Internet can be a valuable place for recruitment but that additional methods may be needed to attract more men and lower educated adults.

Using

First, with regard to continued use, our results showed that native Dutch participants completed more pages than nonnative participants. It is unclear why nonnative visitors were less likely to use the program than native Dutch visitors. More research is needed to identify the needs of specific ethnic populations and the potential reasons for limited usage of health-promoting programs in this group. Ethnic targeting (see for instance [39]) may be a powerful tool to increase exposure rates in specific ethnic populations.

Second, participants who were highly motivated to live a healthy lifestyle were more likely to use the program. This suggests that when people are sufficiently motivated to live a healthy lifestyle, they will be more likely to search the Internet for specific health-related information such as computer-tailored advice. To reach individuals with a weak health motivation, it is conceivable that other types of content that relates to the interests of these individuals but does not necessarily relate to health may be used to attract this target group. If participants’ attention can be attracted with non health-related content, this might make it easier to engage people who are not intrinsically motivated to live a healthy lifestyle. Social marketing strategies may contribute to the development of appealing health-communication websites because, in marketing, much effort is expended to understand the needs of target groups and to create an exchange in which these needs can be fulfilled [40,41].

Revisiting

Our analyses of revisiting at Time 3 showed that age predicted participation at the three-month follow-up: older participants were more likely to participate at Time 3. These results suggest that it can be especially difficult to obtain high exposure rates when targeting online health-promoting programs at young people. Since young people mainly use the Internet for getting in touch with friends and potential friends and chatting [42], research is needed to explore the potential of health-communication programs that aim to make participation more attractive by including possibilities for social interaction. Furthermore, highly educated participants were more likely to participate at Time 3 than participants with a low education.

Future research should investigate how we can design online interventions that are interesting for people with a low education level. Here as well, social marketing principles [40,41] may be helpful.

Our last finding might offer an additional answer to this question. We found that participants were more likely to revisit the program when an earlier visit had resulted in positive feelings whereas there was no significant effect of cognitive user experience on revisiting. This underlines the importance of user experience [28] but suggests that affective experiences might be more important than cognitive experiences. It is also in line with the assertion that an important attraction of the Internet constitutes its vast possibilities for "gratification" [43]. The next question is which elements in the online content produced high levels of positive affective user experience. Future research could investigate which strategies are most effective in increasing positive affect and whether increasing positive affect can result in increased exposure. Positive framing of health-related information might be one way of achieving this [44,45]. Future studies should investigate whether information framing or other techniques, such as cartoons or clips, can be helpful in increasing exposure by eliciting positive feelings. Perhaps this can be of particular use to attract people with a low education level.

Strengths and Limitations

A strength of the present study is the fact that we obtained a sample of participants from the general population and observed them in a real-life health-communication context, which contributes greatly to the ecological validity of our findings. Furthermore, our main outcome measures, visiting, using, and revisiting, did not depend on self-report measures but were objectively assessed.

One limitation of our study was the fact that our sample was predominantly female and modest in size. A more representative and larger sample could have contributed to greater validity and could have provided us with more certainty with regard to whether the results can be generalized. However, the fact that the online intervention investigated in the study attracted more women than men can in itself be an interesting result, suggesting that women are more interested in online health-promoting programs than men (see [46] for similar results). Also, a power calculation showed that the study had adequate power to detect significant effects.

A second limitation of our study was the fact that the intervention that we used was relatively simple, consisting of questionnaires and tailored advice at two points in time. Future studies could offer visitors a much wider range of possibilities, varying from watching videos to participating in chat-boxes. By objectively tracking visitors in such interventions, researchers can obtain more sophisticated information on the determinants of exposure.

A further issue concerns our investigation of continued use. Several questions from the Time 1 questionnaire (ie, demographic variables, mode of recruitment, and health motivation) were included solely for the sake of the study and were not used in the tailored feedback. It could be argued that a lack of interest in answering these questions could have caused participants to drop out of the study. This would then not be an accurate reflection of poor continued use of a health website. Future studies could employ shorter questionnaires or limit questionnaires to contain only questions that are relevant to the tailored feedback. We note, however, that for any tailored intervention, it is essential that visitors continue the program long enough to be able to finish the necessary questions. Even though in the present study not all questions were used for the tailored feedback, we argue that our measure of continued use served as a useful proxy for continued use of online tailored health-promoting programs.

Another potential limitation may have been the fact that a reminder was sent to participants after three months. It is unclear whether participants revisited the intervention because they remembered the intervention or because of the reminder. The reminder email thus constituted a confounding factor. Yet, many online health-promoting programs make use of prompts or reminders by email [47]. It is therefore of interest to investigate predictors of revisiting under such conditions. Future studies could employ an experimental design, in which reminders are sent to only half of the participants, to investigate whether predictors of revisiting are similar when participants receive a reminder versus when no reminder is sent.

A final limitation was the fact that we used an observational design. Research using experimental manipulations aimed to influence exposure rates can offer stronger grounds for the causality of the effects. In a recent study, for instance, Albarracín and colleagues [48] experimentally tested the effects of procedures aiming to increase exposure, called "meta-interventions" by the authors. They found that when the intervention was introduced to potential participants in a way that left them some degree of choice as to whether participants would want to change their health-related behavior, the intervention attracted more participants than when the intervention was introduced as highly effective in changing behavior. Future research should further explore the effectiveness of such meta-interventions. Based on the results of the present study, these interventions could be targeted specifically at men, immigrant groups, young people, people with a low education level, and people with a weak health motivation.

Conclusion

The Internet offers vast possibilities for health-communication efforts. Unfortunately, online health-communication interventions are characterized by low exposure rates. The present study sought to investigate predictors of visiting, using, and revisiting to increase our knowledge of exposure to online interventions. The results showed that women were more likely to visit the website than were men. Furthermore, native Dutch participants and participants with a strong health motivation were most likely to continue usage of the website. Older participants, highly educated participants, and participants who reported high levels of positive affective user experience were most likely to revisit the website. Online health-communication interventions could be specifically targeted at men, young people, immigrants, and people with low education levels.

Engaging non health-related content might be used to attract the attention of those people who are not intrinsically motivated to live a healthy lifestyle. Furthermore, it is important that interventions offer participants sufficient opportunities for enjoyment.

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Conflicts of Interest

None declared

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Abbreviations

IPAQ: International Physical Activity Questionnaire

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Original Paper

Demographic, Behavioral, and Psychosocial Correlates of Using the Website Component of a Worksite Physical Activity and Healthy Nutrition Promotion Program: A Longitudinal Study

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Abstract

Background: Internet-delivered behavior change programs have the potential to reach a large population. However, low participation levels and high levels of attrition are often observed. The worksite could be a setting suitable for reaching and retaining large numbers of people, but little is known about reach and use of Internet-delivered health promotion programs in the worksite setting.

Objective: This study aimed (1) to gain more insight in the use of the website component of a worksite behavior change intervention and (2) to identify demographic, behavioral, and psychosocial factors associated with website use.

Methods: The study was an observational study among participants from 5 workplaces in a cluster randomized controlled trial. At baseline, all participants visited a study website to fill out the baseline questionnaire. Then a physical health check was done followed by face-to-face advice. After this contact, all participants received an email to promote visiting the website to view their health check results and the personal advice based on the baseline questionnaire. In the subsequent period, only participants in the intervention group received monthly email messages to promote website visits and were offered additional Web-based tools (self-monitors and a food frequency questionnaire [FFQ] assessing saturated fat intake) to support their behavior change. Website use was monitored by website statistics registering website access. Complete data were available for 726 employees. Logistic regression analyses were conducted to identify characteristics of employees who visited and used the website.

Results: In total, 43% of the participants visited the website after the email to promote website visits. Participants who were insufficiently physically active were less likely to visit the website (odds ratio [OR] 0.63, 95% confidence interval [CI] 0.45-0.88), whereas individuals with an elevated total cholesterol level visited the website more often (OR 1.44, 95% CI 1.05-1.98). The monthly emails in the intervention group resulted in higher website use during a 3-month period (18% versus 5% in the reference group, OR 3.96, 95% CI 2.30-6.82). Participants with a positive attitude toward increasing physical activity were less likely to visit the website (OR 0.54, 95% CI 0.31-0.93) or to use the self-monitor and FFQ (OR 0.50, 95% CI 0.25-0.99). Female workers visited the website more often to monitor their behavior and to receive advice on fat intake (OR 2.36, 95% CI 1.14-4.90).

Conclusions: Almost half of the participants used the website component of a worksite behavior change program. Monthly emails were a prompt to visit the website, but website use remained low. More women than men used the website to obtain personalized advice for behavior change. No consistently higher participation was found among those with healthier behaviors. This health promotion program did not provide an indication that healthier subjects are more susceptible to health promotion.

Trial Registration: ISRCTN52854353; http://www.controlled-trials.com/ISRCTN52854353 (Archived by WebCite at http://www.webcitation.org/5smxIncB1)

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KEYWORDS

Internet; physical activity; nutrition; behavior change; selective retention; workplace

Introduction

There are indications that Internet-delivered interventions may be effective in improving physical activity, healthy nutrition, and weight reduction [1-5]. Internet-delivered programs have the potential to reach a large population at relatively low costs. However, low participation levels and high levels of attrition are often observed in those programs [5-8]. These rates are of concern since studies with a higher utilization tend to have better behavior change outcomes [5]. The RE-AIM framework stresses the importance of evaluating the reach and representativeness of program participants [9], and Eysenbach [6] and Danaher et al [10] have emphasized the need to address process measures in addition to the effectiveness of Internet-delivered programs. The worksite has been identified as a promising setting to reach large numbers of people in a natural social network, which may increase participation [11,12]. However, the reach and use of Internet-delivered programs in the worksite setting are largely unknown.

In contrast with the high levels of attrition in the general population, Ware et al [13] studied an intervention consisting of an Internet-delivered program at the worksite with an initial face-to-face contact and found a repeated participation over a 12-week period of 69%. Several studies on Internet-delivered behavior change programs suggested that women, people who are more highly educated, and people with positive health behaviors participate more often in Internet-delivered health promotion programs compared with the general population [8,14-16]. However, there are also studies indicating that Internet-delivered programs have attracted individuals who would benefit most from them, that is, participants who are overweight [8,13,16]. It has also been suggested that the provision of regular new content and the possibility to monitor progress toward behavior change could be important factors in encouraging website use [17,18]. Furthermore, a recent review reported several studies with enhanced effectiveness after frequent email prompts [19].

It has been indicated that participants may not be ready to rely solely on Internet-delivered programs [5]. The worksite setting, in which it is feasible to combine face-to-face contact and regular emails, may, therefore, be a good setting for the implementation of interventions. Therefore, we expect that providing an Internet-delivered lifestyle program in the workplace setting with an initial face-to-face contact, a behavior change monitor functionality, and monthly email messages will enhance program use.

More insight into these specific program characteristics could provide information on ways to attract visitors to an Internet-delivered health promotion intervention and to keep them using the program. The aim of the present study is to gain more insight into the use of a website component of a worksite intervention, in order to be able to identify factors related to website use and intervention components that may enhance use. Therefore, the present study investigates the demographic, behavioral, psychosocial, and health-related factors in relation to program use in an Internet-delivered program with a face-to-face contact at the worksite.

Methods

Design, Participants, and Recruitment

An observational study was conducted from March 26, 2008, until February 9, 2009. Participants were employees from 5 different workplaces: 2 companies engaged in commercial services, 2 in health care, and 1 executive branch of government. The participants had enrolled in a 2-year cluster randomized controlled trial in which the departments (64) within these 5 workplaces were the units of randomization. An extensive description of this larger worksite lifestyle promotion program primarily aimed at physical activity and nutrition is described elsewhere [20]. The study was announced through email, the company's intranet and/or a company magazine. In the 2 commercial services companies, all employees directly received an email from a health management organization that had implemented the intervention in which employees were invited to visit the study website. For the other workplaces, interested employees could express their interest in participating in the study through email. These 3 workplaces restricted the maximum number of participants in such a way that the first 200 (2 workplaces) or 300 (1 workplace) interested employees were allowed to participate. Participants enrolled in the study when they visited the website and completed the baseline questionnaire. Participation levels varied from 3% to 61% of all workers per workplace, with a median participation level of 10%. The number of participants per workplace ranged from 33 to 270 (median 175), and workplace sizes varied from 70 to more than 5000 employees (median 1706). Complete data on individual characteristics, behaviors, and health were available for 726 employees. The Medical Ethics Committee of Erasmus MC, University Medical Center in Rotterdam, the Netherlands, approved the study and all participants gave written informed consent.

Figure 1. Screenshot of the website

Mijn HealthGuard

U bent nu ingelogd. Op deze pagina's treft u informatie, tips en adviezen voor uw persoonlijke gezondheid. Via het menu in de rechter kolom kunt u gebruik maken van de interactieve mogelijkheden van HealthGuard. Hier vindt u de vragenlijsten en tests als deze aan u zijn toegewezen, en voor u bestemde berichten.

Via het menu rechtsboven kunt u naar:

Mijn Gezondheid

Via 'Mijn gezondheid' neemt u deel aan de HealthGuard Monitor en verschillende quick tests. Uit uw resultaten en scores volgen persoonlijke rapporten die u direct inzicht geven in uw eigen gezondheid, leefstijl en fitness. Hierover kunt u advies vragen aan een van uw HealthGuard professionals.

Leefstijl

Onder het kopje Leefstijl, vindt u informatie over alles wat u zelf kunt doen om uw gezondheid positief te beïnvloeden. En dat kan eenvoudiger en plezieriger dan u misschien denkt! Leefstijl bevat de onderdelen Bewegen & Sporten, Eten & Drinken, Stress & Ontspanning.

Procedure

All participants visited the study website by using an individualized username and password to fill out the baseline questionnaire and to make an appointment for a physical health check (Figure 1). The health check took place at the workplace and consisted of measurement of height, weight, waist circumference, total cholesterol level, blood pressure, and a bicycle test to estimate maximum oxygen uptake. Immediately after the health check, all participants received an overview of their test results in print. These results were discussed with the participants, and each participant received advice on how to improve or maintain their lifestyle in a face-to-face contact. Participants who were prehypertensive or who had an elevated cholesterol level were advised to visit their general practitioner or the occupational physician. The physical health check took one hour, and workers were allowed to participate during their regular work hours. The test reports were also provided on the study website together with personal advice based on participants' answers on the baseline questionnaire. After all participants in one workplace had completed the health checks, all participants were invited through an email message to visit the website to view their health check results and the personal advice based on the baseline questionnaire (see Figure 2, period 1). The personal advice provided on the website corresponded with the advice in the face-to-face contact and was provided in a structured and reproducible way.

Reference Group

Participants in the reference group had access to their physical health results and reports based on the online questionnaire. These reports consisted of their personal physical activity level and fruit and vegetable intake level and information on the recommended levels. The website provided general lifestyle and health information.

Intervention Group

Participants in the intervention group had access to several additional website functionalities compared with participants in the reference group. Participants in the intervention group received more extensive computer-tailored advice on their self-reported physical activity and nutrition behavior on the questionnaire. The electronically generated advice included personal and action feedback taking into account perceived barriers for participants not meeting the guidelines [20,21]. Perceived barriers were assessed by asking for the most important barrier to engaging in the specific lifestyle behavior.

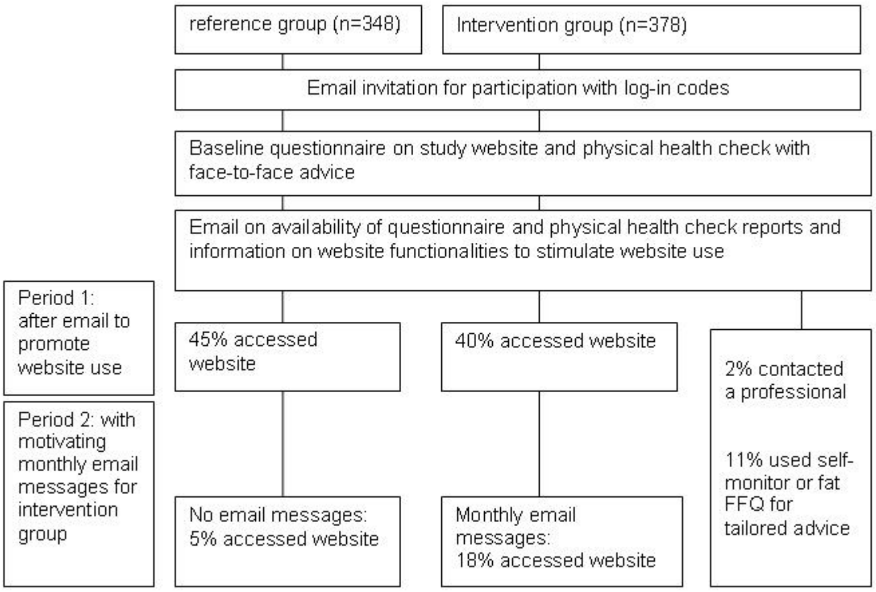
In addition, participants had the opportunity to use the following intervention strategies: (1) online self-monitoring of fruit and vegetable intake, physical activity, and weight to monitor progress toward behavior change and obtain tracking charts; (2) a food frequency questionnaire (FFQ) assessing saturated fat intake for tailored advice (after third email message) [22]; and (3) the ability to ask questions of several professionals.

Finally, to stimulate sustained website use, participants in the intervention group received motivating monthly email messages focusing on physical activity and nutrition. Participants received their first motivating email message 1 month after they received an email to visit the website to view their health check results and the advice based on the baseline questionnaire. With the motivating email messages, the second important period of the website component started (see Figure 2, period 2). Period 2 covered 3 monthly email messages focusing on physical activity and nutrition (duration of 12 weeks). The first monthly email message was tailored to the individual, and if new information was available through the self-monitors, the subsequent email was personalized again. If no new information from the participant was available, the emails contained more general information. The third message announced the opportunity to fill out the fat FFQ for tailored advice. In all monthly email messages, participants were encouraged to fill out the self-monitors and to ask their questions. The monthly email messages were written by a researcher (author SR).

Website Use

Participants had to log in to the website using their personal login details to access their individual reports as well as to read general information on health and lifestyle. All website visits were registered, and for both period 1 and period 2, a variable for website visit (yes/no) was calculated for all the participants. Website use in period 1 was determined as at least 1 website visit within the month after the email was sent to promote website use. Website use in period 2 was determined as at least 1 website visit within 3 months after the first motivating monthly email message to the intervention group. For participants in the intervention group, self-monitor use and fat FFQ use were defined as using these features at least once in period 1 or period 2.

Figure 2. Study design with the two distinct periods for website use



Demographic Characteristics

In the baseline questionnaire, participants were asked about age, sex, education, marital status, and ethnicity. Educational level was assessed as the highest level of education completed and was categorized into low (primary school, lower and intermediate secondary schooling, or lower vocational training), intermediate (higher secondary schooling or intermediate vocational schooling) and high (higher vocational schooling or university). We applied the standard definition of ethnicity of Statistics Netherlands and considered a person to be nonDutch if at least one parent was born abroad [23].

Lifestyle Behavior and Health Indicators

Physical activity level was measured in the baseline questionnaire using the self-administered short version of the International Physical Activity Questionnaire (IPAQ) [24], which assessed vigorous and moderate intensity physical activity. The average time spent on physical activity per day was calculated. For all behaviors we calculated a dichotomous variable for compliance or noncompliance with recommendations. For physical activity level, we used a cutoff point of 30 minutes or more per day. We did not include walking in this calculation since walking at a casual pace is regarded a light-intensity activity [25].

For fruit and vegetable intake, 400 grams of fruit and vegetable intake as measured with a self-administered 9-item validated Dutch Food Frequency Questionnaire was used as cutoff point [26]. Smoking was defined as current smoking status and excessive alcohol use as drinking at least 6 glasses on the same occasion at least once a week. The Short Form-12 (SF-12) questionnaire was used to measure self-reported general, physical, and mental health [27]. General health was dichotomized into “poor or moderate” and “good to excellent.” Physical and mental health were categorized as poor if the summed scores were in the lowest quartile (lower than 48.74 and 46.56, respectively).

Physical Health Check

In the physical health check, height and weight were measured to calculate body mass index (BMI) and to categorize individuals as normal weight (BMI < 25 kg/m^2) or overweight (BMI ≥ 25 kg/m^2). Total blood cholesterol was measured in nonfasting blood through a finger prick (Accutrend GC, Roche Company, Mannheim, Germany), and blood pressure with a fully automated sphygmomanometer (Omron M4-I, Omron HealthCare Europe BV, Hoofddorp, the Netherlands). A total cholesterol level above 5.0 mmol/l and a systolic or diastolic blood pressure above respectively 140 mmHg and 90 mmHg were considered elevated. A submaximal exercise test on a bicycle ergometer was conducted to predict maximal oxygen uptake according to the American College of Sports Medicine's (ACSM) protocol using their sex- and age-dependent cutoff points [28].

Social Cognitive Variables

For physical activity and for fruit and vegetable intake, attitude, social support, self-efficacy, and intention to change were measured in the baseline questionnaire. Intention, self-efficacy, and attitude were measured on a 5-point Likert scale ranging from "certainly not" to "certainly." All variables were dichotomized. Intention was measured by asking if the participant intended to change the behavior in the next month [29]. A high intention was defined as probably or certainly intending to change the behavior. Self-efficacy was assessed by asking if the participant was confident about engaging in the healthy behaviors in the next month [29]. High self-efficacy was defined as probably or certainly confident about changing the behavior. To measure attitude, individuals were asked if they thought improving the behavior would take a lot of effort [30]. Those participants who answered "probably not" or "certainly not" were considered as having a positive attitude. Finally, social support was measured by asking if family and friends support them in changing the specific behaviors. This was measured on a 4-point Likert scale ranging from "seldom or never" to "a lot" [29]. High social support was defined as perceiving "pretty much" support or "a lot" of support.

Statistical Analyses

Descriptive statistics were used to present the baseline characteristics of the study population. The associations of demographic characteristics, behaviors, social cognitive variables, and health indicators with website use were investigated with logistic regression analysis. Separate analyses were conducted for website use in period 1 among the total study population and website use in period 2 among the intervention group. First, univariate logistic regression models were carried out to determine the single effects of the possible determinants. All variables with a *P* value less than .20 in the univariate models were considered for inclusion in the multivariate analysis. A backward regression method was used to determine the multivariate model. In the analyses, age and sex were included by default in each multivariate model. Variables with a *P* value of .05 or less were retained in the multivariate model. The results are presented as the odds ratios (OR) and corresponding 95% confidence intervals (95%CI), with odds ratios below and above 1 representing, respectively, lower and higher website use. All analyses were carried out with SPSS version 15.0 (SPSS Inc, Chicago, IL, USA).

Results

Study Population

In total, 726 employees participated in this study. The baseline characteristics of the study population are presented in Table 1. More than half of the participants (403, 56%) were female workers. The mean age of the study population was 42 years, ranging from 20 to 63 years, and 47% (341) had had higher education. Almost a third of the participants (223, 31%) were not physically active at a moderate intensity for at least 30 minutes per day, and 45% (323) had insufficient fruit and vegetable intake. Complying with the moderate intensity physical activity guideline was associated with sufficient fruit and vegetable intake (not in table). More than half of the participants who did not met the physical activity guideline for moderate intense physical activity had the intention to increase physical activity (122/223, 55%), compared with 45% (225/503) of the participants who did comply with the guideline. For fruit and vegetable intake, 22% (71/323) of the participants who did not meet the recommendation and 13% (52/403) of the participants who did, intended to increase fruit and vegetable intake. Participants complying with the guidelines were more likely to have a positive attitude. No association was found between self-efficacy and complying to the recommended levels for physical activity and fruit and vegetable intake (not in table).

Website Visit

After the first email message, 43% of all the participants visited the website component of the program; 45% (157/348) of the participants in the reference group and 40% (152/378) in the intervention group (odds ratio [OR] 0.82, 95% confidence interval [CI] 0.61-1.10). In the following three months in which the intervention group received a monthly email message, 18% (67/378) of the participants in the intervention group visited the website again compared with 5% (18/348) in the reference group (OR 3.96, 95% CI 2.30-6.82).

Table 1. Baseline characteristics of the total study population and the intervention group in a longitudinal study among 726 employees

	Total Study Population (n = 726)		Intervention Group (n = 378)		Reference Group (n = 348)	
	n	%	n	%	n	%
Demographics						
Female gender	403	56%	209	55%	194	56%
Age (years)						
<30	100	14%	56	15%	44	13%
30-39	203	28%	94	25%	109	31%
40-49	228	31%	112	30%	116	33%
50+	194	27%	115	31%	79	23%
Education level						
Low	131	18%	60	16%	71	20%
Intermediate	253	35%	131	35%	122	35%
High	341	47%	186	49%	155	45%
Dutch ethnicity	615	85%	319	85%	296	85%
Married/cohabiting	547	75%	285	76%	262	75%
Behavior						
Insufficient moderate physical activity	223	31%	115	31%	108	31%
Insufficient vigorous physical activity	502	69%	258	68%	244	70%
Insufficient fruit or vegetable intake	323	45%	159	42%	164	47%
Smoking	117	16%	60	16%	57	17%
Excessive alcohol	27	4%	13	3%	14	4%
Social cognitive variables						
Physical activity						
Positive attitude	355	49%	197	52%	158	45%
High social support	112	15%	55	15%	57	16%
High self-efficacy	562	77%	288	76%	274	79%
Intention to increase physical activity	348	48%	167	44%	181	52%
Fruit and vegetable intake						
Positive attitude	510	70%	265	70%	245	71%
High social support	91	13%	46	12%	45	13%
High self-efficacy	599	83%	319	84%	280	81%
Intention to increase intake	124	17%	68	18%	56	16%
Health indicators						
Overweight/obese	293	40%	152	40%	141	41%
Poor/moderate general health	39	5%	17	5%	22	6%
Lowest quartile mental health	181	25%	97	26%	84	24%
Lowest quartile physical health	181	25%	90	24%	91	26%
Elevated blood pressure	217	30%	113	30%	104	30%
Elevated total cholesterol level	301	42%	161	43%	140	41%
Poor predicted maximum oxygen uptake	90	13%	43	12%	47	15%

Correlates of Website Visit

As shown in the univariate analysis in Table 2, older employees (OR 1.89, 95% CI 1.15-3.13), those with a positive attitude toward increasing physical activity level (OR 1.36, 95% CI 1.01-1.83), and those with an elevated cholesterol level (OR 1.51, 95% CI 1.12-2.04) were more likely to visit the website after the first email message, and participants with insufficient moderate-intensity physical activity (OR 0.66, 95% CI 0.47-0.91) were less likely to do so. In the multivariate analysis, sufficient moderate physical activity (OR 0.64, 95% CI 0.46-0.90 for insufficient physical activity) and an elevated cholesterol level (OR 1.44, 95% CI 1.05-1.98) remained significantly associated with website visit in period 1. Attitude to increase physical activity did not remain statistically significant in the multivariate analysis (OR 1.34, 95% CI 0.98-1.82). Table 3 shows that among the participants in the intervention group, those with a positive attitude toward increasing their level of physical activity (OR 0.57, 95% CI 0.33-0.97) and fruit and vegetable intake (OR 0.55, 95% CI 0.32-0.96) were less likely to visit the website in the period with monthly email messages. In the multivariate analysis, only attitude toward increasing physical activity level (OR 0.54, 95% CI 0.31-0.93) remained statistically significant.

Table 2. Univariate and multivariate odds ratios and 95% confidence intervals of individual characteristics, behaviors, social cognitive variables, and health indicators for visiting the website in the first period after the health check (n = 726)

	Univariate Analysis		Multivariate Analysis	
	OR	95% CI	OR	95% CI
Demographics				
Female gender	0.93	0.69-1.25	1.00	0.74-1.36
Age (years)				
<30	1.00		1.00	
30-39	1.35	0.82-2.23	1.35	0.81-2.24
40-49	1.35	0.83-2.21	1.18	0.72-1.96
50+	1.89[b]	1.15-3.13	1.65	0.97-2.79
Education level				
Low	0.92	0.62-1.39		
Intermediate	0.76[a]	0.55-1.06		
High	1.00			
Dutch ethnicity	0.96	0.64-1.45		
Married/cohabiting	1.34[a]	0.94-1.89		
Behavior				
Insufficient moderate physical activity	0.66[b]	0.47-0.91	0.64[b]	0.46-0.90
Insufficient vigorous physical activity	1.01	0.73-1.39		
Insufficient fruit or vegetable intake	1.01	0.75-1.36		
Smoking	0.71[a]	0.47-1.07		
Excessive alcohol consumption	0.83	0.37-1.85		
Social cognitive variables				
Physical activity				
Positive attitude	1.36[b]	1.01-1.83		
High social support	0.84	0.55-1.27		
High self-efficacy	1.00	0.71-1.43		
Intention to increase physical activity	1.11	0.83-1.49		
Fruit and vegetable intake				
Positive attitude	1.22	0.88-1.69		
High social support	0.97	0.62-1.52		
High self-efficacy	0.89	0.60-1.31		
Intention to increase intake	0.70[a]	0.47-1.05		
Health indicators				
Overweight/obese	0.96	0.71-1.30		
Poor/moderate general health	1.29	0.68-2.46		
Lowest quartile mental health	1.18	0.84-1.66		
Lowest quartile physical health	0.97	0.69-0.37		
Elevated blood pressure	0.82	0.59-1.13		
Elevated total cholesterol level	1.51[b]	1.12-2.04	1.44[b]	1.05-1.98
Poor predicted maximum oxygen uptake	0.83	0.53-1.31		

[a] $P < .20$, considered for inclusion in the multivariate logistic regression analysis

[b] $P < .05$

Table 3. Characteristics of the intervention group and univariate and multivariate odds ratios and 95% confidence intervals of individual characteristics, behaviors, social cognitive variables, and health indicators for visiting the website in the second period in the intervention group (n = 378)

	Univariate Analysis		Multivariate Analysis	
	OR	95% CI	OR	95% CI
Demographics				
Female gender	1.32	0.77-2.27	1.35	0.78-2.33
Age (years)				
<30	1.00		1.00	
30-39	0.97	0.39-2.39	1.02	0.41-2.54
40-49	1.26	0.54-2.97	1.47	0.62-3.52
50+	1.14	0.49-2.69	1.37	0.57-3.28
Education level				
Low	0.57	0.24-1.36		
Intermediate	1.04	0.59-1.84		
High	1.00			
Dutch ethnicity	1.05	0.50-2.20		
Married/cohabiting	1.01	0.54-1.87		
Behavior				
Insufficient moderate physical activity	1.06	0.60-1.87		
Insufficient vigorous physical activity	0.86	0.49-1.51		
Insufficient fruit or vegetable intake	1.45[a]	0.85-2.46		
Smoking	0.46[a]	0.19-1.13		
Excessive alcohol consumption	0.41	0.05-3.24		
Social cognitive variables				
Physical activity				
Positive attitude	0.57[b]	0.33-0.97	0.54[b]	0.31-0.93
High social support	0.80	0.36-1.78		
High self-efficacy	0.83	0.45-1.51		
Intention to increase physical activity	1.11	0.65-1.89		
Fruit and vegetable intake				
Positive attitude	0.55[b]	0.32-0.96		
High social support	0.42[a]	0.14-1.20		
High self-efficacy	1.07	0.51-2.25		
Intention to increase intake	0.89	0.44-1.80		
Health indicators				
Overweight/obese	1.27	0.75-2.17		
Poor/moderate general health	0.99	0.28-3.54		
Lowest quartile mental health	0.65[a]	0.34-1.24		
Lowest quartile physical health	1.01	0.55-1.89		
Elevated blood pressure	0.75	0.41-1.38		
Elevated total cholesterol level	0.89	0.52-1.52		
Poor predicted maximum oxygen uptake	0.56	0.21-1.47		

[a] *P* < .20, considered for inclusion in the multivariate logistic regression analysis

[b] $P < .05$

Use of Interactive Website Elements in the Intervention Condition

Of the website visitors in the intervention group, 11% (41/378) used the self-monitors or the FFQ, and 2% (8/378) contacted a professional via the website (Figure 2). Table 4 shows that female workers were more likely to use the self-monitor or fat FFQ compared with male workers (OR 2.36, 95% CI 1.14-4.90). As for website use in period 2, those workers with a positive attitude toward increasing their physical activity level were less likely to visit the website to use the specific website functionalities (OR 0.50, 95% CI 0.25-0.99).

Table 4. Univariate and multivariate odds ratios and 95% confidence intervals of individual characteristics, behaviors, social cognitive variables, and health indicators for self-monitor and fat FFQ use in the intervention group (n=378)

	Univariate Analysis		Multivariate Analysis	
	OR	95% CI	OR	95% CI
Demographics				
Female gender	2.41[b]	1.17-4.96	2.36[b]	1.14-4.90
Age (years)				
<30	1.00		1.00	
30-39	0.93	0.34-2.55	0.99	0.36-2.77
40-49	0.92	0.35-2.45	1.09	0.40-2.98
50+	0.67	0.24-1.86	0.85	0.30-2.43
Education level				
Low	0.87	0.34-2.28		
Intermediate	0.94	0.46-1.93		
High	1.00			
Dutch ethnicity	1.77	0.61-5.17		
Married/cohabiting	1.00	0.47-2.13		
Behavior				
Insufficient moderate physical activity	1.21	0.61-2.40		
Insufficient vigorous physical activity	1.00	0.50-2.01		
Insufficient fruit or vegetable intake	1.69[a]	0.88-3.24		
Smoking	0.54	0.19-1.58		
Excessive alcohol consumption	0.68	0.09-5.35		
Social cognitive variables				
Physical activity				
Positive attitude	0.49[b]	0.25-0.96	0.50[b]	0.25-0.99
High social support	0.80	0.30-2.13		
High self-efficacy	0.73	0.36-1.49		
Intention to increase physical activity	1.37	0.72-2.63		
Fruit and vegetable intake				
Positive attitude	0.63[a]	0.32-1.24		
High social support	0.34[a]	0.08-1.46		
High self-efficacy	1.09	0.44-2.72		
Intention to increase intake	1.33	0.60-2.92		
Health indicators				
Overweight/obese	0.94	0.48-1.83		
Poor/moderate general health	1.82	0.50-6.63		
Lowest quartile mental health	0.93	0.44-1.97		
Lowest quartile physical health	1.37	0.67-2.82		
Elevated blood pressure	0.45[a]	0.19-1.05		
Elevated total cholesterol level	1.06	0.55-2.03		
Poor predicted maximum oxygen uptake	1.63	0.67-3.96		

[a] *P* < .20, considered for inclusion in the multivariate logistic regression analysis

[b]$P < .05$

Discussion

In this study, we examined the use of the website component of a worksite physical activity and nutrition promotion program. In total, 43% of the participants visited the website after an email to promote website visits to view their personal health results and the personal advice based on the baseline questionnaire. Participants who did not meet the recommended level of physical activity were less likely to visit the website, whereas individuals with an elevated total cholesterol level were more likely to visit the website. Participants in the intervention group visited the website more often during a 3-month period than those in the reference group (18% versus 5%). Participants with a positive attitude toward increasing physical activity were less likely to use self-monitors for tracking their behavior and to complete the fat FFQ to receive tailored advice. Compared with male workers, more female workers visited the website to monitor their behavior and/or weight or to receive tailored advice on fat intake.

Website Visits

Compared to previous studies, website visiting after the first email reminder was relatively high [6,8]. The face-to-face contact may have had a positive influence and may be one of the reasons for the relatively high initial number of visitors. However, website use was not optimal, since it was intended that all participants would visit the website. By not using the website component, a substantial part of the study group was not exposed to the content provided on the website. Leslie et al [31] found in a study investigating a physical activity website in the workplace setting that a comparable 46% of the participating employees visited the website at least once. There are studies, however, that have found higher levels of website usage. Ware and colleagues [13], for example, found in a study with a face-to-face contact and an Internet-delivered physical activity and weight management program that 78% of the participants were still using the website after 12 weeks. An important difference between our study and the study of Ware and colleagues is the role of the initial contact. In our study, the face-to-face contact consisted of feedback of test results and personal advice, while in the study of Ware it was a screening and an information session on how to use the Internet-delivered program. One of the explanations for the lower usage level in our study may be that people participated in the study primarily to get insight into their health status (cholesterol level and blood pressure) and that they were less interested in changing their behavior. The fact that participants could visit the website component after a series of tests and advice based on these tests in a face-to-face contact may have made it less relevant for them to visit the website to review their results and to obtain additional advice and information about a healthy lifestyle. Another explanation might be a lack of new content on the website. It has been suggested by experts as well as potential users that the provision of regular new content could be an important factor in encouraging website use [17,18].

Correlates of Website Visits

Participants with an elevated cholesterol level were more likely to visit the website, which may indicate that visiting the website component was relevant for participants with less favorable test outcomes. In contrast, in the month after the email to promote website use was sent, individuals meeting the physical activity guideline were more likely to visit the website. Verheijden et al [8] also reported contradictory findings, with more participation among people with healthier lifestyles and among overweight or obese participants. It could be hypothesized that those with poorer outcomes on health indicators had a higher risk perception as compared with those not complying with lifestyle recommendations. However, elevated cholesterol level was the only health indicator associated with website use, and this finding was not corroborated by other health indicators such as blood pressure and self-reported health and, thus, the finding that elevated cholesterol level was associated with website use may be spurious. The finding that participants not meeting the physical activity guideline were less likely to use the website might be related to the communication to encourage the individual to change their behavior. However, this lower website use was only found in the first period and not in the period with monthly email messages. Based on our results, no consistent higher participation was found among those with healthier behaviors, and, thus, a health-based selection in website use could not be demonstrated.

Use of Interactive Website Elements in the Intervention Condition

In line with other studies, we found that Internet access in the following 3 months was low [5-8]. Even though the 3 email reminders sent in this period resulted in a higher percentage of website visits compared with the reference group, only 18% visited the website. The difference between the reference group and the intervention group provides evidence that monthly email messages function as a prompt to visit the website; however, it may be a weak prompt. Ware et al found a high repeated participation with an Internet-delivered program using an accelerometer and weighing scale as monitoring devices [13]. The availability of such devices might increase compliance with the use of self-monitors. Experts have suggested that the possibility to monitor progress could be a factor to encourage website use [17]. In a focus group, study participants mentioned that the possibility of asking questions on a website for behavior change would increase use [32]. However, the findings of our study do not seem to support these notions. We do not know, however, why participants visited the website again in the 3-month period. Additional qualitative information of website use may shed more light on this in future studies.

Participants with a positive attitude (ie, those who thought that it would not take a lot of effort to increase physical activity and fruit and vegetables intake) were less likely to track their behavior or to obtain tailored advice on fat intake. This may indicate that they did not need the website component to visit it again. Whereas women and men did not differ with respect to website visits, more women used the website to track their behavior or to obtain tailored advice on fat intake. In a systematic review on participation in worksite health promotion programs, a higher initial participation among female workers was found except for programs offering access to a fitness centre [33]. Other studies have also reported a higher participation among women in Internet-delivered programs [2,8,34]. This may be explained by a higher interest in health issues among women [14].

Limitations

This study has some limitations. First, 2 measures of website use are reported: website access and the use of a self-monitor and a fat questionnaire to obtain tailored advice. These measures do not provide any information as to what extent the participants actually read the available information or how much time they spent on the website. Second, because of the combination of the website component with a face-to-face contact, we cannot generalize the results to website use of programs without face-to-face contact in the worksite settings. Third, departments within workplaces instead of individuals or workplaces were randomized. Since employees do not share their work space with employees from other departments, we do not think contamination was a major issue in our study. Furthermore, the programs for the intervention and reference groups were quite similar, with both groups having the opportunity to participate in a face-to-face contact and to use the website. Therefore, it would be difficult for a participant to find out that different programs were offered. Fourth, the participation levels as well as the populations of the participating workplaces differed. Not all employees had equivalent access and use of computers and email during their workday. Therefore, we estimated for all occupations in the study population if the work is primarily done using a computer. The group spending a major part of the day with computer work was not found to have an increased website use compared with workers with less or no computer work. Strengths of the study were that the user statistics are linked to the individual level and the availability of objective health indicators.

Conclusion

This study demonstrated that almost half of the participants used the website component of a worksite physical activity and healthy nutrition promotion program in the period after a face-to-face contact with personal advice. Monthly email messages were a prompt to visit the website. However, over the longer term, low use was found in this target group. More women than men used the website to obtain personalized advice for behavior change. No consistent higher participation was found among those with healthier behaviors. This health promotion program did not provide an indication that healthier subjects are more susceptible to health promotion.

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Conflicts of Interest

Dennis Lindeboom is employed at Lifeguard Inc, which developed and has proprietary interests in the program described in this paper. All analyses for the article were supervised and performed by personnel not part of Lifeguard Inc.

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Abbreviations

ACSM: American College of Sports Medicine
BMI: body mass index
FFQ: food frequency questionnaire
IPAQ: International Physical Activity Questionnaire
SF-12: Short Form-12

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Original Paper

Effects Of Internet-Based Tailored Advice on the Use of Cholesterol-Lowering Interventions: A Randomized Controlled Trial

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Abstract

Background: Elevated low-density lipoprotein (LDL) cholesterol is a leading risk factor for cardiovascular disease. Despite the availability of proven interventions to lower LDL cholesterol, their use remains subobtimal. Many websites provide interactive, tailored advice on cardiovascular risk in an attempt to help bridge this evidence-practice gap, yet there is little evidence that provision of such a tool is effective in changing practice.

Objectives: The objective was to define the effects on use of cholesterol-lowering interventions of a consumer-targeted tailored advice website.

Methods: This was a prospective, double-blind, randomized controlled trial open to any adult Australian with access to the Internet. A total of 2099 participants were randomized. Of these, 45% were male, the mean age of all participants was 56, and 1385 (66%) self-reported hypercholesterolemia. Follow-up information was obtained for 1945 (93%). Participants completed a brief online questionnaire. Individuals assigned to intervention received immediate, fully automated, personally tailored advice (based on current guidelines) regarding the need for commencement of statin therapy, increased statin therapy in those already on treatment, and nondrug intervention strategies. Control group participants were directed to static Web pages providing general information about cholesterol management.

Results: The primary outcome was the proportion of participants that commenced or increased use of prescribed cholesterol-lowering therapy. Of the total 2099 randomized participants, 304 (14%) met eligibility criteria for cholesterol-lowering therapy but were not prescribed treatment, and 254 (12%) were prescribed treatment but were not achieving the recommended target level. Treatment was commenced or increased in 64 (6.0%) of the 1062 intervention group participants and 79 (7.6%) of the 1037 control group participants (% difference = -1.6%, 95% confidence interval [CI] -3.75 to 0.57, *P* = .15). No differences were found between the randomized groups for the secondary outcomes of “discussed treatment with a health professional” (% difference = -3.8%, 95% confidence interval [CI] -8.16 to 0.19, *P* = .08), “had their cholesterol checked” (% difference = -1.5%, 95% CI -5.79 to 2.71, *P* = .48), “had their blood pressure checked” (% difference = 1.4%, 95% CI -2.55 to 5.34, *P* = .49) or made a lifestyle change (*P* values between .49 and .96).

Conclusions: Despite providing specific carefully tailored advice, this website had no detectable effect on cholesterol management strategies. This finding raises considerable uncertainty about the value of Internet-based tools providing tailored advice directly to consumers.

Trial Registration: NCT00220974; http://clinicaltrials.gov/ct2/show/NCT00220974 (Archived by WebCite at http://www.webcitation.org/5sdq63rrY)

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KEYWORDS

Heart disease; cholesterol; computers; Internet; World Wide Web; randomized trial

Introduction

An elevated level of low-density lipoprotein (LDL) cholesterol is one of the leading risk factors for cardiovascular disease and has been targeted by the lipid management guidelines of many organizations worldwide [1-3]. Despite proven cost-effectiveness [4,5], the use of cholesterol-lowering interventions remains suboptimal, with many eligible individuals untreated and many of those treated failing to reach the recommended target levels [6-8].

Research has shown that tailored information is more effective than generic communications in influencing health behaviors [9]. Delivery of health information via computer has also been shown to increase efficacy [10]. Widespread community access to the Internet [11] and increasing use of the Internet as a source of information about health [12] provide a novel opportunity for low-cost, Internet-based, community-mediated health care delivery. Previous studies have shown that highly interactive health communications applications that allow multiple interactions with participants over time may have a positive effect on knowledge and social support. In addition, there is some evidence that use of these applications results in improved behavioral and clinical outcomes in people with chronic disease [13]. There is also some evidence that such applications can positively influence behaviors related to cardiovascular risk such as nutrition and physical activity [14].

In the field of cardiovascular prevention, providing tailored behavior change messages has been shown to enhance uptake of information compared with simple provision of health risk information [15], with some websites offering such tailored advice directed at the consumer [16-17]. These websites tend to be simple, without the highly interactive features that have been shown to be effective in changing behavior. If shown to be effective, these simpler websites may help bridge the evidence-practice gap in cardiovascular disease prevention in a more cost-effective manner than larger, more complex Web-based interventions. Studies of simpler, Internet-based applications providing tailored advice in real-life settings have varied in size and effectiveness with more recent, larger studies showing promise [18-21]. At the time of our trial, there were few data that precisely and reliably defined the impact of websites offering simple tailored advice on objective outcomes.

In an attempt to address this research gap, we report here the results of the Internet-based Cholesterol Assessment Trial (I-CAT), which sought to define the effects on cholesterol management of a simple, real-life consumer-mediated website offering tailored advice typical of those available on the Internet. The website provided individually tailored advice to adult Australians about their need for cholesterol-lowering treatment according to established Australian guidelines [22-23].

The primary aim of this trial was to determine the effects on the use of prescribed cholesterol-lowering treatment of access to a website that provided fully automated, individually tailored advice about eligibility for cholesterol-lowering treatment according to established national guidelines. This was compared against access to typical static Web pages. The null hypothesis of no effect of the intervention compared to control on the primary outcome was tested. The secondary aim of the trial was to evaluate whether it was possible to improve the cholesterol management of the friends and relatives of the index participants as measured by the same outcomes.

Methods

The I-CAT was a double-blinded, randomized, controlled trial conducted from October 6, 2004, through July 5, 2006. The trial was approved by the Human Ethics Committee of the University of Sydney with all participants providing informed consent. Aside from mail and telephone contact with initial nonresponders to follow-up, the study was done entirely through a secure website established for the trial with access for participants achieved through use of unique individual usernames and passwords.

Participants and Recruitment

The trial was open to all adults aged 18 years or over resident in Australia, although recruitment strategies were targeted toward individuals likely to require cholesterol-lowering therapy by focusing recruitment initiatives on health care facilities and seniors' organizations. Recruitment was achieved by using a range of approaches including posters, printed and electronic invitations, website links, radio broadcasts, newspaper advertisements, and direct referrals to the study website by health care providers. Potential participants were required to read an online participant information sheet and complete an online consent form. Participants were not informed of the precise randomized comparison being made and were simply told that they were participating in a trial that sought to "find out if advice about cholesterol provided on the Internet can improve your cholesterol management." If participants were randomized to the active arm, they were immediately asked to refer their friends and relatives to the website in order to determine whether or not the website was able to gain access to networks of friends and relatives via personal referral and thus influence the health behavior of friends and relatives as well. Control group participants were requested to do the same only after completing follow-up for the primary and secondary outcomes at which time they received individualized advice. Friends or relatives who responded to referral from a randomized participant were not randomized; they were simply asked to provide informed consent, asked to complete the baseline and 8 week follow-up questionnaires, and were then documented as a referral from a randomized participant for the purposes of outcome evaluation. Information was collected from the referred participant in an effort to link them back to the referrer in order to determine any differences in referral patterns between intervention and control participants.

Baseline Data Collection

The baseline questionnaire was administered to all consenting participants and sought demographic details, cardiovascular disease history, risk factors, cholesterol levels, use of any medications or other strategies to reduce their cholesterol-related cardiovascular risk, and any family history of cardiovascular disease or high cholesterol levels (see Multimedia Appendix 1). The information sought was sufficient to define (1) eligibility for statin therapy according to the February 2004 Australian Prescriber Benefit Scheme criteria [22]; (2) the need for increased statin therapy to achieve the lipid targets recommended by the Cardiac Society of Australia and New Zealand guidelines [23]; (3) the need for commencement of nondrug intervention strategies that might be used to lower their risk of a cholesterol-related event (including recommending weight loss if their body mass index (BMI) was greater than 24 and they were not trying to lose weight; taking regular exercise; starting a healthy diet; and, if they were not already doing so, using cholesterol-lowering margarine if they had been diagnosed with high cholesterol or were indicated for cholesterol-lowering treatment [24]); and (4) the likelihood of there being a familial tendency to cholesterol-related disease (if their total cholesterol > 9 mmol/L, they were of aboriginal heritage, or they had been diagnosed with genetic hypercholesterolemia or a had a family history of premature heart disease and previous diagnosis of high cholesterol). The questions were simple to answer and took no more than a few minutes to complete. Individuals were not required to be able to answer all questions to proceed to randomization, but it was made clear that the more information that was provided the better.

Randomization

Randomization followed immediately after baseline data collection. Randomization was done automatically in real time by a central computerized service run by the investigators at The George Institute for International Health. There was no stratification since the large number of participants would ensure reasonable balance of characteristics between randomized groups. Investigators were blinded to the allocation of all individuals throughout the trial. This was true both for the collection of data by the automated email prompts and for the data collected by phone or mail. Unblinding only occurred once follow-up of all participants was complete.

Intervention and Control

The intervention group received immediate personally tailored cholesterol management advice from a fully automated computer algorithm that used the information collected in the baseline questionnaire. If data were missing from the questionnaire, the response was assumed to be negative except for responses to the question about lipid levels. If lipid levels were absent, the tailored advice was qualified and participants were informed that full assessment of their situation was not possible without lipid values and that it would be helpful if they had their cholesterol measured. The computer algorithm was tested using multiple hypothetical scenarios to ensure that the advice given was accurate.

The advice provided comprised specific recommendations about the need for commencement of statin therapy, increased statin therapy in those already on treatment, and nondrug intervention strategies. Based on each individual’s likelihood of a family history of cholesterol-related disease, participants were also advised that their relatives could also benefit from visiting the site. Participants could print each recommendation and the associated reasons for that recommendation in the form of an automatically generated individually tailored letter that could be taken to their doctor. Participants could also print off information that might be suitable for passing on to friends or relatives or directly email the website details to these people. The information was badged with the logos of The George Institute for International Health, the University of Sydney, Western Sydney Area Health Service, and the Institute of Clinical Pathology and Medical Research, and it was made clear that the advice provided was based upon the recommendations of the 2004 Pharmaceutical Benefit Scheme Lipid Management Guidelines and the 2001 Australian and New Zealand Lipid Management Guidelines. The credibility of the output was further enhanced by the advice being electronically signed by one of the authors (SL) who was identified as the Director of the Lipid and Cardiovascular Risk Assessment Service, Westmead Hospital. An example of the tailored advice is shown in Figure 1. In addition to the tailored advice, participants were referred to links on the website containing generic information on cholesterol.

Figure 1. Screenshot of sample tailored advice

Participants in the control group were provided with only general information about lowering cholesterol in the form of links to relevant sites containing static Web pages, but control group participants were given no specific management recommendations. Control group participants, however, were provided with 35 links to fact sheets and information including pages from the National Heart Foundation, the Australian Department of Health and Aging, the NSW Department of Sport and Recreation and many others (all links can be viewed on the website, www.cholesterolcheck.info) [25].

All relatives and friends that were referred to the website, irrespective of whether they were referred by an individual assigned to the intervention or the control group, received immediate personally tailored cholesterol management advice from the computer algorithm. The control group participants were not specifically asked to refer friends or relatives until after they had completed follow-up to reduce the risk of contamination. (For example, if the friend or relative showed the control group participant the specific advice that was generated, this may have impacted the control group participant’s decision and/or timing in returning to the website to complete the next questionnaire.)

Follow-up

All randomized participants were scheduled for follow-up 8 weeks after randomization. Follow-up comprised an email reminder to log on and complete an online questionnaire seeking information about each of the study outcomes. The follow-up questions were phrased such that they were simple to answer and designed such that the entire follow-up questionnaire would take no more than a few minutes to complete (see Multimedia Appendix 2). Participants that failed to return to the website after initial email prompting (including friends and relatives) were contacted successively by mail and phone to achieve follow-up data collection. Participants in the control group received their individually tailored advice after completing the second questionnaire. All participants were invited to fill in a feedback questionnaire at the completion of the study in order to ascertain their views on the usefulness of the website and the information provided.

Study Outcomes

The primary outcome was the number of participants that reported commencing or increasing treatment with lipid lowering medication. Secondary outcomes were the number of participants that had their cholesterol levels checked, visited a doctor, commenced eating a healthy diet, started trying to lose weight, started taking regular exercise, started using special cholesterol-lowering margarine, stopped smoking, had their blood pressure checked, or recommended the website to a friend or relative.

Adverse Events

No significant adverse events were anticipated as a result of our intervention although some participants potentially may have been falsely reassured of being at low risk of vascular disease by our tailored advice if they did not provide full details of their clinical situation. This issue was addressed by carefully advising participants that our intervention may not take into account their full medical history and that they should discuss their results with their regular doctor. Participants were not specifically asked if they had experienced any adverse effects as a result of our study.

Statistics

Power

The trial was initially planned to recruit 3938 individuals to achieve 90% power (alpha = .05) to detect a 2.5% or greater difference between randomized groups in the proportion reporting the primary outcome. This estimate assumed that the primary outcome event rate in the control group would be about 5% and that it would be increased by a half, to about 7.5% in the intervention group. The trial actually randomized 2099 individuals with an event rate of 7.6% in the control group, and this provided 90% power (alpha = .05) to detect a 4% or greater absolute difference between randomized groups in the proportion reporting the primary outcome. The power calculations were carried out with PASS 2008 software (NCSS Statistical and Power Analysis Software, Kaysville, UT, USA) using Mantel-Haenszel, likelihood ratio, and *z* tests.

Analysis

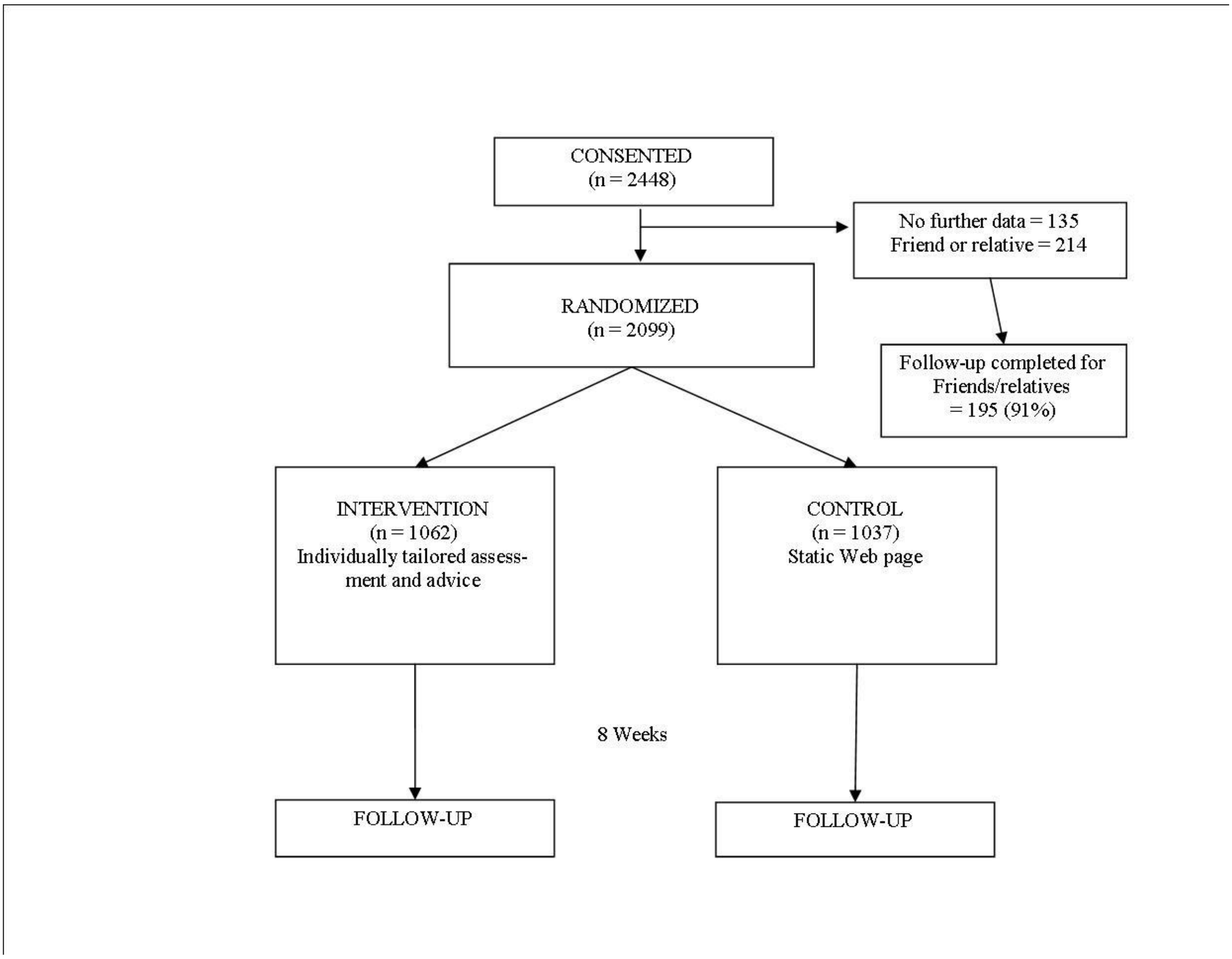
Statistical analyses were done with SAS version 9.1 (SAS Institute Inc, Cary, NC, USA). Characteristics of participants were summarized as proportions or means with standard deviations. Comparisons of proportions were done using Pearson’s chi-square test without continuity correction. Estimates of effect size for the outcomes summarized as proportions are presented as differences in proportions and 95% confidence intervals. For these analyses the denominators were the total number randomized in each group such that wherever possible, estimates were unbiased “intention-to-treat” analyses. Comparisons between the mean values of continuous outcome measures were made using *t* tests, and estimates of effect sizes were presented as mean differences with 95% confidence intervals. These latter analyses included only those individuals for whom the data were not missing. All tests were two-sided and univariate, missing values were not imputed, and a *P* value of .05 or less was interpreted as unlikely to have arisen by chance.

Results

Recruitment and Follow-up

In total, 2448 individuals consented to participate comprising 2099 randomized participants, 214 friends or relatives referred by randomized participants, and 135 individuals that consented but provided no further data and were not randomized (Figure 2). Recruitment was terminated prior to the target recruitment number due to the prolonged time taken to recruit participants. Of the total number of randomized participants, 1062 were assigned to intervention and 1037 to control; 93% of the total provided follow-up data with 750 (36%) requiring mail and/or telephone follow-up to achieve this. Follow-up data was collected at a median of 10 weeks (range 7 to 42 weeks) after randomization with the active group taking slightly longer to respond than the control group (median 10.3 vs 10.1 weeks).

Figure 2. Flow chart



Participant Characteristics

Trial participants were an average of 56 years old and 918 out of 2099 (44%) were male (Table 1). About two-thirds (1387/2099) had a self-reported prior diagnosis of hypercholesterolemia, one-third (689/2099), a family history of premature coronary heart disease, and one in ten (241/2099) had been told that they or a family member had a possible heritable component to their elevated cholesterol levels. Most participants reported that they were on a healthy diet and taking regular exercise, although nearly two-thirds (1258/2099) responded that they were trying to lose weight. The overall mean body mass index (BMI) of participants was 26.7kg/m^2. The baseline characteristics of the intervention and control groups were generally well balanced—the exception to this was that the intervention group had a slightly greater likelihood of having family members at high risk of hypercholesterolemia.

Table 1. Baseline characteristics of randomized participants

	Number with Data	Intervention (n = 1062)	Control (n = 1037)
Male	2099	482 (45)	436 (42)
Medical history			
High cholesterol, n (%)	2098	710 (67)	677 (65)
Hypertension, n (%)	2086	364 (34)	390 (38)
Diabetes mellitus, n (%)	2099	129 (12)	123 (12)
Coronary heart disease, n (%)	2098	94 (9)	84 (8)
Peripheral vascular disease, n (%)	2097	26 (2)	21 (2)
Cerebrovascular disease, n (%)	2099	32 (3)	37 (4)
Familial hypercholesterolemia, n (%)	2093	34 (3)	33 (3)
Participant or family has been told they have genetic hypercholesterolemia, n (%)	2095	111 (10)	130 (13)
Family history of premature coronary heart disease, n (%)	2098	331 (31)	358 (35)
Lifestyle factors			
Current smoker, n (%)	2098	75 (7.1)	77 (7.4)
Eating a health diet, n (%)	2086	892 (84)	862 (83)
Trying to lose weight, n (%)	2090	620 (58)	638 (62)
Taking regular exercise, n (%)	2088	770 (73)	766 (74)
Using cholesterol-lowering margarine, n (%)	2091	339 (32)	325 (31)
Currently on lipid modifying treatment, n (%)	2088	295 (28)	266 (26)
Awareness of own lipid subfractions, n (%)	2057	309 (29)	274 (26)
Not on medication and indicated for treatment[a], n (%)	2024	160 (15)	144 (14)
On medication but not reaching target, n (%)	2076	141 (13)	113 (11)
Family at risk[b], n (%)	2021	330 (31)	239 (23)
Age (years), mean ± SD (n)	2099	55.8 ± 12.21 (1062)	56.3 ± 11.88 (1037)
Weight (kg), mean ± SD (n)	2074	77.3 ± 17.74 (1049)	76.5 ± 16.54 (1025
Height (cm), mean ± SD (n)	2075	170 ± 9.32 (1053)	169.1 ± 9.46 (1022)
BMI (kg/m2), mean ± SD (n)	2054	26.7 ± 5.34 (1042)	26.6 ± 4.93 (1012)
Highest total cholesterol (mmol/L), mean ± SD (n)	1139	6.7 ± 1.41 (577)	6.9 ± 1.85 (562)
Recent total cholesterol (mmol/L), mean ± SD (n)	1196	5.6 ± 1.25 (614)	5.7 ± 1.28 (582)
Recent LDL cholesterol (mmol/L), mean ± SD (n)	535	3.5 ± 1.20 (285)	3.5 ± 1.15 (250)
Recent HDL[c] cholesterol (mmol/L), mean ± SD (n)	551	1.7 ± 0.75 (296)	1.7 ± 0.68 (255)
Recent triglyceride (mmol/L), mean ± SD (n)	539	1.6 ± 1.05 (277)	1.7 ± 1.71 (262)

[a] Calculation based on lipid guidelines and Pharmaceutical Benefit Scheme guidelines current at time of trial

[b] Calculation based on participant answers indicating possible high risk of hypercholesterolemia among family members

[c] High density lipoprotein

Eligibility for Starting or Increasing Cholesterol Lowering Treatment

Based on our algorithm, among the 2099 randomized participants there were 561 (27%) that were using prescribed treatment of which 254 were not meeting recommended targets and were deemed eligible for increased treatment. Of those not on treatment, 20% (304/1538) met the criteria for treatment.

Effects of Intervention Compared With Control

Tables 2 and 3 show the results for the primary and secondary outcomes for the main study aim. The primary outcome, commencement or increase in cholesterol-lowering therapy, was observed in 6.8% (143/2099) of the randomized participants, 6.0% (64/1062) in the intervention group and 7.6% (79/1037) in the control group (% difference = -1.6, 95% confidence interval [CI] -3.75 to 0.57). For new treatment, the percent difference was -1.4% (95% CI -2.87 to 0.23), and for increased treatment, it was -0.3% (95% CI -1.83 to 1.29).

Table 2. Effects of treatment on primary and secondary outcomes (binary) among randomized participants

Primary outcome	Intervention (n = 1062) n (%)	Control (n = 1037) n (%)	% Difference (95% CI)	*P* value
Commenced or increased cholesterol-lowering therapy	64 (6.0)	79 (7.6)	-1.6 (-3.75 to 0.57)	.15
Commenced treatment	29 (2.7)	42 (4.1)	-1.4 (-2.87 to 0.23)	.09
Increased treatment	35 (3.3)	37 (3.6)	-0.3 (-1.83 to 1.29)	.73
Secondary outcomes (binary)				
Discussed treatment with a health professional	521 (49.1)	549 (52.9)	-3.8 (-8.16 to 0.19)	.08
Had blood cholesterol checked	465 (43.8)	470 (45.3)	-1.5 (-5.79 to 2.71)	.48
Commenced eating a healthy diet	85 (8.0)	86 (8.3)	-0.3 (-2.63 to 2.05)	.81
Commenced trying to lose weight	107 (10.1)	103 (9.9)	0.2 (-2.42 to 2.71)	.91
Commenced taking regular exercise	112 (10.5	100 (9.6)	0.9 (-1.67 to 3.50)	.49
Commenced using cholesterol-lowering margarine	112 (10.5)	105 (10.1)	0.4 (-2.18 to 3.03)	.75
Stopped smoking	9 (0.8)	9 (0.9)	-0.1 (-0.81 to 0.77)	.96
Blood pressure checked	744 (70.1)	712 (68.7)	1.4 (-2.55 to 5.34)	.49
Referred friend or relative to the website	176 (16.6)	91 (8.8)	7.8 (4.97-10.62)	<.001
Number of friends or relatives that visited the website	69 (7)	23 (2)	3.1 (1.9-5.0)	<.001

Table 3. Effects of treatment on secondary outcomes (continuous) among randomized participants

Secondary Outcomes (Continuous)	Mean ± SD	Mean ± SD	Mean Difference (95% CI)	*P* value
Recent total cholesterol (mmol/L)	5.45 ± 1.21 (n=600)	5.51 ± 1.23 (n=593)	-0.07 (-0.21 to 0.07)	.34
Recent low-density lipoprotein (LDL) cholesterol (mmol/L)	3.38 ± 1.13 (n=317)	3.31 ± 1.06 (n=306)	0.07 (-0.1 to 0.24)	.43
Recent high-density lipoprotein (HDL) cholesterol (mmol/L)	1.65 ± 0.69 (n=330)	1.67 ± 0.67 (n=314)	-0.03 (-0.14 to 0.08)	.59
Recent triglyceride (mmol/L)	1.71 ± 1.29 (n=323)	1.62 ±1.59 (n=312)	0.10 (-0.13 to 0.32)	.40
Current weight (kg)	77 ± 17.2 (n=937)	77 ± 16.74 (n=926)	0.03 (-1.51 to 1.57)	.97

In regard to the secondary outcomes, there were no significant differences between randomized groups in the proportions that visited a doctor, had their cholesterol levels checked, commenced eating a healthy diet, started trying to lose weight, started taking regular exercise, started using cholesterol-lowering margarine, stopped smoking, or had their blood pressure checked (all *P* > .08) (Table 2). The one exception was that more individuals in the intervention group (176/1062, 17%) than the control group (91/1037, 9%) referred one or more friends or relatives to the website (% difference = 7.8 %, 95% CI

4.97-10.62, *P* < .001). These referrals resulted in 69 friends or relatives of the intervention group participants and 23 friends or relatives of the control group participants actually visiting the website within the follow-up period (ie, prior to the index case returning to complete the second questionnaire). The population visiting the website within this time frame was used to calculate the outcomes for friends and relatives, as only intervention group participants were specifically asked to refer friends and relatives to the website after the first questionnaire, whereas the control group received this request after completing the second questionnaire. In addition, 92 other friends and relatives that visited the website did not provide sufficient information to link them back to the referring index participant. Of the 69 friends or relatives of intervention participants, 5 commenced or increased cholesterol-lowering therapy compared with none of the friends or relatives of the control group participants (0.5% vs 0%; *P* = .06). Significantly more of the intervention group participants had friends or relatives discuss treatment with a health professional (26/1062, 2% vs 5/1037, 0.5%, *P* < .001), had their cholesterol checked (26/1062, 2% vs 6/1037, 0.6%; *P* < .001), commenced cholesterol-lowering margarine (6/1062, 0.6% vs 0/1037; *P* = .03), were checked for diabetes (19/1062, 2% vs 8/1037, 0.8%; *P* = .04) or had their blood pressure checked (40/1062, 4% vs 16/1037, 2%; *P* = .002) after receiving individualized advice from the website, but otherwise there were no differences for the other outcomes (all *P* > .09).

In total, 1144 of the 2448 (47%) participants provided written feedback about one or other aspect of the study. The study was generally perceived as providing useful (926/1144, 81%), trustworthy (857/1119, 95%) and clear (1027/1126, 91%) information. Important issues that arose in the “free text” section were around the issues of participants not understanding cholesterol levels or not having been given test results and so being unsure of how to respond to those questions. In addition, a third (51/156, 33%) of those that put a “free text” comment remarked on the inappropriateness of the questionnaire for their particular circumstances.

Adverse Events

To our knowledge, no adverse events occurred during the course of the study.

Discussion

Our intervention provided consumers with individualized user-friendly advice from a credible source but had no detectable impact on any important aspect of participant treatment or participant behavior related to cholesterol management. This finding raises doubt about the value of the multitude of consumer-targeted websites that seek to improve participant health and medical care using this type of simplified approach.

There are many possible reasons why there was no clear effect of the intervention in our study. First, achievement of change in treatment required the successful completion of a sequence of events. Specifically, the participant had to decide to act upon the advice received from the website, print out the materials provided, make an appointment to visit their doctor, and then attend the visit. The stages of change model outlines a complex cycle that takes place in order to change behavior [26]. A website offering tailored advice is only likely to affect people who are already motivated to change and are on the brink of taking action and therefore targets people at one point of the change cycle only. Furthermore, recent large-scale trial data and meta-analysis has confirmed that increased depth of tailoring and use of multiple behavioral change techniques based on established models of behavioral change are more effective [21,27]. Based on this evidence as well as our trial outcome, there can be little justification for expecting significant effects on clinical outcomes from simple tailored advice websites. It is likely that health websites must provide more comprehensive support to help users achieve the changes in behavior sought, that is, health websites must provide a more highly interactive tool or one that provides an additional resource.

If the participant did attend his or her general practitioner’s clinic, the doctor then had to be persuaded by the advice and commence or increase cholesterol-lowering treatment accordingly. There are multiple points at which this chain of events could break down, and there is evidence from other sources to suggest why this may not occur [28].

Another issue of primary importance is the willingness of physicians to respond to information provided to them by their patients. While doctors frequently use computerized systems and the Internet to seek information, they may be less likely to act upon material they receive indirectly from the Internet via their patients [29]. That said, the credibility of the information provided by the website did not appear to be a major issue, with the majority of participants that gave feedback about visiting their doctor indicating that both they and their physicians viewed the website outputs as useful and trustworthy.

A further consideration is that the study was relatively short, providing a limited time frame during which change in treatment had to occur. In retrospect, it may have been too brief a period to make treatment changes for some participants although it is of note that there were no effects of the intervention on actions intermediate to treatment change. For example, the number of participants making visits to the doctor or having assays of blood lipids was not greater in the intervention compared with the control group and could reasonably have been expected to be increased in the time period available.

It is also possible that cholesterol management was a more difficult management problem among our study participants as compared with the general population at risk of cholesterol-related disease. Individuals prepared to seek out solutions on the Internet may previously have been through multiple other efforts to control their lipid levels; the website may not have had much new to offer, and this could have reduced the potential for the intervention to impact upon treatment. There was some participant feedback to indicate that this was the case, with some respondents reporting that they found the website to be inappropriate to their situation because they had already tried most of the suggested interventions, had side effects to suggested treatment, or had high levels of cholesterol that were resistant to usual therapy. The approach used by the I-CAT website, which was to address the usual cholesterol problems with the usual cholesterol-lowering solutions, may not be appropriate for the real-world setting of health websites because it may actually be the more unusual cases that comprise a large proportion of website users.

An alternate interpretation of the study findings might be that while the tailoring component of the website intervention we evaluated was not important, the large numbers of participants across the two groups that reported taking some action suggest that the website was producing some effect. It is possible that simply completing the risk factor questionnaires was sufficient to drive people to consult a health care provider or have their cholesterol checked even if tailored advice was not provided. However, a more likely explanation is that the individuals that enrolled in this study were a self-selected and highly motivated group that would have taken these actions irrespective of anything they did as part of the trial. It is also possible that a ceiling effect had been reached for some of the recommendations, with significant numbers already reporting some actions at the baseline assessment. Clearly this study cannot reliably address the question of whether simply accessing static Web pages can change health-related behaviors, although it is generally agreed that simply viewing general information is not an effective means of achieving individual behavioral change [30].

Contamination of our control arm could have occurred if some family members in a given household were randomized to the control group and some to the intervention group. This would have had the effect that participants in the control arm would then have been aware that personalized information was provided to other participants and may have influenced them to return to the website for follow-up more promptly than other control group participants. In relation to the primary outcome, we believe it is unlikely to have importantly influenced the results as the advice was specifically tailored to the recipient and was not generalizable to other participants. In addition, rather few control group participants had friends or relatives visit the website.

The finding that the intervention group referred more friends or relatives to the website compared with control participants was the one positive result from the trial and might be of some value. The targeted identification and referral of individuals in this way might, for example, be a method that could be used as part of genetic cascade follow-up programs for conditions such as familial hypercholesterolemia [31].

The chief strength of this study was its large scale, robust randomized design, and real-world evaluation of the intervention under investigation. There has been no prior study that begins to approach I-CAT in regard to this combination of characteristics, and on this basis, the data presented here represent a major advancement of knowledge. However, the study also had some shortcomings. First, while the study was large, there were challenges with recruitment, and the original recruitment target was not met. It is possible, therefore, that the study failed to detect a small real effect of the intervention on the primary outcome. That said, the absence of any effect on intermediate outcomes for which there was much better statistical power suggests that this is probably not the case. Second, the study relied upon participant-reported data both at baseline and follow-up and in many cases this was incomplete in regard to lipid levels. Since detailed knowledge of lipid levels is key to fully applying lipid management guidelines [22-23], this made it difficult to provide a specific recommendation to all participants. This may have reduced the perceived value of the website, but once again the absence of full information reflects the real-world setting in which such websites operate. Finally, in regard to outcome assessment for the trial, lipid data were collected opportunistically and were incomplete, raising uncertainty about that component of the study outcomes. Nonetheless, the completeness of data for the primary outcome and many of the other secondary outcomes was good, with a strong likelihood that most participants would have been able to report reliably about these other fairly objective measures.

In conclusion, this large, carefully conducted trial found no clear beneficial health effects from a website that was designed to incorporate some of the current features of Internet-based interactive health communications applications targeted at consumers. The evidence provided here serves to again highlight the need for the comprehensive evaluation of all new strategies designed to improve population well-being if maximum value is to be extracted from the health care dollar.

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Conflicts of Interest

None declared

Authors' Contributions

Ruth Webster was involved in data collection, ongoing management of the study, data analysis and writing of the paper.
Stephen Li was involved in study design, ongoing management of the study, data analysis and critical revision of the paper. David Sullivan was involved in the study design and critical revision of the paper.
Kathy Jayne was involved in the study design, ongoing management of data collection, and critical revision of the paper.

Steve Su was involved in data analysis and critical revision of the paper.
Bruce Neal was involved in study design, ongoing management of the study, data analysis and critical revision of the paper.
Bruce Neal acted as guarantor of the study.
All authors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of data analysis.

Multimedia Appendix 1

Questionnaire 1

[PDF file (Adobe PDF File), 143 KB - jmir_v12i3e42_app1.pdf]

Multimedia Appendix 2

Questionnaire 2

[PDF file (Adobe PDF File), 171 KB - jmir_v12i3e42_app2.pdf]

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Abbreviations

BMI: body mass index
I-CAT: Internet-based Cholesterol Assessment Trial
HDL: high-density lipoprotein
LDL: low-density lipoprotein

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Original Paper

Supporting Informed Decision Making for Prostate Specific Antigen (PSA) Testing on the Web: An Online Randomized Controlled Trial

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Abstract

Background: Men considering the prostate specific antigen (PSA) test for prostate cancer, an increasingly common male cancer, are encouraged to make informed decisions, as the test is limited in its accuracy and the natural history of the condition is poorly understood. The Web-based PSA decision aid, Prosdex, was developed as part of the UK Prostate Cancer Risk Management Programme in order to help men make such informed decisions.

Objectives: The aim of this study was to evaluate the effect of the Web-based PSA decision aid, Prosdex, on informed decision making.

Methods: A Web-based randomized controlled trial was conducted in South Wales, United Kingdom. Men aged 50 to 75 who had not previously had a PSA test were randomly allocated to two intervention and two control groups. Participants in the intervention groups either viewed Prosdex or were given a paper version of the text. The main outcome measures were the three components of informed decision making: (1) knowledge of prostate cancer and PSA, (2) attitude toward PSA testing, (3) behavior using a proxy measure, intention to undergo PSA testing. Decisional conflict and anxiety were also measured as was uptake of the PSA test. Outcomes were measured by means of an online questionnaire for the Prosdex group, the paper version group, and one of two control groups. Six months later, PSA test uptake was ascertained from general practitioners' records, and the online questionnaire was repeated. Results are reported in terms of the Mann-Whitney U-statistic divided by the product of the two sample sizes (U/mm), line of no effect 0.50.

Results: Participants were 514 men. Compared with the control group that completed the initial online questionnaire, men in the Prosdex group had increased knowledge about the PSA test and prostate cancer (U/mn 0.70; 95% CI 0.62 - 0.76); less favourable attitudes to PSA testing (U/mn 0.39, 95% CI 0.31 - 0.47); were less likely to undergo PSA testing (U/mn 0.40, 95% CI 0.32 - 0.48); and had less decisional conflict (U/mn 0.32, 95% CI 0.25 - 0.40); while anxiety level did not differ (U/mn 0.50, 95% CI 0.42 - 0.58). For these outcomes there were no significant differences between men in the Prosdex group and the paper version group. However, in the Prosdex group, increased knowledge was associated with a less favourable attitude toward testing (Spearman rank correlation [ρ] = -0.49, $P < .001$) and lower intention to undergo testing (ρ = -0.27, $P = .02$). After six months, PSA test uptake was lower in the Prosdex group than in the paper version and the questionnaire control group ($P = .014$). Test uptake was also lower in the control group that did not complete a questionnaire than in the control group that did, suggesting a possible Hawthorne effect of the questionnaire in favour of PSA testing.

Conclusions: Exposure to Prosdex was associated with improved knowledge about the PSA test and prostate cancer. Men who had a high level of knowledge had a less favourable attitude toward and were less likely to undergo PSA testing. Prosdex appears to promote informed decision making regarding the PSA test.

Trial Registration: ISRCTN48473735; http://www.controlled-trials.com/ISRCTN48473735 (Archived by WebCite at http://www.webcitation.org/5r1TLQ5nK)

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KEYWORDS

Decision aid; Informed decision making; Internet; Prostate cancer; Prostate Specific Antigen (PSA) test

Introduction

Informed decision making is difficult to deliver for men who are considering the prostate specific antigen (PSA) test. Web-based PSA decision aids potentially provide a solution.

The decision to undergo PSA testing for prostate cancer is a very difficult one for men. On the one hand, the disease is gaining prominence, largely due to an aging population and increased detection. On the other hand, the usefulness of the only widely available test for prostate cancer, PSA, is limited not only by its poor sensitivity and specificity but also by the uncertainty relating to the natural history and the management of the disease [1,2]. It is for this reason that the UK National Cancer Screening Programme in 2001 established the Prostate Cancer Risk Management Programme (PCRMP), a strategy that had, as one of its key goals, the promotion of informed decision making about PSA testing [2]. An informed decision, as outlined in the measure of informed decision making developed by Marteau et al for prenatal Down's syndrome testing [3,4], could be characterized by relevant knowledge of the subject as well as by attitudes congruent with subsequent behavior. In the case of PSA testing, therefore, what was important was not the actual decision made vis-à-vis the test. Instead, the aim of the PCRMP was for men to both acquire knowledge about PSA and prostate cancer and make decisions about the test that reflected their attitudes toward it.

In order to facilitate informed decision making, all general practitioners (GPs) in the United Kingdom were provided with information leaflets about PSA testing to be provided to patients on request. Nonetheless, it was accepted by policymakers that a more publicly engaging source of information was required. Consequently, attention turned to decision aids, which already had a strong record in facilitating difficult decisions across a range of conditions including prostate cancer [5]. In addition, the Web was identified as a suitable medium for delivering these decision aids to UK men. Therefore, the Web-based PSA decision aid, Prosdex [6], was commissioned by Cancer Research UK and launched in 2004. It was, and remains, an innovative intervention in eHealth, combining text and multimedia features with deliberation tools designed to directly promote informed decision making, reflecting the standards set by the International Patient Decision Aid Collaboration [7].

It is not known whether PSA decision aids have an effect on informed decision making. Systematic reviews have consistently shown these aids improve knowledge about PSA and prostate cancer, which is the initial, essential component of informed decision making [5,8-10]. In addition, PSA decision aids have been shown to affect behavior, that is, use of these aids typically results in a reduced likelihood of PSA testing [8,9]. However, to date there is no evidence that such conservative behavior is associated with greater knowledge of prostate cancer and PSA testing and with negative attitudes toward the test, as would be expected with informed decision making.

There is no specific measure of informed decision making in PSA testing, and therefore, for this study, a composite evaluation was used based on three key components: knowledge, attitude, and behavior. Knowledge about PSA and prostate cancer was taken as the principal outcome for the study due to its key role in informed decision making: without knowledge, informed decision making cannot take place. The behavior component assessed was intention to undertake PSA testing, and this was measured at the same time as the attitude toward the PSA test. Crucially, to determine an effect on informed decision making, correlations between the knowledge, attitude, and behavior outcomes were examined. Our hypothesis was that, at group level, men using the Prosdex Web-based PSA decision aid would improve their knowledge and thereby develop both a less favorable attitude toward the test and a reduced intention to undergo testing, principally because increased knowledge would lead to an understanding of the uncertain benefits of the PSA test. Finally, six months later, we evaluated a second behavioral outcome, PSA test uptake. The hypothesis here, for the same reasons, was that PSA test uptake would be reduced in those men who had demonstrated informed decision making.

The potential of the Web was exploited in two ways in this study. First, as described, the decision aid was hosted on the Web. Second, an online research methodology was employed, namely, a four-armed randomized controlled trial with two intervention and two control groups, which allowed a comparison between Prosdex and a control group, between Web-based Prosdex and a paper version of the same information, and, between the two control groups in order to consider the Hawthorne effect of an outcome questionnaire. Our expectation was that participants presented with the questionnaire would be more likely to undertake PSA testing due to an increased awareness of the subject and exposure to popular opinions and media coverage, which tend to be uncritically positive about the benefits of PSA testing. The aim of this study, therefore, was to evaluate the effect of a Web-based PSA decision aid, Prosdex, on knowledge, attitudes and behavior—the components of informed decision making—using a Web-based questionnaire.

Methods

Study Design

A Web-based randomized controlled trial (RCT) was designed, composed of four groups: two intervention groups and two control groups.

Setting

Men were invited to participate by their general practitioners (GPs) in South Wales, United Kingdom.

Participants

Inclusion Criteria

Men aged 50 to 75 were invited to participate. This is the age range in which men typically request or are offered the PSA test. The participants accessed the study via the Internet and had to be able to use a computer, and they were asked to indicate this on the consent form. Those unable to participate due to inability to use a computer and those who did not respond to the invitation were counted separately, in line with CONSORT guidelines [11].

Exclusion Criteria

Participants who could not read English were excluded, as were those whose general practice records indicated that they had previously had prostate cancer or a PSA test.

Recruitment Process

Potential participants were identified from electronic patient registers. A staff member from each practice generated a list of potential participants aged 50 to 75 who had not had a PSA test or prostate cancer. A random sample of 100 men was selected from the list. A staff member with knowledge of the patients—usually a GP—was asked to screen out men who were unsuitable for the trial due to serious ill-health, specifically a terminal illness, dementia, or severe mental illness. Finally, invitation letters signed by the GP, participant information sheets, and consent forms were sent by mail to eligible potential participants.

Affirmative consent forms from each practice were transferred to the research officer (author NJ-W) who allocated each participant with a number provided remotely by the trial statistician (author RN) to ensure concealment. The process ensured individual level randomization to one of two intervention groups or to one of two control groups, as we were interested in individual decision making after an intervention used independently by each participant. There was unlikely to be an intracluster correlation for these outcomes, because men would view the Web at home [12].

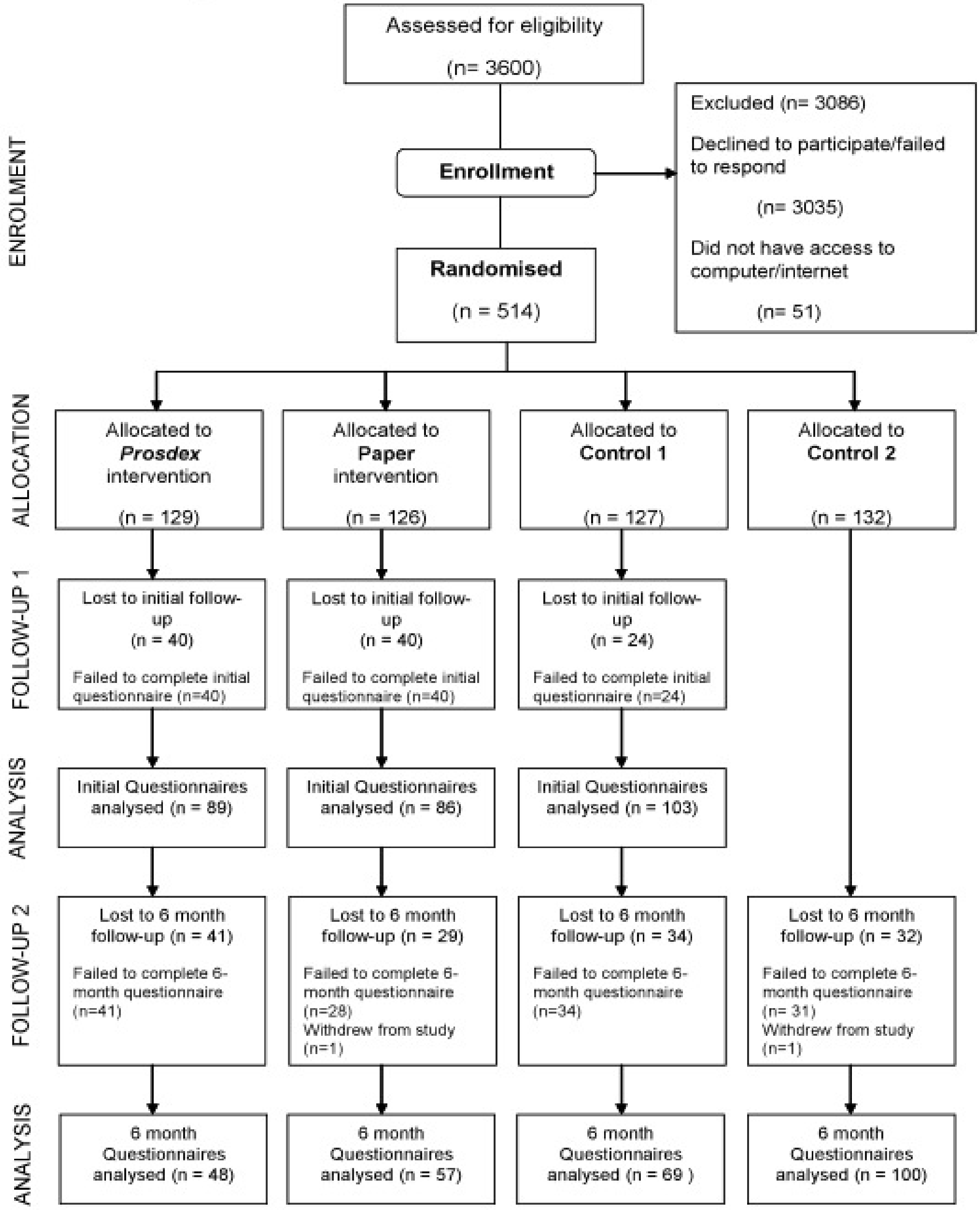
Sample Size

The sample size aimed for was 600 participants: 150 in each of the four groups. This figure was derived from our systematic review of PSA decision aids in which these interventions were found to have resulted in knowledge that had improved by 19.5% (SD 45.1) [9]. Thus, 150 men per group would allow the detection of a 20% absolute difference in knowledge with power greater than 90%. Assuming a recruitment rate of 30%, we aimed to invite 2000 potential participants from 20 GP practices, 100 men from each practice [13].

Intervention and Controls

The intervention used in this study, the Web-based PSA decision aid Prosdex [6], presents evidence-based information about prostate cancer and PSA testing, encouraging users to weigh the pros and cons of testing [14]. In addition, Prosdex includes video clips of enacted patient experiences about the PSA test and subsequent investigations and treatments. There is also information about shared decision making and a deliberation tool named a “decision stacker,” which visualizes attitudes toward the PSA test. Prosdex aims to actively encourage informed decision making. A specific version of the Prosdex website was developed for the study. Participants in the Prosdex intervention group were able to view the intervention in their own homes or in other settings. Participants in the second intervention, the paper version group, received a paper document, comprising the text of the website but not the name, to reduce the risk of participants in this group discovering Prosdex on the Web. Participants in the control groups received neither the Prosdex URL nor the paper version of the website (Figure 1).

Figure 1. Prosdex RCT CONSORT participant flow chart



Outcomes

Components of informed decision making were evaluated. Components were: (1) knowledge of prostate cancer and PSA, the primary outcome of the study; (2) attitude toward PSA testing; and (3) behavior, using the proxy measure of intention to undergo PSA testing.

Knowledge, attitude, and intention were assessed by a set of questions previously used in an evaluation of a brief paper-based PSA decision aid [15]. Twelve true or false questions were posed, and participants received a score of 1 for a correct answer, -1 for an incorrect answer, and 0 for unanswered items. In the attitude section, twelve statements, six favorable and six unfavorable to PSA testing, were presented. For the intention outcome, a single item question with a five-point Likert-like response scale, "How likely are you to have the PSA test?" was used, and a mean rank score was then calculated for each group.

Two other outcomes, anxiety and decisional conflict, were measured by the questionnaire as these are outcomes that are commonly used in evaluations of decision aids [9]. Anxiety was assessed using the six-item short form of the Spielberger State Anxiety Inventory [16,17], and decisional conflict was measured by the Decisional Conflict Scale (DCS) [18,19]. Finally, at 6-months post intervention, actual uptake of the PSA test was measured.

Measurement of Outcomes

Baseline Outcomes Immediately Following the Intervention

Data for all outcomes, apart from test uptake, were gathered from responses to an online questionnaire. Participants allocated to the two intervention groups (the Prosdex group and the paper version group) and the first control group (named the "questionnaire control group") were asked to complete a questionnaire. These 3 groups were asked to access the study website using a unique password that was provided them. Participants' exposure to interventions and the questionnaire is shown in Figure 1, as is the pathway for participants in the second control group. The second control group, which was not asked to complete a questionnaire, was named the "no questionnaire control group." The data were collected in an SQL-server database, transferred to Excel spreadsheets, and analyzed using SPSS, version 12 (SPSS Inc, Chicago, IL, USA).

Outcomes at Six Months

At 6 months after the participants were allocated to the four groups, GPs were asked to review participants' medical records to ascertain whether participants had had a PSA test in the 6-month interval. All participants, including those in the no questionnaire control group, were also asked to repeat the online questionnaire in order to evaluate any changes to the baseline outcomes, such as knowledge, over a 6-month period.

Comparisons and Statistical Analysis

To determine the effect on informed decision making, the main comparison was Prosdex group versus questionnaire control group. There were also two other comparisons. The first was the Prosdex group versus the paper version group to compare the effect of format and media. Also compared were the questionnaire control group versus the no questionnaire control group to assess the Hawthorne effect of the questionnaire on PSA testing as our expectation was that answering the questionnaire itself would encourage PSA testing. Also, in order to further assess the effect on informed decision making, correlations between knowledge, attitudes, and behavior outcomes were examined.

Most of the analyses in this study were undertaken on a group basis. However, according to the model of informed decision making, we should be able to demonstrate high knowledge, negative attitude/intention, and reduced uptake of PSA testing at the level of an individual participant as evidence of informed decision making by the individual. The data were therefore analyzed accordingly, and participants whose knowledge scores were above the median were defined as "high knowledge." The attitude and intention outcomes were then also dichotomized on the basis of the median scores to "high" and "low." Finally, the PSA test uptake data for individuals were analyzed in relation to the dichotomized outcomes, and the odds ratios for test uptake were calculated.

Comparability of the four groups for characteristics of age, ethnicity, marital status, and education was assessed. Demographic data for the two intervention groups and the questionnaire control group were obtained from the baseline questionnaire, and demographic data for the no questionnaire control group was obtained from the 6-month follow-up questionnaire. Outcomes were compared between groups on an ”intention to treat" basis. Results were reported in terms of an effect size derived from the Mann-Whitney U-statistic divided by the product of the two samples sizes (U/mn) [20]. The statistic U/mn is applicable to continuous and ordinal outcomes alike. The expected value under the null hypothesis is 0.5, and the measure takes the value 0 or 1 in extreme cases in which there is no overlap between the two samples. Therefore, for comparisons, U/mn is greater than 0.5 when the first group scores higher than the first; also, for confidence intervals, the line of no effect is set at 0.5 [20].

The study received ethical approval from South East Wales Research Ethics Committee (REC reference number 06/WSE04/13). All participants gave informed consent before taking part in the trial.

Results

Recruitment of General Practices

We invited 60 general practices from 9 Local Health Board (primary care organization) areas in South Wales. Of these, 27 practices agreed to participate, 33 declined, and 2 subsequently withdrew.

Recruitment of Participants

In 2008, 25 practices were sent 100 invitations each, and in response to lower than anticipated recruitment, 11 of these practices agreed to send an additional 100 invitations. A total of 3600 invitations were sent. Consent forms were returned from 646 potential participants (18%), of whom 565 (16%) agreed to participate. Excluded were 51 participants due to reported difficulties with Internet access and/or computer literacy, giving a final number of 514 participants (Figure 1). Of the 382 participants allocated to the Prosdex group, the paper version group, and the questionnaire control group, 278 (73%) completed the first online questionnaire in 2008. For the comparison of the Prosdex group versus the questionnaire control group, 89 versus 103 participants, a power of 87% was achieved to detect a 20% improvement in knowledge. For the Prosdex group versus the paper version group, 89 versus 86 participants, a power of 85% was achieved to detect a 20% improvement in knowledge.

Characteristics of Participants

Details of participant characteristics are given in Table 1. Of the participating men, 236 of 379 (62%), were between 50 and 59 years of age, 367 (97.4%) were white, 79 (88%) were married or cohabitating, and 334 (45%) had either a college or university degree, indicating volunteer bias towards those who are younger and those with higher educational attainments. There were no statistically significant differences between the groups.

Table 1. Characteristics of trial participants

Characteristic	Prosdex Group n (%)	Paper Version Group n (%)	Questionnaire Control Group n (%)	No Questionnaire Control Group n (%)	Total n (%)
Age group					
50-59	61 (68)	54 (63)	63 (61)	58 (58)	236 (62)
60-69	22 (24)	27 (31)	35 (34)	36 (36)	120 (32)
70 or over	7 (8)	5 (6)	5 (5)	6 (6)	23 (6)
Highest level of education					
None	9 (10)	9 (11)	12 (12)	14 (14)	44 (12)
CSE or equivalent	7 (8)	3 (4)	4 (4)	5 (5)	19 (5)
O level or equivalent	10 (11)	16 (19)	14 (14)	13 (13)	53 (14)
A level or equivalent	9 (10)	8 (9)	10 (10)	12 (12)	39 (10)
Clerical or commercial	7 (8)	18 (21)	22 (21)	8 (8)	55 (15)
College or university degree	48 (53)	32 (37)	41 (40)	48 (48)	169 (45)
Marital status					
Married or cohabiting	79 (88)	76 (88)	90 (87)	89 (89)	334 (88)
Widowed	1 (1)	0 (0)	4 (4)	0 (0)	5 (1)
Never married	3 (3)	5 (6)	4 (4)	6 (6)	18 (5)
Divorced or separated	7 (8)	5 (6)	5 (5)	5 (5)	22 (6)
Ethnicity					
White	89 (99)	83 (98)	97 (95)	98 (99)	367 (98)
Black African	0 (0)	0 (0)	1 (1)	0 (0)	1 (3)
Indian	0 (0)	0 (0)	1 (1)	0 (0)	1 (3)
Mixed race	1 (1)	2 (2)	1 (1)	1 (1)	5 (1)
Other	0 (0)	0 (0)	2 (2)	0 (0)	2 (5)

Comparisons and Correlations at Baseline

The two sets of comparisons at baseline, the Prosdex group versus the questionnaire control group and the Prosdex group versus the paper version group, are demonstrated in Table 2 with U/mn values. Results shown in Table 2 are based on 278 to 283 participants for whom full data were available. For the main comparison, the Prosdex group versus the questionnaire control group, participants in the Prosdex group were found to have significantly higher knowledge scores than those in the questionnaire control group. Men in the Prosdex group also had less favorable attitudes to the PSA test than those in the questionnaire control group, and intention to undergo PSA testing was lower in the Prosdex group than in the questionnaire control group. The decisional conflict score was lower in the Prosdex group than in the questionnaire control group, and there was no statistical difference between the two groups in terms of their anxiety regarding the PSA test.

Regarding the Prosdex group versus the paper version group, there was no significant difference in the knowledge scores of the participants. However, the mean knowledge score was slightly higher in the paper version group than in the Prosdex group (5.4 out of 12 vs 4.9 out of 12). Also, no significant differences were found between the Prosdex and the paper version groups in attitude toward PSA testing, intention to undergo PSA testing, decisional conflict score, and anxiety outcomes.

Table 2. Summary of outcome results

Outcome Measure	Prosdex Group vs Questionnaire Control Group				Prosdex Group vs Paper Version Group			
	Mean scores	U/mn	95% CI	*P* value	Mean scores	U/mn	95% CI	*P* value
Knowledge	4.90 vs 2.17	0.70	0.62 - 0.76	<.001	4.90 vs 5.40	0.47	0.39 - 0.55	.48
Attitude	9.10 vs 11.90	0.39	0.31 - 0.47	.007	9.10 vs 8.48	0.54	0.45 - 0.62	.39
Intention to undergo PSA testing[a]	40% vs 58%	0.40	0.32 - 0.48	.02	40% vs 53%	0.43	0.35 - 0.51	.10
DCS	40.37 vs 47.73	0.32	0.25 - 0.40	<.001	40.37 vs 38.49	0.56	0.47 - 0.64	.18
Anxiety	4.98 vs 4.88	0.50	0.42 - 0.58	.98	4.98 vs 4.78	0.51	0.43 - 0.60	.74

[a] Figures reported for these cells are percentages of men who indicated they were very likely to or definitely would take the test.

The correlations between outcomes are shown in Table 3. There was a substantial inverse correlation between overall knowledge and attitude scores in the two intervention groups but not in the questionnaire control group. That is, greater knowledge was associated with a less favorable attitude toward the test in the two intervention groups. There was also a negative correlation between knowledge and intention to undergo PSA testing in the Prosdex group but not in the other two groups. In other words, for participants in the Prosdex group alone, greater knowledge was associated with reduced intention to take the PSA test. For all three groups, attitude and intention outcomes were strongly correlated. Therefore, as hypothesized at the outset of the study, participants in the Prosdex group demonstrated greater knowledge and had negative but congruent attitudes and behavior.

Table 3. Correlation of knowledge, attitude, and intention outcomes for the Prosdex, paper version, and questionnaire control groups

Outcome	Intention Group		
	Prosdex Group (n = 89)	Paper Version Group (n = 86)	Questionnaire Control Group (n = 103)
Knowledge-Attitude			
Spearman rank correlation	-0.49	-0.49	-0.03
P value[a]	< .001	< .001	.78
Knowledge-Intention			
Spearman rank correlation	-0.27	-0.10	-0.02
P value[a]	.01	.38	.87
Attitude-Intention			
Spearman rank correlation	0.68	0.54	0.61
P value[a]	< .001	< .001	< .001

[a] 2-tailed significance

Comparisons at 6-month Follow-up

Although the trial design was not powered to demonstrate a difference at the level of PSA test uptake, there was a difference between the groups which achieved statistical significance. As shown in Table 4, PSA uptake by men in the Prosdex group was 3% (4/127) and in the questionnaire control group was 9% (11/123), *P* = .014. The Hawthorne effect of the questionnaire was also demonstrated, as the PSA test uptake in the no questionnaire control group was 2% (2/126), that is, less than that in the questionnaire control group.

In Table 5 we demonstrate the odds ratio of PSA testing, for individual participants, with respect to dichotomized knowledge/attitude/intention. PSA testing was found to be increased twofold for individuals with high attitude and high intention in the presence of high knowledge, although the confidence intervals were very wide. Finally, at six months, as shown in Table 6, knowledge was found to be significantly lower in both intervention groups but particularly so in the paper version group.

Table 4. Percent PSA test uptake by group

PSA Test Uptake[a]	Intervention and Control Groups (Percent Uptake)				
	Prosdex Group	Paper Version Group	Questionnaire Control Group	No Questionnaire Control Group	All Groups
No PSA test	96.9	90.9	91.1	98.4	94.4
PSA test	3.1	9.1	8.9	1.6	5.6

[a] Pearson chi-square: *P* = .014

Table 5. Odds ratios showing the relationship of PSA test uptake to attitude and intention scores, dichotomized at their medians

Dichotomized Outcome	Odds Ratio[a]	95% Confidence Interval
Attitude	1.80	0.5 - 6.3
Intention	1.41	0.6 - 7.7

[a] Based on 131 men with knowledge scores above the median on knowledge, and below the median on attitude and intention

Table 6. Mean knowledge scores at baseline and at 6 months by group

Timing of Questionnaire	Intervention and Control Groups[a]			
	Prosdex Group (n = 47)	Paper Version Group n = 57)	Questionnaire Control (n = 69)	No Questionnaire Control (n = 100)
Baseline				
Mean knowledge score[b]	5.13	5.79	2.30	-
6 months				
Mean knowledge score[b]	3.70	3.96	2.80	1.75

[a] Restricted to 273 men with full data available at both assessment points

[b] Knowledge scale ranges from -12 to +12

Discussion

Summary of Main Findings

The Web-based decision aid was found to promote informed decision making about the PSA test. It increased knowledge about the PSA test and prostate cancer, generated less favorable attitudes to PSA testing, and lessened the intention to undergo testing. Participants who used Prosdex and who demonstrated a high level of knowledge had less favorable attitudes and lower intentions to undergo PSA testing. This congruence between attitude and intention in the context of higher knowledge accords with our definition of informed decision making in PSA testing.

PSA test uptake was less in the no questionnaire control group than in the questionnaire control group, confirming the Hawthorne effect of increased testing in participants presented with the questionnaire. PSA test uptake was found to be lower in the Prosdex group than in the paper version group and the questionnaire control group, suggesting that, in effect, exposure to Prosdex counters the Hawthorne effect of participation, so that PSA uptake is more likely to return to background levels. Finally, the data suggested that individual participants with high knowledge but negative attitudes and intentions were less likely to undertake PSA testing.

Strengths and Limitations of the Study

This is the first Web-based four-arm randomized controlled trial of informed decision making in PSA testing that has evaluated a Web-based PSA decision aid. The intervention has been shown to be associated with informed decision making and reduced PSA test uptake. The employment of an online questionnaire linked to a Web-based decision aid represents a departure from the traditional methods of evaluating decision aids where, normally, the participant would use the decision aid in a clinic setting, sometimes after seeing a clinician, and then be given a written questionnaire. A researcher would usually facilitate the whole process [10,21,22]. In contrast, participants in this trial used the decision aid and completed the online questionnaire in a setting of their choice, usually their own homes, with no training, thereby reducing researcher bias. In total, 514 participants were recruited for this study. This was less than the original recruitment target of 600 but sufficient to attain a power of 85% for the primary outcome, knowledge. Those men who did participate were mostly well educated and in the youngest of the three age groups, which limits the generalizability of the results. There was a significant loss to follow-up: 27% were lost between allocation and the first questionnaire despite use of a reminder questionnaire for those who initially failed to participate.

The intervention used in the study, Prosdex, had previously been the subject of a rigorous development process, which included field-testing [14,15], and the outcome measurements used in the questionnaire had previously been validated in other studies. The paper version of Prosdex contained the same textual information as the Web-based decision aid. However, participants in the paper version group retained their intervention while completing the questionnaire, unlike those in the Prosdex group who were led automatically from Prosdex to the online questionnaire and had no means of reviewing it while answering the questions. We have no means of ascertaining the impact of this potential contamination. Finally, the construction of the research website resulted in the baseline questionnaire being completed after viewing Prosdex, and it is possible that this may have had an effect on the impact of the intervention

Comparison with Existing Literature

This trial builds on earlier studies that have considered the effect of PSA decision aids on the constituent components of informed decision making: knowledge, attitude, and behavior. Knowledge, as previously noted, has consistently been shown to improve with PSA decision aids [8], and recent studies have shown this to be the case with Web-based PSA decision aids [10,23]. With respect to attitude, Watson et al, in their trial of a paper-based PSA decision aid, found that their decision aid led to a less favorable attitude to PSA testing. Finally, in terms of behavior, we previously found in a systematic review of PSA decision aids that PSA testing decreased by 3.5% after using this aid [9]. This finding was reinforced in a more recent review by Volk and colleagues who found that men given a decision aid were less likely to take the PSA test (odds ratio 0.88) [8]. None of these studies, however, considered the three components of informed decision together as in our trial.

Implications for Research and Practice

The controversy surrounding PSA testing has recently been reignited by two contrasting studies of prostate cancer screening, published simultaneously. First, a large European randomized study reported a 20% reduction in prostate cancer mortality. The authors estimated, however, that in order to prevent 1 death from prostate cancer, 1410 men would need to undergo PSA testing and 48 men would need to be treated for prostate cancer [24]. In the second study, another large randomized prostate cancer screening trial from the United States, no significant reduction in mortality was found after 7 to 10 years of follow-up [25]. Whatever the outcome of the screening debate, the fact remains that the PSA test has significant limitations and those men considering it will still require balanced information in order to make informed decisions. Moreover, the information will need to be easily and repeatedly accessible, as highlighted by the significant attrition in knowledge in this study after 6 months. The Web provides the ideal medium for this accessibility, and therefore, it is our opinion that it is not a question of whether Web-based PSA decision aids are required, but instead it is a question of how best to present the information to facilitate informed decision making.

This study has demonstrated that the Web-based PSA decision aid Prosdex has a positive impact on informed decision making in accordance with the UK Prostate Cancer Risk Management Strategy [2]. However, to maximize its impact and benefit the greatest number of men, its use needs to be promoted among the public as well as among health professionals. Prosdex requires an implementation strategy.

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Conflicts of Interest

None declared

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Abbreviations

CONSORT: consolidated standards of reporting trials
DCS: Decisional Conflict Scale
GP: general practitioner
PCRMP: Prostate Cancer Risk Management Programme
PSA: prostate-specific antigen
RCT: randomized controlled trial

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Original Paper

Feasibility of Internet-Based Health-Related Quality of Life Data Collection in a Large Patient Cohort

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Abstract

Background: Patient registries are commonly used to track survival and medical outcomes in large cohorts. However, large-scale collection of health-related quality of life (HRQOL) data is more challenging because such data must be collected directly from patients. Internet-based HRQOL questionnaires are a potential solution, allowing home data collection with immediate storage in a central database.

Objectives: Our objectives were to investigate the sociodemographic predictors of Internet use and willingness to convey HRQOL information over the Internet in a Canadian tertiary care patient population and to determine whether Internet use patterns of tertiary care patients differ from those of the general Canadian population. Additionally, we sought to identify the success of home completion of Internet-based HRQOL questionnaires, as well as factors hindering home completion.

Methods: We surveyed 644 patients at the Toronto General and St. Michael’s Hospitals from November 2003 through July 2006 within a prospective, longitudinal cohort study of HRQOL in patients with lung disease or lung transplants. Using multiple logistic regression, we assessed patient age, gender, rurality, marital status, and employment or education status as potential sociodemographic predictors of having an Internet-accessible home computer, using email at least weekly, and willingness to complete a quality of life questionnaire over the Internet. Patients electing to complete questionnaires over the Internet were followed from September 2005 through March 2008 to assess completion of HRQOL questionnaires from home, identify barriers for noncompletion, and determine sociodemographic predictors for home completion.

Results: Of the 644 patients, the median age was 51 years, with a similar number of males and females. Most were urban Ontario residents, were unemployed, and were married or in a common-law relationship. Having an Internet-accessible home computer was reported by 79.7% (513/644) of patients and use of email at least weekly by 66.5% (414/623) of patients. A majority of patients (57.1% 368/644) were willing to complete HRQOL questionnaires over the Internet via an emailed link. Of the participating 644 patients, 368 elected to complete future questionnaires from home and, as part of a gradual roll-out of the home HRQOL questionnaire, 211 were sent emails inviting them to do so. Of the invited patients, 78% (165/211) completed at least one questionnaire from home. The most common reason for noncompletion was a lack of or an inability to find time to complete the questionnaire. No statistically significant sociodemographic predictors of Internet use were associated with completion or noncompletion of questionnaires from home.

Conclusions: Home, Internet-based HRQOL assessment is feasible in tertiary care patient populations with a high predicted rate of Internet usage based on sociodemographic parameters. A large minority of patients were unwilling or unable to take part in home HRQOL assessments indicating that alternative methods of data collection are still required. However, the majority of patients electing to complete home HRQOL assessments went on to do so over the Internet.

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KEYWORDS

Quality of life; cohort studies; Internet; feasibility studies; lung diseases

Introduction

Disease registries and multicenter cohort studies are widely used to capture large amounts of observational data regarding epidemiology, treatment, and outcomes of common and rare disorders [1]. One example is the registry of the International Society of Heart and Lung Transplantation (ISHLT), which tracks a wide variety of procedural and outcome data, including survival and complication rates, from transplant programs around the world [2].

Registries and multicenter observational studies typically focus on survival and other easily classifiable medical outcomes. While health-related quality of life (HRQOL) is widely recognized as an important outcome [1,3] large-scale collection of HRQOL data has lagged behind. Health-related quality of life can be broadly defined as "an individual's satisfaction or happiness with life in domains he or she considers important…insofar as they affect or are affected by factors that are generally considered to fall under the purview of health care providers, or that are likely to be the target of a health care intervention" [4].

Lung transplantation is one clinical area where HRQOL data are needed to improve clinical decision-making [5]. Current clinical guidelines recommend lung transplantation based on expected improvement in survival because the factors that impact upon HRQOL in advanced lung disease before and after transplantation are poorly characterized [6]. However, lung transplantation may greatly improve HRQOL even for conditions where the survival benefit is unclear, and the risks of surgery and immunosuppressive drugs introduce important trade-offs that are difficult to understand on the basis of survival considerations alone.

Unlike "hard" medical outcomes, HRQOL data must be collected directly from patients, scored, and entered into a centralized database. This requires time, money, and access to patients, all of which may be limited for centers voluntarily reporting health outcome data. The Internet provides an ideal method of obtaining HRQOL data from multiple home and clinic sites following which data can be automatically saved and scored in a central database. Electronic HRQOL instruments have several additional advantages including the ability to automatically prompt subjects to correct missing or invalid responses, skip irrelevant items, and track the time, date, and duration of each assessment [7]. However, reliable home follow-up is essential for optimal usage of Internet technology, and stated willingness to transmit information does not always translate into action. In studies where prior Internet survey participants were invited by email to participate in an Internet survey, the participation rate was as low as 30%, and the rate of invalid email addresses was 23%, illustrating several potential obstacles [8].

Internet use for health purposes is a global phenomenon [9]. In a recent cross-sectional study of individuals in the metropolitan Paris area, those having Internet access as well as a medical condition were more likely to use the Internet to search for health information [10].

While predictors of Internet use have been identified for the general population [9], tertiary care clinic patients may have different rates and predictors of Internet usage. On one hand, access to highly specialized care may indicate a savvy health care consumer with above-average computer usage; on the other hand, the deleterious effects of chronic illness on education, employment, and income may limit access to home computers and the Internet. A recent study by Wangberg et al showed that individuals with higher reported levels of subjective health status were more likely to use the Internet to seek health information [11]. In a hospital care setting among new patients in a teaching rheumatology clinic, 62.5% reported having researched their symptoms and condition on the Internet prior to their first visit [12].

With close to 73% of the Canadian adult population accessing the Internet and 59% of adult home users using the Internet for health or medical information, the Internet is rapidly becoming a primary source of medical information for Canadians [9]. Additionally, for patients with chronic conditions, Internet-based tools for patient communication of symptom and disease information have been shown to be feasible models for patient-physician communication [13,14].

However, broad use of the Internet for direct communication between health care providers and patients is limited. For patients to communicate HRQOL information over the Internet, they require secure Internet access and must be willing to transmit potentially sensitive information over the Internet.

Our research aims were as follows: (1) to characterize Internet access and usage patterns of tertiary care patients; (2) to determine whether Internet access and usage in tertiary care patients differ from those of the general Canadian population; (3) to quantify the willingness of tertiary care patients to communicate HRQOL information over the Internet; (4) to define sociodemographic and health-related predictors of both Internet use and willingness to communicate HRQOL information over the Internet; and (5) in a subset of patients who indicated willingness to communicate information over the Internet, to assess actual completion rates when patients were invited to submit information from home.

Methods

This study was a part of an ongoing, prospective, longitudinal cohort study of HRQOL using an Internet-based questionnaire (Multimedia Appendix 1). The study was approved by each institution's research ethics board, and all subjects provided written informed consent.

Subjects

Patients attending selected Toronto General Hospital and St. Michael's Hospital outpatient clinics were enrolled as study subjects from November 2003 through July 2006. The study population consisted of adult subjects who had been diagnosed with one of the four most common indications for lung transplantation (cystic fibrosis (CF), chronic obstructive pulmonary disease (COPD), interstitial lung disease (ILD), and pulmonary arterial hypertension; a small adult population of subjects with other indications for lung transplantation; and a sixth group of subjects who had received a lung transplant. All posttransplant patients were eligible for the study while other patients were included if they were potential future transplant patients (ie, age ≤ 75, clinically significant lung disease with prespecified criteria for each disease, nonsmokers, and no other significant comorbidities which would preclude transplantation). We attempted to enroll a consecutive sample of stable patients presenting to clinic. Ability to read and understand English was a prerequisite. In total, six patients were not included because of an inability to understand English.

Study Design

Participating patients in each group completed an Internet-based questionnaire that assessed HRQOL and computer and Internet use habits. The final question asked subjects whether they would prefer to complete the questionnaire in the future over the Internet from their own home using their home computer. Subjects who indicated they preferred this option were asked to provide their email address. Following the initial questionnaire, subjects completed questionnaires at least annually either at clinic visits or at home over the Internet.

Questionnaires were housed on a secure, encrypted website. The website was designed for use in a Windows environment using MS Internet Explorer version 5.5 or higher. Patients were informed that the website was not accessible through Netscape Navigator or Mozilla Firefox. Website security involved 128-bit public key encryption, and access was restricted to registered users with a valid ID number and password. Subjects consenting to participate in the study were supplied with a unique 6 digit ID number corresponding to their hospital ID number and asked to generate their own unique password. Account creation was verified during the first clinic visit when subjects underwent an initial HRQOL assessment. Computer operating system and/or Internet browser type were not factors in patient recruitment.

Patients electing to complete future questionnaires at home over the Internet were contacted by email one week before follow-up clinic appointments and were provided with a Web address to access the questionnaire. In the event of unsuccessful email transmission due to an incorrect email account, the patient was contacted by phone to provide an updated address. This phase of the study took place from September 2005 through March 2008. For logistical reasons the second phase of the study was restricted to clinic patients from the Toronto General Hospital and did not include patients from the other participating clinics. During this second phase of the study, then, 211 patients who had said they were willing to complete the questionnaire from home were contacted and asked to complete the questionnaire. Patients declining home completion completed the questionnaire during their clinic appointment using a hospital computer.

In this paper, we report data from the 644 participating patients' initial assessments, which took place in a supervised clinic environment, as well as follow up assessments for a subset of 211 patients (described above) who requested future assessments over the Internet and were then asked to complete these assessments.

The 211 patients were invited to complete a questionnaire from home prior to each transplant clinic visit following the first clinic visit during which they were recruited for the study. Depending on the severity of lung disease pretransplant or time since transplant, the interval between follow-up assessments ranged from 3 months to one year. Nonresponders were approached during clinic visits and requested to provide a reason for not responding to the initial emailed survey request.

Measurements

The HRQOL assessment

Components of the online HRQOL assessment included the Standard Gamble utility for current health, a population preference-weighted utility measure (EQ-5D), a general health survey (SF-36), a disease-specific health index (St George's Respiratory Questionnaire, SGRQ), and a visual analog scale. Completion of the entire HRQOL assessment in the clinic environment required an average of 26 minutes. The HRQOL assessment could only be completed in one session and could not be saved and finished at a later date.

Outcome Variables

Computer use questions assessed past computer use, possession of a home computer with or without Internet access, Internet connection speed (high-speed vs dial-up), and the frequency of computer, email, and Internet use. We chose home Internet access, checking email at least weekly, and stated willingness to do home HRQOL assessments as the primary outcome measures for the initial in-clinic assessment as all of these were necessary if Internet-based HRQOL assessment from home was feasible. We revised the computer use questionnaire shortly after the study's inception, so that some patients did not answer all the computer use questions. We examined home HRQOL completion rate and reasons for noncompletion in patients who were invited to do home assessments.

Predictor Variables

Sociodemographic parameters collected during the assessment included age, gender, province of primary residence, employment or school status, and marital status. Primary lung disease, transplant status, and HRQOL were also considered as predictor values. Rurality and median household income were determined based on patient's permanent home address postal code retrieved from medical records.

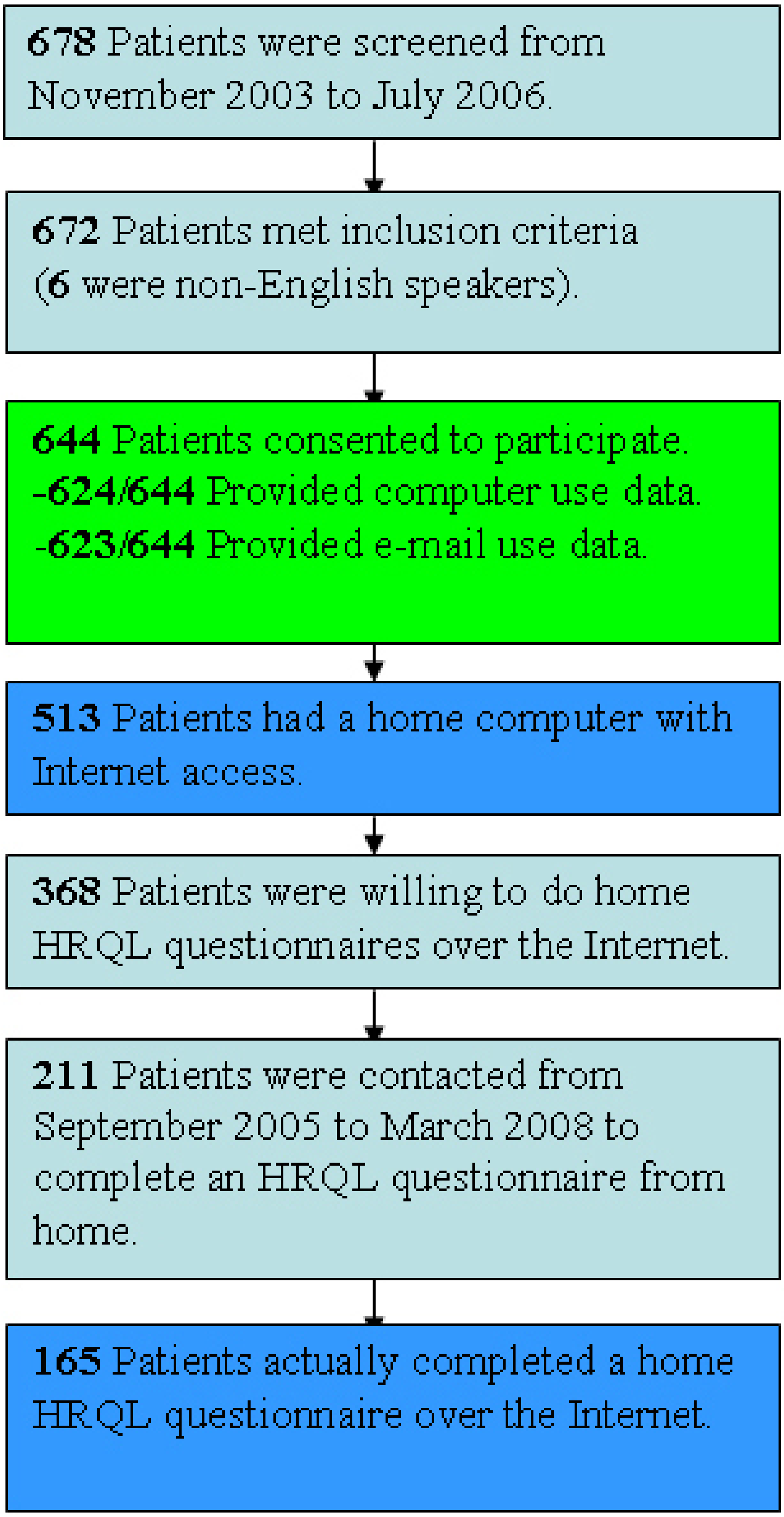
For age data, the median value was used to define the boundary between dichotomized categories. Frequencies of computer use, email use, and Internet searching/browsing data were dichotomized into the following categories: at least once a week and less than once a week. Rurality was determined through comparison of patient postal codes and Canada Post urban and rural forward sortation area (FSA) postal codes. Median household income was inferred using Statistics Canada median household income data by FSA region [15]. As median household income was inferred from FSA codes and not directly collected from patients, it was used for descriptive purposes only. Median household income was categorized into quartiles as found in the National Population Health Survey [16]. The four quartiles were: less than Can $30,000; Can $30,001 to Can $60,000; Can $60,001 to Can $80,000; and greater than Can $80,000. Characteristics of Internet use among the general Canadian population were obtained from the 2007 Canadian Internet Use Survey (CIUS) [9].

Analysis

We used two-sided one-sample test for binomial proportions to compare our data with the proportions provided by Canadian Internet Use Survey (CIUS) dataset representing the Canadian population's usage of the Internet. Two sample *t* tests were performed to compare baseline HRQOL between subjects willing and not willing to complete future HRQOL assessments over the Internet. To examine associations between health-related predictors (lung disease and transplant status) of Internet use and willingness to communicate HRQOL information over the Internet, we assessed bivariate associations using Chi-square tests with Yates continuity correction. Binary logistic regression was used to assess the independent effects of six sociodemographic predictor variables on each of the four outcomes: home Internet access, regular email usage, stated willingness to complete future HRQOL questionnaires over the Internet, and actual completion of at least one follow-up HRQOL assessment over the Internet. For each outcome, the fitted model included all the predictor variables. We did not test for interactions, nor did we adjust for multiple comparisons.

Statistical analyses were performed using the SAS System version 9.1 for MS Windows (SAS Institute, Inc, Cary, NC, USA) and $P < .05$ was taken to indicate statistical significance.

Figure 1. Patient flow through our study



678 Patients were screened from November 2003 to July 2006.

672 Patients met inclusion criteria (**6** were non-English speakers).

644 Patients consented to participate.
-**624/644** Provided computer use data.
-**623/644** Provided e-mail use data.

513 Patients had a home computer with Internet access.

368 Patients were willing to do home HRQL questionnaires over the Internet.

211 Patients were contacted from September 2005 to March 2008 to complete an HRQL questionnaire from home.

165 Patients actually completed a home HRQL questionnaire over the Internet.

Results

Out of 672 patients approached to participate in the study, 644 consented and completed the initial assessment. Among nonconsenting patients, reasons for nonparticipation were: not interested in research studies (14 patients); already enrolled in other studies (1 patient); not feeling well enough to participate (1 patient); had been through enough tests (2 patients); or not emotionally prepared to participate (2 patients). An additional 8 patients did not provide a reason for not participating. Data for email use was collected from 623 patients out of a total of 644 patients who completed the survey. Data for computer use as well as Internet searching/browsing was collected from 624 patients, and data for the speed of home Internet connections (high-speed versus dial-up) was collected from 232 patients. A subset of the study cohort was contacted later to complete the assessment from home. A diagram of patient flow through our study is shown in Figure 1.

Table 1 highlights the sociodemographic characteristics for our entire consenting patient cohort, as well as for subgroups categorized by pretransplant pulmonary disease and posttransplant status. The majority of our patients were between 35 and 64 years of age. Most were urban, Ontario residents, were unemployed or not in school, and were either married or involved in common-law relationships.

Table 1. Sociodemographic characteristics of our patient cohort

		PreTransplant (n = 364)					Post Transplant
	Whole Cohort	COPD	ILD	Pulmonary Hypertension	CF	Other	
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
	n = 644	n = 76	n = 66	n = 90	n = 109	n = 23	n = 280
Age (years)							
18-34	121 (18.8)	2 (2.6)	0 (0)	6 (6.7)	65 (59.6)	3 (13.0)	45 (16.1)
35-54	246 (38.2)	20 (26.3)	20 (30.3)	50 (55.6)	41 (37.6)	12 (52.2)	103 (36.8)
55-64	179 (27.8)	35 (46.1)	29 (43.9)	22 (24.4)	3 (2.8)	6 (26.1)	83 (29.6)
65 and over	98 (15.2)	19 (25.0)	17 (25.8)	12 (13.3)	0 (0)	2 (8.7)	49 (17.5)
Gender							
Male	312 (48.4)	37 (48.7)	37 (56.1)	26 (28.9)	62 (56.9)	10 (43.5)	140 (50.0)
Female	332 (51.6)	39 (51.3)	29 (43.9)	64 (71.1)	47 (43.1)	13 (56.5)	140 (50.0)
Rurality							
Urban	524 (81.4)	55 (72.4)	51 (77.3)	76 (84.4)	94 (86.2)	19 (82.6)	229 (81.8)
Rural	120 (18.6)	21 (27.6)	15 (22.7)	14 (15.6)	15 (13.8)	4 (17.4)	51 (18.2)
Employment/school							
Full-time	146 (22.7)	11 (14.7)	13 (19.7)	24 (26.9)	53 (48.6)	1 (4.3)	42 (15.0)
Part-time	56 (8.7)	7 (9.3)	2 (3.0)	3 (3.4)	10 (9.2)	2 (8.7)	32 (11.5)
Unemployed	442 (68.6)	57 (76.0)	51 (77.3)	62 (69.7)	46 (42.2)	20 (87.0)	205 (73.5)
Marital status							
Married/common-Law	420 (65.2)	48 (63.2)	51 (77.3)	56 (62.2)	52 (47.7)	14 (61.0)	197 (70.9)
Divorced/separated	74 (11.5)	17 (22.4)	7 (10.6)	15 (16.7)	6 (5.5)	1 (4.3)	25 (9.0)
Single	134 (20.8)	8 (10.5)	5 (7.6)	16 (17.8)	50 (45.9)	3 (13.0)	50 (18.0)
Widowed	16 (2.5)	3 (3.9)	3 (4.5)	3 (3.3)	1 (0.9)	5 (21.7)	6 (2.1)
Province of residence							
Ontario	577 (89.6)	68 (89.5)	56 (84.9)	85 (94.4)	105 (96.3)	18 (78.3)	245 (87.5)
Atlantic Canada	62 (9.6)	7 (9.2)	10 (15.1)	4 (4.4)	4 (3.7)	4 (17.4)	33 (11.8)
Other	5 (0.8)	1 (1.3)	0 (0)	1 (1.1)	0 (0)	1 (4.3)	2 (0.7)
Estimated median household income							
Lowest quartile	9 (1.4)	0 (0)	0 (0)	0 (0)	6 (5.5)	0 (0)	3 (1.1)
Second quartile	425 (65.9)	57 (75.0)	41 (62.1)	55 (61.1)	69 (63.3)	16 (69.6)	186 (66.4)
Third quartile	193 (30.1)	16 (21.1)	17 (25.8)	23 (25.6)	25 (22.9)	6 (26.1)	60 (21.4)
Highest quartile	17 (2.6)	3 (3.9)	8 (12.1)	12 (13.3)	9 (8.3)	1 (4.3)	31 (11.1)

Table 2 details the characteristics of computer and Internet use among participating patients. In total, 79.7% (513/644) of patients had a home computer with Internet access. Data for the speed of home Internet connections (high-speed versus dial-up) was collected from 232 patients. Among these patients, 187 or 80.6% connected to the Internet through a high-speed connection. Of 623 patients who responded to the question, 66.5% (414/623) were accessing email at least weekly. Of the total 644 participating patients, 57% (368/644) were willing to complete HRQOL questionnaires over the Internet, indicating that a sizable minority were not prepared to do this.

Table 2. Computer use questionnaire and responses in 644 subjects

	n (%)
Have you used a computer before today?	
Yes	558 (86.6)
No	86 (13.4)
Do you have a computer at your current residence?	
Yes	544 (84.5)
No	100 (15.5)
If yes, do you have Internet access? (n = 544)	
Yes	513 (94.3)
No	31 (5.7)
Connection speed (n = 232)	
High-speed	187 (80.6)
Dial-up	45 (19.4)
Computer use (n = 624)	
Never/in the past	137 (22.0)
Monthly	35 (5.6)
Weekly	108 (17.3)
Daily	344 (55.1)
Email use (n = 623)	
Never/in the past	189 (30.3)
Monthly	20 (3.2)
Weekly	107 (17.2)
Daily	307 (49.3)
Internet searching/browsing (n = 624)	
Never/in the past	187 (30.0)
Monthly	44 (7.1)
Weekly	144 (23.0)
Daily	249 (39.9)
In the future, would you prefer to complete from home? (n = 644)	
Yes	368 (57.1)
No	276 (42.9)

Table 3. Comparison of Internet use habits among our tertiary care patient cohort and the general Canadian population

Computer Use Parameter:	Prevalence of Computer Access and Use		*P*
	Study Population n (%)	General (Canadian) Population in 2007 (%)[a]	
Internet access among urban residents	423/443 (95.5)	76.0	< .001
Internet access among rural residents	90/101 (89.1)	65.0	< .001
High-speed Internet access	187/232 (80.6)	88.0	< .001
Regular Internet use	437/624 (70.0)	73.0	.09
Daily Internet use	249/624 (39.9)	68.0	< .001

[a] Statistics Canada. The Daily, Canadian Internet Use Survey. 2008.

Table 3 presents a comparison of the Internet use habits of our cohort of tertiary care patients to the general Canadian population as reported in the Canadian Internet Use Survey [9]. Of patients in our cohort, 70% (437/624) were regular Internet users compared with 73% of Canadian adult population. However, 68% of Canadians used the Internet on a daily basis while 40% of our patients (249/624) were daily Internet users. Our urban and rural patients were more likely to be Internet users compared with those in the general Canadian population. High-speed Internet access was available for 81% of our patients (187/232), which was lower than the 88% reported for the Canadian population.

No statistically significant differences in computer use characteristics or willingness to complete the questionnaire from home were observed between pretransplant and posttransplant patients, or between patients with different lung diseases. According to transplant status, 56% of pretransplant patients (204/364) and 59.3% (166/280) of posttransplant patients were willing to complete future questionnaires from home (*P* = .40).

There was no difference in any of the assessed quality of life measures between subjects willing and not willing to complete HRQOL assessments from home (*P* < .10 for all comparisons, data not shown).

Table 4 presents the multiple logistic regression for predictors of computer and Internet use. Access to an Internet-accessible home computer, use of email at least weekly, and stated willingness to complete the HRQOL questionnaire from home were all associated with age younger than 51 years and employment or school enrollment. Patients younger than 51 years of age were twice as likely as their older peers to have an Internet accessible home computer and to use email at least weekly. Patients employed or in school were over three times as likely to have an Internet accessible home computer and use email at least weekly. No significant variables were identified to differentiate the characteristics of patients who completed one or more HRQOL questionnaires from their home computers versus those who did not.

Table 4. Binary logistic regression analysis of factors associated with computer and Internet use

	Internet Access for Computer at Current Residence (n = 644)			Email Use (n = 623)			Willing to Complete Questionnaire From Home Over the Internet (n = 644)			Actual Completion of One or More Questionnaires From Home Over the Internet (n = 211)		
	Odds Ratio	95% CI	*P*	Odds Ratio	95% CI	*P*	Odds Ratio	95% CI	*P*	Odds Ratio	95% CI	*P*
Age < 51 years	1.99	1.17–3.38	.01	2.02	1.39–2.93	.001	1.56	1.11–2.19	< .01	1.01	0.99–1.03	.61
Male gender	1.07	0.66–1.75	.77	0.99	0.69–1.42	.95	1.09	0.79–1.50	.61	0.95	0.48–1.86	.95
Urban residence	1.00	0.55–1.85	.98	1.04	0.66–1.64	.86	1.37	0.91–2.06	.13	0.69	0.28–1.70	.42
Employed or in school	3.24	1.60–6.56	.001	3.71	2.35–5.88	< .001	1.48	1.02–2.13	.04	1.38	0.64–3.01	.31
Married/ common-law	1.38	0.82–2.32	.23	0.70	0.47–1.04	.08	0.87	0.62–1.24	.45	0.80	0.39–1.69	.35
Ontario resident	1.50	0.75–3.03	.25	0.92	0.52–1.64	.79	1.00	0.59–1.69	.99	1.28	0.46–3.55	.60

For the 368 patients that preferred to complete future questionnaires from home, 211 patients received emails inviting them to do so during the study period, and 78% (165/211) of these patients went on to complete at least one questionnaire from home. Of the 211 patients invited to complete questionnaires from home, 27 patients (13%) were contacted by phone to update their email address following unsuccessful email transmission. An additional 46 patients (21.8%) received one or more email invitations but did not complete a questionnaire from home. For these patients, reasons for noncompletion were collected during clinic visits and are depicted in Table 5. The most common reason for noncompletion was a lack of time to complete the questionnaire; 17 of the 46 patients (37%) gave this reason while 15% (7/46) did not provide a reason for noncompletion. Among the 211 patients who were invited to complete questionnaires from home, there were no significant sociodemographic predictors of actual completion.

Table 5. Reasons for noncompletion of home HRQOL questionnaires over the Internet (n = 46)

Reasons for Noncompletion	n (%)
Did not find time	17 (37)
Incompatible hardware/software	6 (13)
Computer was non-functional or under repair	5 (11)
Infrequently checked email	5 (11)
Changed email address	3 (7)
Email directed to “junk” folder	2 (4)
Patient withdrew from study	1 (2)
Patient did not provide a reason	7 (15)

Discussion

In this study, we surveyed participants enrolled in a longitudinal cohort study of HRQOL regarding home Internet access and usage, self-reported willingness to do Internet-based HRQOL assessments, and actual completion rates for these assessments. We found a majority of patients have the necessary equipment and are willing to communicate HRQOL information over the Internet. However, the success of Internet-based HRQOL data collection will depend upon the characteristics of the patient cohort under study. Similar to the general population [9], young, single urban dwellers who are working or in school are much more likely to have Internet access and be willing to participate than subjects without these characteristics.

Within our study cohort of tertiary care patients, for example, the group of cystic fibrosis patients is fairly well described by these parameters (as can be appreciated by the characterization of this cohort in Table 1) and might be an excellent candidate population for longitudinal home HRQOL monitoring over the Internet. On the other hand, older patients such as the group with COPD or ILD might be less suited to HRQOL data collection exclusively from home, and might require supplemental strategies such as data collection in clinic, by telephone, or via mailed paper questionnaires. While not directly assessed in our study, the impact of the age of patients with specific diseases or the resulting functional and cognitive impact of these diseases on the abilities of patients should be considered when designing Internet-based data collection strategies.

Most patients agreeing to complete questionnaires from home went on to do so. For the minority of patients that remained noncompleters from home, time constraints and use of an incompatible Web browser (ie, Firefox and Netscape) or operating system (ie, Macintosh) were largely responsible for preventing home completion. Infrequent access to email, incorrect address, or spam filters accounted for a small percentage for reasons of noncompletion. No sociodemographic factors were statistically significant in predicting home completion.

Compared with the Canadian population, our patients were more likely to have Internet-accessible computers in both urban and rural residences. However, frequency and regularity of Internet use among our patients was statistically less than that of the Canadian population. Infrequent Internet use may reflect the characteristics of our cohort of older, unemployed, or retired individuals that have lower occupational need for daily Internet and email use. However, similar prevalence of Internet access and high-speed connections suggests that population-based estimates of Internet usage may be useful for planning Internet-based studies in tertiary care populations.

With respect to our HRQOL instrument, the questionnaire required completion in one session and could not be saved and returned to at another time. This design limitation may have affected stated patient willingness to complete it over the Internet as well as the lack of time cited by some patients who failed to do home assessments. The questionnaire also would not run in a Macintosh operating system or on a mobile phone browser, and this may have accounted for some subjects’ unwillingness or inability to do home assessments. Our results suggest several strategies that may be helpful in improving response rates, including designing questionnaires to run on multiple operating systems and browsers, providing ample time for survey completion including the capability to save and return to partially completed questionnaires, and sending email reminders after the initial invitation.

Internet-based HRQOL assessment will become increasingly important as disease registries and multicenter cohort studies move to add HRQOL to the other outcomes data they collect [17]. HRQOL is widely recognized as an essential outcome measure even for “lifesaving” interventions such as cancer care or organ transplantation [18-20].

Even for patients without home Internet access, collection of HRQOL data in clinic through an Internet site offers advantages over traditional, paper HRQOL forms. Electronic HRQOL instruments include the ability to automatically prompt subjects to correct missing or invalid responses, to skip irrelevant items, to track the time, date and duration of each assessment, and to automatically save and score the HRQOL measures in a central database [7]. Several studies have favorably compared paper and electronic versions of HRQOL instruments, including the SF-36 [21] and a visual analog scale for global health [22]. These studies indicate that electronic HRQOL instruments are valid, reliable, are completed more quickly and with fewer errors, and are preferred by the majority of patients.

While prior studies have examined the feasibility of Internet-based HRQOL assessment, some have focused on HRQOL assessment in the clinic setting as a tool for clinicians to better understand patients' health. For example, Gutteling et al deployed a voluntary Internet-based HRQOL assessment in a single academic hepatology clinic [23], while Rogausch et al demonstrated the feasibility and acceptance of electronic HRQOL instruments (including a subgroup of patients with chronic lung disease) in a multicenter general practice cohort [24]. Our study confirms that clinic-based HRQOL is feasible and acceptable to patients in a tertiary care clinic setting. While these prior studies relied on busy clinic staff to explain the questionnaire and invite patients to participate, with variable results, our study employed dedicated research assistants for this purpose. This explains our high participation rate and reflects a "best possible" scenario that would not easily be replicated as part of routine clinical care.

However, perhaps the most powerful argument for Internet-based HRQOL instruments is that the Internet can bring data collection into patients' homes anywhere in the world. Previous studies of Internet-based HRQOL assessment have included samples of members of the general public [25] or patients who self-identify as having a particular clinical condition and who are recruited through a patient website [26,27]. While each of these study designs provides valuable information, they are limited by the inability to determine whether participants in fact have the disease of interest, and, therefore, the data collected cannot be compared with clinical HRQOL data.

Our study combined recruitment of a well-characterized cohort of patients in subspecialty clinics with ongoing Internet-based HRQOL assessment from home. This strategy would allow HRQOL data to be available to easily supplement the traditional medical data reported to disease registries and multicenter studies. Our study demonstrates the feasibility of this approach and highlights some of the current limitations. We found that the majority of tertiary care clinic patients in our Canadian cohort possessed the necessary computer equipment to communicate HRQOL information over the Internet and were willing to participate in Internet-based home HRQOL data collection. For researchers involved in Internet-based HRQOL data collection, our findings demonstrate proof of concept for large-scale data collection through an Internet-based platform. However, we also highlight some of the challenges that still exist.

Despite the high prevalence of Internet access, our study indicates that there are still barriers to home Internet-based HRQOL data collection from patients. As many as 74% of respondents to the Canadian Internet Use Survey reported that they were concerned, or very concerned, about Internet privacy [28]. This may partly explain why patients with Internet access may still decline to transmit HRQOL information from home. However, the quantitative approach we used in our study did not allow us to determine why patients chose not to transmit HRQOL data over the Internet. A qualitative study could use open-ended questions to better elucidate patients' concerns in this regard, and would be an essential adjunct to our analysis.

Our study has some notable limitations. The cohort consisted largely of patients residing within the Greater Toronto Area, and there was an underrepresentation of rural residents, which likely reflects, to some extent, referral patterns to the participating clinics. However, Internet contact with rural patients is particularly important as these are the most difficult patients to access. Furthermore, our study measured only patient willingness to complete an HRQOL questionnaire for research purposes and should not be assumed to reflect willingness to transmit medical or other personal information over the Internet. Patients understood that Internet completion of the questionnaire was voluntary and would not affect their medical care. Patient willingness could change if the transmitted information could alter the care they receive.

One additional limitation relates to our use of an English HRQOL questionnaire. As ability to read and understand English was a prerequisite for our questionnaire, six nonEnglish speakers were excluded from our study.

Internet-based home HRQOL assessment in large patient cohorts depends on the availability of an accessible and secure Internet connection, email use that is regular enough to facilitate dialogue, a willingness to communicate HRQOL information over the Internet, and the time and technical requirements to allow such communication. Studies in which the participants are likely to be young, educated or employed, single, and urban would have a high predicted rate of response. For more heterogeneous populations, additional means of HRQOL assessment remain necessary to ensure that HRQOL outcomes data are generalizable across study cohorts.

Given the movement in clinical medicine toward therapies and interventions that generate survival benefit and improvement in quality of life, Internet-based home HRQOL data collection has the potential to allow for collection of vast quantities of data that may be applicable to better defining patient populations that may or may not benefit from therapeutic intervention. Additionally, with major clinical and surgical interventions being deployed in community hospitals and community clinics engaging in long-term follow-up, Internet-based HRQOL data collection provides for both secure data collection from distributed community sites as well as centralized data collection for analysis and interpretation. Convenient home HRQOL data collection has the potential to increase access to patients capable of participating in research and decrease the number of patients lost to follow-up. We anticipate that home Internet-based HRQOL assessment will play an increasing role in research and clinical care.

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Conflicts of Interest

None declared

Multimedia Appendix 1

Online questionnaire: health-related quality of life in advanced lung disease and lung transplantation

[PPT file (Microsoft Powerpoint File), 7781 KB - jmir_v12i3e35_app1.ppt]

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Abbreviations

CF: cystic fibrosis
CIUS: Canadian Internet Use Survey
COPD: chronic obstructive pulmonary disease
FSA: forward sortation area
HRQOL: health-related quality of life
ILD: interstitial lung disease
ISHLT: International Society of Heart and Lung Transplantation
SGRQ: St George's Respiratory Questionnaire

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Original Paper

Consumers’ Use of Web-Based Information and Their Decisions About Multiplex Genetic Susceptibility Testing

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Abstract

Background: Few data exist to inform concerns raised by online direct-to-consumer marketing of genetic susceptibility tests, such as those offered by commercial entities like 23andme, Navigenics, and DNA Direct. The Multiplex Initiative, a population-based study of healthy adults, provides the first opportunity to evaluate how use of a Web-based decision tool that conveyed information about a genetic susceptibility test influenced individuals’ test decisions.

Objective: To inform the ongoing debate over whether individuals offered genetic susceptibility testing without the involvement of a health care provider (eg, through direct-to-consumer testing) can make informed decisions about testing when guided by online decision aids.

Methods: Participants were 526 members of a large health maintenance organization aged 25 to 40 years old who visited a study website. Multivariate logistic regression models were tested to examine the association of website usage with downstream test decisions.

Results: Participants viewed an average of 2.9 of the 4 pages introducing the multiplex test, 2.2 of the 8 pages describing the health conditions, and 3.2 of the 15 pages describing the genes. For each page viewed, participants were more likely to describe their decision-making as easy (odds ratio [OR] 1.04, 95% confidence interval [CI] 1.01-1.07) and to decide to be tested (OR 1.08, 95% CI 1.05-1.11).

Conclusions: Healthy adults in this study perceived Web-based genomic information presented using evidence-based communications approaches to be helpful in supporting both decisions to test and not to test. Continued research is needed to ensure that these results generalize to target groups with lower literacy and less Internet savvy.

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KEYWORDS

Genetic testing/methods; genetic testing/psychology; genetic predisposition to disease/psychology; health knowledge, attitudes, practice; health surveys; internet/utilization; polymorphism, single nucleotide; public health/methods; risk assessment/methods

Introduction

Several new genetic tests provide individuals with information about their susceptibilities to a wide array of common health conditions. The availability of these tests is expected to increase greatly over the next decade as more gene-disease associations are identified [1]. Despite the lack of data on clinical effectiveness, commercial entities are even now marketing such tests online directly to consumers (eg, 23andme, Navigenics, and DNA Direct), a practice growing in prominence in the United States [1-4]. This report presents data from the Multiplex Initiative [5,6] to inform the ongoing debate over whether individuals offered genetic susceptibility testing without the involvement of a health care provider—that is, direct-to-consumer (DTC)—can make informed decisions about testing when guided by online decision aids.

One of the most hotly contested issues has been focused on the challenges of communicating complex information about genetic risk for common, chronic diseases [7,8]. Given the complex etiology of common diseases, critics have expressed concern that the public will not understand genomic information without the assistance of a health care provider and will be unable to make informed decisions about taking genetic susceptibility tests [7,9,10]. Of particular concern is whether individuals can understand the limitations of the information generated by these tests and appreciate what cannot be learned from such tests [7].

Direct-to-consumer companies’ reliance on interactive Web-based approaches adds complexity to these communication issues [11,12]. The Internet increases dissemination potential, thereby enabling reach to ever-increasing proportions of the population with health information and genetic testing [5,13,14]. However, Web-based approaches also may be inadequate for communicating complex genetic susceptibility information, particularly for individuals with limited computer or health literacy skills, when compared with interpersonal approaches [15,16,17]. Indeed, existing DTC marketing websites have been shown to use language that is too difficult for most of the US public to comprehend and to have limited content in areas that may be critical for decision-making [18].

Most prior research regarding comprehension and uptake of genetic testing has occurred in the context of high-risk familial cancer syndromes. The majority of those who present for such testing have already decided to be tested [19,20]. These studies, therefore, have provided little insight into differences among those who decide to be tested and those who considered testing but decided not to test or into whether online information can support such decision-making. To date, there have been no population-based studies evaluating whether or not individuals can use information made available online to make an informed decision about testing. These questions can be examined using data generated by the Multiplex Initiative [1].

The Multiplex Initiative was designed to develop the infrastructure needed to evaluate a multiplex test (ie, a test that includes multiple genetic variants for multiple health conditions) taken by healthy adults insured through a large managed care organization. The study provided the first opportunity to systematically present genetic susceptibility information based upon best communication practices and then to examine individuals’ responses to the information. Despite the fact that testing was offered at no cost and the target population was insured, we reported previously that those who logged on to a study website to consider testing and subsequently elected to be tested were significantly more likely to be college educated and white than those who did not log on or were not interested in testing [6].

In this report, we pose three specific research questions: (1) How do participants in the Multiplex Initiative engage with different content areas of information provided on the website? (2) How do participants rate the quality and usefulness of the website information? (3) Is website use associated with decisions about genetic testing?

Methods

Study Design and Participants

The Multiplex Initiative has previously been described in detail [6]. In brief, study participants were selected from a pool of 350,000 members of a large Midwestern health maintenance organization. Selection criteria included being between the ages of 25 and 40 years, having been enrolled in the plan for at least two years, and not having any of the health conditions included on the Multiplex test. Groups traditionally underrepresented in genetics research (ie, men, blacks, and those with lower education) were oversampled as described in detail elsewhere [6]. All procedures were approved by the institutional review boards of the National Human Genome Research Institute and the Henry Ford Health System.

A baseline telephone assessment was attempted with 6348 sampled individuals. Of these, 1930 completed the assessment and were invited to visit the study website. Individuals completed a consent process as part of the initial Web module. Participants were told that they would be asked to complete brief questionnaires and to review Web content. A total of 612 individuals visited the website, and 527 completed all four website-based assessments. Although website visitors who did not complete all four assessments were similar to those who completed all assessments based on age, gender, educational attainment, and marital status, white participants were more likely to complete all assessments than black participants ($P = .002$). Following completion of the website portion of the study, interested individuals completed an in person clinic visit, and then a blood draw was performed on those individuals who decided to undergo testing. The analyses presented here are based on 526 individuals who visited the website, completed all four website assessments, and for whom data regarding the testing decision were available. These 526 individuals had a mean age of 34.6 years. Half (263/526) were white. A majority were female (297/526 or 56.5%), and most were married or in a partnered relationship (336/526 or 63.9%).

Website Content

The content of the Multiplex Initiative study website was developed by an interdisciplinary team of researchers, drawing on prior research and best practices in health literacy and risk communication. Health literacy principles were used to develop the information content of the website. For example, the scope of the content was limited to what the team considered the most essential information needed to support participant decision-making [21]. In addition, the information was organized using a layered approach [21,22]. Participants were offered a menu of content topics and could then choose the order and amount of content reviewed, allowing those participants who wanted more detailed content to find that information. We avoided using technical jargon where possible (eg, using “risk version” instead of “risk-increasing gene variant”) and defined jargon where it was used (eg, “a risk factor is anything that increases your chance of getting a health condition”). We drew upon prior risk communication research to convey risk information on the website. For example, risk estimates were given using an “n in 100” format, which prior research has shown to convey risk information best to lay individuals [23,24]. In addition, we selected pictograph graphics to visually convey the risk information, a type of graphic that has been shown to convey this information to lay audiences more effectively than alternative graphic formats [24].

The website content was organized into four modules: (1) Multiplex Genetic Testing: What it Can and Cannot Tell You; (2) Diseases and Genes on the Multiplex Genetic Test; (3) Your Rights if You Take Part in Multiplex Genetic Research; and (4) Your Decision to be Tested or Not (see Textbox 1). Two examples of website pages are shown in Figures 1 and 2. The participants received small incentives (gift cards up to US $50 from a national retail chain) for completing the website assessments.

Textbox 1. Study website content and assessment points

Module 1: Multiplex Genetic Testing: What it Can and Cannot Tell You (4 pages)

Content topics

- Definition of multiplex genetic testing
- Testing procedures
- Overview of health conditions and genes
- Meaning of “genetic risk”
- Importance of health habits and other factors in disease risk

Module 2: Diseases and Genes on the Multiplex Genetic Test (23 pages)

Content topics

For the eight health conditions:

- Description of condition
- Known risk factors for condition
- Genes that affect risk of condition

For the 15 genes:

- Brief description of gene action
- Increased risk associated with gene variant
- Prevalence of risk-increasing gene variant in population
- Limitations of what is known about gene-disease association
- Scientific references

Assessment used in analysis

- · Perceptions of website information in Module 2

Module 3: Your Rights if You Take Part in Multiplex Genetic Research (4 pages)

Content topics

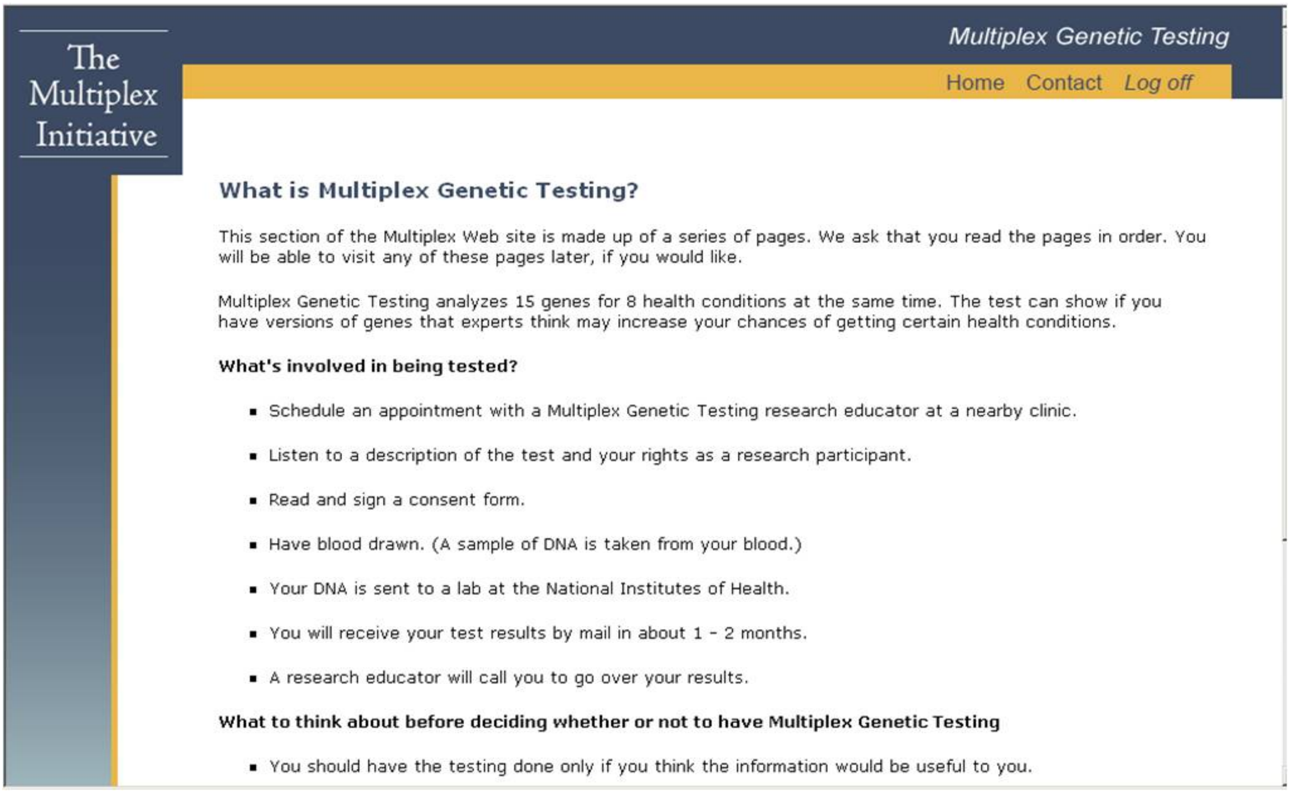
- Researcher responsibilities
- Rights of research participants
- Test procedures

Module 4: Your Decision to be Tested or Not (1 page)

Assessments used in analysis

- Ease or difficulty of decision making
- Interest in making clinic appointment

Figure 1. Example website page providing information about Multiplex Genetic Testing



What is Multiplex Genetic Testing?

This section of the Multiplex Web site is made up of a series of pages. We ask that you read the pages in order. You will be able to visit any of these pages later, if you would like.

Multiplex Genetic Testing analyzes 15 genes for 8 health conditions at the same time. The test can show if you have versions of genes that experts think may increase your chances of getting certain health conditions.

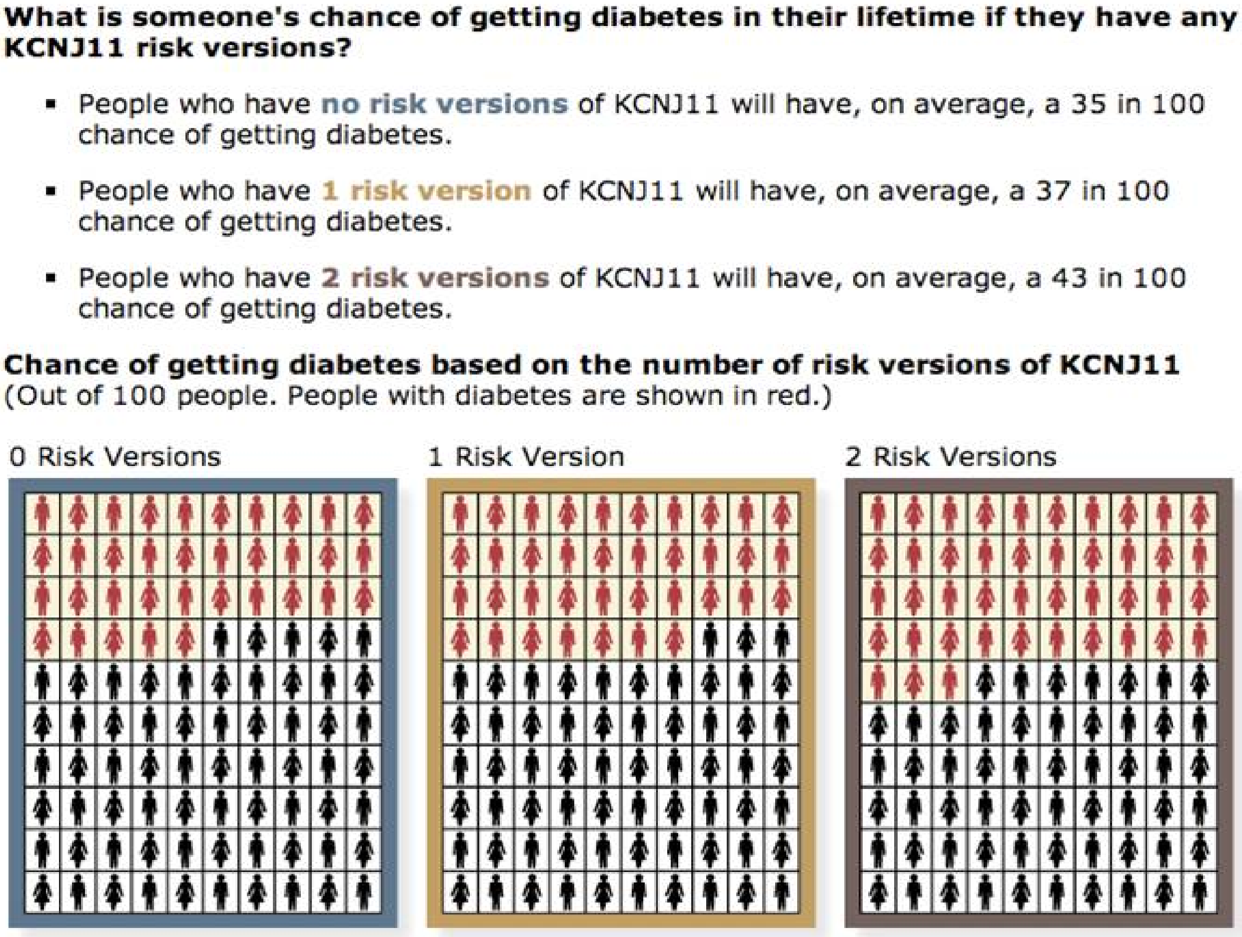
What's involved in being tested?

- Schedule an appointment with a Multiplex Genetic Testing research educator at a nearby clinic.
- Listen to a description of the test and your rights as a research participant.
- Read and sign a consent form.
- Have blood drawn. (A sample of DNA is taken from your blood.)
- Your DNA is sent to a lab at the National Institutes of Health.
- You will receive your test results by mail in about 1 - 2 months.
- A research educator will call you to go over your results.

What to think about before deciding whether or not to have Multiplex Genetic Testing

- You should have the testing done only if you think the information would be useful to you.

Figure 2. Example website page providing information about a gene on the test



What is someone's chance of getting diabetes in their lifetime if they have any KCNJ11 risk versions?

- People who have **no risk versions** of KCNJ11 will have, on average, a 35 in 100 chance of getting diabetes.
- People who have **1 risk version** of KCNJ11 will have, on average, a 37 in 100 chance of getting diabetes.
- People who have **2 risk versions** of KCNJ11 will have, on average, a 43 in 100 chance of getting diabetes.

Chance of getting diabetes based on the number of risk versions of KCNJ11
(Out of 100 people. People with diabetes are shown in red.)

Website Tracking

Each study participant was given a unique log-in ID/password pair that enabled their visit to the Multiplex website to be tracked. Each time a page on the website was accessed, a tracking database stored the participant's unique log-in ID, the session number for that user (ie, whether this was their first, second, or subsequent visit to the Multiplex website), and the date and time that the page was requested. Log-in IDs were randomly generated and created so that the responses of a particular individual could not be identified.

Measures

The measures included in the report were collected at three time points: baseline telephone assessment, website assessments (about 1 to 2 weeks after baseline), and whether individuals attended the clinic visit for a blood draw (up to 60 days after baseline).

Outcome Variables

The primary outcome variable, ease of decision making, was assessed in the fourth website module (see Textbox 1). Participants were asked on a 7-point Likert scale to "tell us how easy or hard it is for you to decide whether or not to get multiplex genetic testing." Due to the skewed distribution, responses were dichotomized at the midpoint. The second outcome was whether participants had blood drawn for testing.

Predictor Variable

The primary predictor variable was the number of website pages viewed for each module. Each page was assigned a value of 0 or 1 depending on whether or not participants viewed that page. The number of pages viewed was then summed overall and within content areas.

Mediating Variable

Individuals' perceptions of the content of the second module (see Textbox 1), which described the health conditions and genes on the test, were rated with respect to trustworthiness, satisfactoriness, helpfulness, and clarity of the information (eg, "I trusted that the information presented was true"). Participants indicated strength of agreement with each item on 7-point Likert scales ranging from "strongly disagree" to "strongly agree." Four items were reverse coded so that "strongly agree" reflected more positive perceptions for all items. The standardized Cronbach alpha was .76.

Covariates

Covariates assessed were based on the Risk Information Seeking and Processing Model [25]. Sociodemographic covariates included gender, age, educational attainment, race, and marital status. Participants also identified which multiplex health conditions ran in their family. A 6-item measure of genetic self-efficacy was adapted from Parrott et al [26]. The items (eg, "You would be able to explain to others how genes affect health") were answered on 7-point Likert scales ranging from "strongly disagree" to "strongly agree." Health information seeking was assessed using the item, "In the past 30 days, how often would you say you have looked for information about ways to stay healthy or to feel better?" Responses were dichotomized as daily or weekly versus less than weekly or never. Importance of genetic information was assessed with the item, "How important is it to you to learn more about how your genes affect your chance of getting certain health conditions?" Response choices ranged from 1, not at all important to 7, very important.

Analysis

Data were analyzed using SAS Version 9.2 for Windows (SAS Institute Inc, Cary, NC, USA). Descriptive statistics were first examined for all variables. Differences by the predictor variable, possible mediating variable, and covariates in the two outcome variables were assessed using chi-square tests. We then tested multivariate logistic regression models to evaluate the association of number of pages viewed with the two outcome variables, employing forward checking and backward elimination methods to determine which covariates to include in the final models [27]. We used a $P < .20$ criterion for inclusion of covariates [28,29]. The potential mediator was tested using the approach of Baron and Kenny [30]. Statistical significance was assessed as $P < .05$.

Results

Participant Engagement With Website

Of the 27 possible pages in modules 1 and 2 (Textbox 1), participants viewed, on average, about 8 pages (mean 8.2, standard deviation [SD] 7.2), although the number of pages viewed ranged from 1 to 27. On average, participants viewed about 2.9 of the 4 pages introducing the multiplex test, 2.2 of the 8 pages describing the health conditions on the test, and 3.2 of the 15 pages describing the genes. Over 60% (326/526) of participants viewed the Web page for diabetes, which was the first health condition listed on the website menu. However, less than 25% of participants viewed any of the other health condition pages. Similarly, between 40% and 50% viewed the first gene pages listed on the website menu (for *KCNJ11*, *CAPN10*, *PPARG*, and *TCN7L2*), but less than 20% viewed any of the other genes pages. Education was the only significant sociodemographic predictor of the number of Web pages viewed in the multivariate model. Participants with a high school degree or less viewed about 3 1/2 pages fewer, on average, than participants with a college degree or higher (beta = -3.52, $P < .001$), while participants with some college viewed about 2 pages fewer than those with a college degree or higher (beta = -2.10, $P = .002$).

In bivariate analyses, the number of pages viewed was associated with each of the two outcomes (see Table 1). The group of participants who rated their decision to test as easy had looked at more pages within each content area than those who rated the decision as difficult. This difference was about a half page for general test information ($P = .001$) and health condition information ($P = .02$) and about a page for gene information ($P = .003$). Similarly, participants who had blood drawn for the test had viewed more website content than those who declined testing, with differences of about 1 page for information about the test and the health conditions and about 2 pages for information about the genes ($P < .001$).

Table 1. Association of website content viewed and ratings of content with decision outcomes (n = 526)

	Ease of Decision		Test Decision	
	Easy Decision (n = 337) Mean (SD)	Difficult Decision (n = 186) Mean (SD)	Received Test (n = 266) Mean (SD)	Did Not Receive Test (n = 260) Mean (SD)
Pages viewed				
General test information (4 pages)	3.0 (1.3)	2.6 (1.4) [b]	3.2 (1.2)	2.5 (1.4) [c]
Health conditions information (8 pages)	2.4 (2.8)	1.8 (2.5) [a]	2.7 (3.0)	1.6 (2.3) [c]
Genes information (15 pages)	3.6 (4.5)	2.5 (4.0) [b]	4.4 (5.0)	2.0 (3.1) [c]
Perceptions of content				
Overall perceptions of content	5.5 (1.0)	4.9 (1.0) [c]	5.5 (1.0)	5.2 (1.0) [a]
Trusted information	6.2 (1.1)	5.5 (1.5) [c]	6.0 (1.2)	5.8 (1.4) [a]
Satisfied with information	5.9 (1.2)	5.1 (1.5) [c]	5.9 (1.2)	5.4 (1.4) [c]
Easy to understand	5.7 (1.4)	5.0 (1.6) [c]	5.6 (1.5)	5.3 (1.6) [b]
Able to understand	5.6 (1.7)	5.0 (1.8) [c]	5.5 (1.8)	5.2 (1.8)
Helped decision	5.4 (1.7)	4.7 (1.5) [c]	5.4 (1.6)	4.9 (1.6) [b]
Minimal effort to understand	5.3 (1.8)	4.6 (1.9) [c]	5.2 (1.8)	4.9 (1.9)
Sufficient information	4.8 (1.9)	4.4 (1.9) [a]	4.7 (1.9)	4.6 (2.0)

[a] *P* < .05

[b] *P* < .01

[c] *P* < .001

Participant Ratings of Quality and Usefulness of Information About Health Conditions and Genes

Participants rated the quality and usefulness of the information about the health conditions and genes positively. These ratings were significantly associated with each of the two outcomes (see Table 1). Participants who rated their decision as easy perceived the website information more positively overall than those who rated their decision as difficult (*P* < .001). This general pattern was also true for individual ratings of trustworthiness of the information (*P* < .001), satisfaction (*P* < .001), ease of understanding (*P* < .001), feeling able to understand the information (*P* < .001), helpfulness of the information (*P* < .001), needing minimal effort to understand the information (*P* < .001), and sufficiency of the information (*P* = .033). Individuals who decided to test rated the website information more positively than those who declined testing (*P* < .001). In the individual ratings, participants who decided to test rated the trustworthiness (*P* = .038), satisfactoriness (*P* < .001), ease of understanding (*P* = .010), and helpfulness of the information (*P* = .001) more positively than those who declined the test.

Association of Website Usage With Decision-Making

As shown in Table 2, the number of pages viewed was significantly associated with ease of decision-making in multivariate analyses (odds ratio [OR] 1.04, 95% confidence interval [CI] 1.01-1.07). The results of this model showed that for every page viewed, participants were about 4% more likely to describe their decision as easy, on average, controlling for the sociodemographic and psychological covariates. In this model, genetic self-efficacy and involvement with genetic information were significant covariates. Participants with higher genetic self-efficacy (OR 1.27, 95% CI 1.05-1.52) and who placed greater importance on genetic information (OR 1.18, 95% CI 1.03-1.36) were more likely to describe their decision to test or not as easy.

Table 2. Prediction of ease of decision making by number of pages viewed in a multivariate logistic regression model (n = 523)

	Odds Ratio	95% Confidence Interval
Number of pages viewed	1.04	(1.01-1.07)
Male gender	0.87	(0.58-1.29)
Age	0.99	(0.94-1.04)
Education[a]		
High school or less	0.81	(0.47-1.39)
Some college	0.74	(0.49-1.13)
Race[b]		
White	1.00	(0.49-2.05)
Black	0.58	(0.29-1.19)
Married/partnered	0.96	(0.64-1.45)
Number of conditions with family history	0.94	(0.82-1.07)
Genetic self-efficacy	1.27	(1.05-1.52)
Involvement with genetic information	1.18	(1.03-1.36)

[a] Comparison category is college degree or higher.

[b] Comparison category is “other.”

As shown in Table 3, the number of pages viewed also was significantly associated with deciding to test (OR 1.08, 95% CI 1.05-1.11). For every page viewed, participants were about 8% more likely to decide to test, controlling for the sociodemographic and psychological covariates. In this model, education, genetic self-efficacy, and involvement with genetic information were also significant covariates. Individuals with a high school degree or less were about half as likely to be tested compared with those with a college degree or higher (OR 0.51, 95% CI 0.29-0.88). Participants with higher genetic self-efficacy (OR 1.24, 95% CI 1.03-1.50) and those who placed greater importance on genetic information (OR 1.24, 95% CI 1.07-1.44) were more likely to test.

Table 3. Prediction of decision to test by number of pages viewed in a multivariate logistic regression model (n = 523)

	Odds Ratio	95% Confidence Interval
Number of pages viewed	1.08	(1.05-1.11)
Male gender	1.26	(0.85-1.89)
Age	1.03	(0.99-1.08)
Education[a]		
High school or less	0.51	(0.29-0.88)
Some college	1.04	(0.69-1.59)
Race[b]		
White	1.65	(0.84-3.26)
Black	0.66	(0.33-1.30)
Married/partnered	0.91	(0.60-1.38)
Number of conditions with family history	1.10	(0.97-1.26)
Genetic self efficacy	1.24	(1.03-1.50)
Involvement with genetic information	1.24	(1.07-1.44)

[a] Comparison category is college degree or higher.

[b] Comparison category is “other.”

We tested whether perceptions of the quality and usefulness of the information about the health conditions and genes mediated the significant associations of number of pages viewed with decision outcomes. In the first step, we found a low correlation between the number of Web pages viewed and perceptions of the information (r = .097). Therefore, we did not proceed to additional steps to test mediation and concluded that perceptions of the website information did not mediate the associations.

Discussion

This report describes unique data suggesting how individuals respond to Web-based offers of genetic susceptibility tests. This is especially notable because multiplex genetic susceptibility tests currently being offered by many DTC companies have unknown clinical utility. We examined test decisions in a population-based sample where nearly half of participants who visited the website to consider testing ultimately decided not to be tested. This is in contrast to most of the prior genetic testing literature, in which the majority of study participants already had decided to obtain a genetic test [19,20].

Individuals generally had positive perceptions of the quality and usefulness of the website information. Viewing more of the information was associated with finding it easier to decide about testing regardless of whether the individual decided to test or not. Thus, patients found the website helpful in supporting their decision-making—both the decision to test and the decision not to test.

In addition, the results presented here shed light on aspects of the online information that might be most useful in supporting individuals' decision-making. Participants engaged most with the introductory section that described the test, testing procedures, and what could and could not be learned from the results. This suggests that this information may have been most relevant for their test decisions. In contrast, individuals generally did not delve very deeply into content related to health conditions and gene pages. However, it is noteworthy that participants who described their decision to test as easiest had viewed more of the pages describing the health conditions and genes than those who found it harder to decide. This suggests that more extensive processing about the specifics of the genetic test might have made it easier to decide about testing.

The findings observed here underscore the importance of attending to best communication practices such as layering information in website development. For example, we placed the most important information about the test in the introductory module and then supplemented that with detailed information about each health condition and gene on separate pages. We believe that our observation that participants generally viewed little of the detailed information supports using health literacy best practices. Specifically, the results suggest that information thought to be most essential to individual decision-making be presented first [21,22]. By contrast, a recent analysis of websites offering genetic tests directly to consumers showed that there is wide variability in the content, language, and organizational structure of these sites [18], differences likely to greatly influence their usefulness to consumers.

Despite our attention to health literacy issues (such as reducing technical jargon) in the design of this website, the results showed that educational attainment was the primary predictor of how much information participants viewed. Prior Multiplex Initiative analyses also have shown that educational attainment was associated with whether participants logged onto the website [6]. Supplemental or alternative approaches may be needed to facilitate decision-making among participants with more limited educational attainment or health literacy skills. Individuals with limited health literacy may face substantial challenges in using Web-based information about genomics [16,17], and such consumers might face particular difficulties in making decisions about DTC genetic susceptibility testing [18]. Other factors may also influence the effectiveness of this type of Web-based educational approach, including computer literacy, genetic literacy, and decision-making preferences, all of which are important areas for future research.

Although this population-based study had many strengths, the limitations should also be considered. The observational design did not allow us to examine the effects of individual Web design features or to investigate the effects of the educational material separately from the cognitive characteristics of the participants. For example, some of the observed results may be affected by educational differences in preferences for (or competencies in) reading lengthier text. These are important issues that could be considered in experimental lab-based studies, perhaps with analyses stratified by educational attainment or cognitive characteristics such as information seeking preferences. Similarly, we were not able to drill down to specific information content and decisions about testing. In addition, although we initially drew a population-based sample, participants who logged on to consider genetic testing were more educated and savvier Internet users. Thus, these results may not generalize beyond these early adopters.

The results of this analysis show that consumers perceived a carefully designed website consistent with best practices in communication to be helpful in deciding about genetic susceptibility testing. Critical next steps in this area will be to examine individuals' understanding and interpretation of such website information and how it affects responses to test feedback. For example, is better understanding of the limitations of genetic susceptibility testing associated with more accurate interpretations of test feedback?

As genomic discovery advances, Web-based delivery likely will continue and expand as an avenue for education and decision support regarding genetic testing. These results suggest that individuals perceive Web-based tools designed based on evidence-based communication approaches as supporting decision-making about genetic testing in some target groups. However, continued research is needed to ensure that these tools or other appropriate decision support approaches are available to all groups including those having lower literacy.

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Conflicts of Interest

None declared

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Abbreviations

CIDR: Center for Inherited Disease Research
DTC: direct-to-consumer
NHGRI: National Human Genome Research Institute

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Original Paper

A Review of Online Evidence-based Practice Point-of-Care Information Summary Providers

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Abstract

Background: Busy clinicians need easy access to evidence-based information to inform their clinical practice. Publishers and organizations have designed specific tools to meet doctors' needs at the point of care.

Objective: The aim of this study was to describe online point-of-care summaries and evaluate their breadth, content development, and editorial policy against their claims of being "evidence-based."

Methods: We searched Medline, Google, librarian association websites, and information conference proceedings from January to December 2008. We included English Web-based point-of-care summaries designed to deliver predigested, rapidly accessible, comprehensive, periodically updated, evidence-based information to clinicians. Two investigators independently extracted data on the general characteristics and content presentation of summaries. We assessed and ranked point-of-care products according to: (1) coverage (volume) of medical conditions, (2) editorial quality, and (3) evidence-based methodology. We explored how these factors were associated.

Results: We retrieved 30 eligible summaries. Of these products, 18 met our inclusion criteria and were qualitatively described, and 16 provided sufficient data for quantitative evaluation. The median volume of medical conditions covered was 80.6% (interquartile range, 68.9% - 84.2%) and varied for the different products. Similarly, differences emerged for editorial policy (median 8.0, interquartile range 5.8 - 10.3) and evidence-based methodology scores (median 10.0, interquartile range 1.0 - 12.8) on a 15-point scale. None of these dimensions turned out to be significantly associated with the other dimensions (editorial quality and volume, Spearman rank correlation $r = -0.001$, $P = .99$; evidence-based methodology and volume, $r = -0.19$, $P = .48$; editorial and evidence-based methodology, $r = 0.43$, $P = .09$).

Conclusions: Publishers are moving to develop point-of-care summary products. Some of these have better profiles than others, and there is room for improved reporting of the strengths and weaknesses of these products.

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KEYWORDS

Point-of-care system; Internet information; evidence-based practice; evidence-based medicine; information science

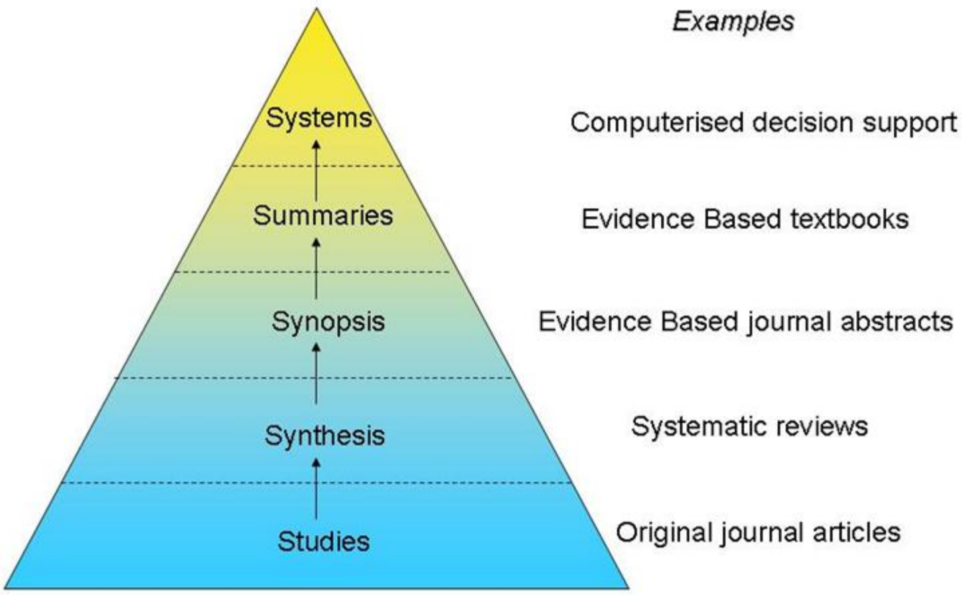
Introduction

In 1996, Richard Smith sought to identify the main characteristics that medical information sources developed over the next decade should have to guide doctors in their practice [1,2]. He concluded that these tools should be able to answer complex questions, be connected to a large, valid database, and be electronic. Today, busy clinicians have access not only to Medline, but to many online information solutions that are now faster, have a broader and deeper reach into the plethora of medical literature, and can quickly provide current information directly related to their everyday practice. This approach, supported by advances in the technical areas of powerful real-time information systems, fits well with medical information consumed when patients and practitioners interact at the so-called point of care, which requires information formatted differently than traditional information sources, such as textbooks [3].

The unquestionable advantage of online point-of-care tools is that they facilitate the selection and summary of research findings and provide friendly interfaces to improve retrieval, synthesis, organization, and application of this information [4]. The model within evidence-based practice (EBP) information summaries was first described is the “5S” paradigm, which provides guidance for using the most “evolved” information services when searching for the best current evidence [5,6]. This model guides those seeking information related to a clinical problem to begin their search at the highest level resource available, such as comprehensive and sophisticated information tools (ie, systems and summaries). Lower level resources, such as systematic assemblies of the evidence (ie, synthesis and synopsis) and individual studies, should only be searched when there is no evidence-based information system available (Figure 1) [5,6].

In the context of the 5S paradigm, summaries have been described as having a pivotal role as they can integrate the best available evidence from lower layers (drawing on studies and synthesis) to provide information on management options for a given health condition. Summaries are also the basis on which more interactive computerized decision support tools, or “systems,” are usually developed [6].

Figure 1. The ‘‘5S’’ levels of organization of evidence from health care research (adapted from Haynes [6])



Most online summaries are promoted as “evidence-based” [7] implying that their contents are developed through a periodic and systematic search and critical evaluation of medical literature. The claim of being “the most authoritative and accessible point-of-care medical reference available to physicians and other health care professionals on the Internet” is just one example of the emphatic marketing claims used for product advertising [8]. However, criteria for selecting clinically important evidence are not always explicit, raising questions about the quality of information [9]. As online EBP point-of-care summary providers are mushrooming and a substantial a priori trust by clinicians is to be expected, it is of prime importance to assess the relevance and validity of point-of-care summaries, particularly in terms of quality of the content and comprehensiveness.

The objective of this study was to describe online EBP point-of-care summary providers and to evaluate their content and editorial policy against their claims of being “evidence-based.” As for all research, the quality of point-of-care summaries needs to be evaluated to ensure the real usefulness of these products for clinical practitioners. We arbitrarily postulated that coverage of medical knowledge, editorial policy, and content quality (three desirable criteria) would have been among the properties of the best products, being fully aware that basing our evaluation on these criteria would constitute a content-centred evaluation rather than a user-centered or experience/satisfaction evaluation.

Methods

Eligible EBP Point-of-Care Summary Providers

This study focused on providers of EBP point-of-care summaries, which can be broadly defined as web-based medical compendia specifically designed to deliver predigested, rapidly accessible, comprehensive, periodically updated, and evidence-based information (and possibly also guidance) to clinicians (see Table 1 for definitions). Thus, in order to be included in our analysis, a product had to be an online-delivered tertiary publication (summary) that is regularly updated, claims to provide evidence-based information to physicians and other health professionals, and is to be used at the bedside. As previously stated, the term “point of care” indicates the point where patients and practitioners interact, particularly referring to the context of the provider-patient dyad. Here, “point of care” applies to a summarized reference content describing alternative options in clinical practice, rather than technical solutions optimized for the use at the bedside. We restricted our analysis to summaries published in English as the primary language.

The following online information resources were excluded (see Table 1 for definitions): (1) guideline databases (as they are intended to provide recommendations rather than information); (2) medical meta-lists and search engines, both medicine-specific and general (as they point the user toward the right place to find information rather than providing information themselves) [10]; (3) literature surveillance alerting systems (as they monitor a defined set of journals reporting articles selected for validity and relevance); (4) online books (as they are not regularly updated); (5) original studies reported in medical journals, practice articles, abstracts of papers (ie, primary literature); (6) secondary literature (as it primarily comprises synthesized content, ie, level 2 of the “5S” levels of organization of evidence) [6]. No restrictions were placed on product development status, disease or medical area, or access or charging agreements.

Table 1. Definitions helpful to explain criteria for inclusions and exclusions

	Definition
Evidence-based practice	Evidence-based practice refers to the process of systematically finding, appraising, and using contemporaneous research findings as the basis for clinical decisions. Evidence-based practice follows four steps: formulate a clear clinical question from a patient's problem; search the literature for relevant clinical articles; evaluate (critically appraise) the evidence for its validity and usefulness; implement useful findings in clinical practice.
Point of care	Point of care refers to the specific point in the workflow when health professional and patient interact and applies to any service provided to patients at the bedside or during patients' consultations.
Update	Update refers to renovation or integration of content within a maximum of five years.
Rapidly accessible	Rapidly accessible content should be easily available on searching by keywords or browsing by topics or alphabetically ordered menus. The research output should be sufficiently summarized and relevant.
Studies (primary literature)	Studies (primary literature) are publications that illustrate or comment on original scientific research findings, typically in journal articles.
Synthesis (secondary literature)	Syntheses (secondary literature) are published materials that provide an examination of recent or current literature. Review articles can cover a wide range of subject matter at various levels of completeness and comprehensiveness based on analyses of literature that may include research findings. The Cochrane Library is an example.
Synopsis	Synopsis is the selection and summary of clinically important articles in the medical literature (usually in specific fields), which include newly published, high-quality, clinically relevant original studies and systematic reviews. Online journal clubs are an example.
Summaries (tertiary literature)	Summaries (tertiary literature) are abstracts that integrate evidence from many sources (eg, primary literature, systematic reviews, and guidelines) to provide a full range of information on management options for a given health problem.
Systems (decision aid)	Systems (decision aids) are clinical information systems that integrate and summarize all relevant and important research evidence about a clinical problem and automatically link, through an electronic medical record, a specific patient's circumstances to the relevant information.
Literature surveillance alerting systems	Literature surveillance alerting systems provide regular monitoring of a defined set of journals and the reporting of article selection on the basis of validity and relevance (ie, Evidence UpDates, ACP Journal Club, InfoPOEMs)
Meta-lists	Meta-lists are information retrieval tools that contain links to other relevant sites on the Web. The links are usually collected by the meta-list site coordinator, who acts as a clearinghouse.
Search engine	Search engines are information retrieval tools aimed at searching for information on the whole Web or on medicine-specific websites. The strength of a medicine-specific search engine is its ability to filter out any sites that are not (according to programmed criteria) medical sites.
Guideline databases	Guideline databases are online repositories of clinical documents aimed at providing recommendations rather than information to clinicians (ie, SIGN, NICE).
Online books	Online books are electronic versions of paper-based publications. These are not regularly updated.

Identification of EBP Point-of-Care Summary Providers

To our knowledge, there is no single repository of online information summaries. In order to retrieve relevant summary products we performed a Medline search using the following terms: (("evidence-based medicine"[Mesh]) AND ("information storage and retrieval"[Mesh])) AND (("online systems"[Mesh]) OR ("point-of-care systems"[Mesh])).

We collected additional information from the references cited in the papers retrieved. Google was extensively used as the search engine to explore products not reported in the medical literature but available on the market. The following terms were used: "medical information system," "point of care," and "evidence-based medicine." We also screened several publisher and librarian association websites, such as the Council of Science Editors [11], the World Association of Medical Editors [12], the Medical Librarian Association [13], the European Association for Health Information and Libraries [14], and the American Medical Informatics Association [15]. Finally, we analyzed the publishing products presented at several scientific information conferences and exhibitions during the period 2006 through 2008, such as the London Online Information Expo and Medical Library Association Meeting and Exhibition.

We repeated our search and collection during the one-year period from January through December, 2008.

Information Sought for Each EBP Point-of-Care Summary Provider

For each provider, two reviewers independently retrieved information through an analysis of the official website. As reported in detail below, for any EBP point-of-care summary provider we extracted general characteristics, volume and breadth of the conditions considered, and information regarding the quality of the editorial process and EBP approach to content development (evidence-based methodology). Decisions to select items describing these features were informed by evidence whenever possible. Detailed operational definitions are reported in Multimedia appendix 1.

The features selected were qualitatively described; for editorial and evidence-based methodology indicators, an empirical quantitative evaluation was also included in order to assign a score for each item and rank the EBP point-of-care summary providers. For each quality indicator a point score was assigned: 3 points if the quality indicator was completely fulfilled, 1 point if partially fulfilled or unclear, and 0 points if not fulfilled or not reported. (See Multimedia Appendices 2 and 3.) We arbitrarily decided to award 3 points instead of 2 for adequate fulfilment to give more weight to a more transparent and accountable reporting style and increase the variability within the sample. This policy was somewhat similar to the three-points-for-win rule in soccer [16].

General Characteristics

We first sought general information, such as product name, year of first release, and vendor and/or publisher. We also reported the marketing claim as stated in the homepage and/or in the "about us" section. We collected information on different formats (eg, online, desktop, or PDA) and whether the website is open-access or a subscription fee is required to access the whole content. In the latter case, we reported the costs for a single-user subscription per year and the types of subscription available, that is, single user, institutional, "à la carte" (ie, different products assembled in one subscription), or pay per view. We also described the primary target audience, for example, general practitioners, specialty physicians, or other health care workers who could benefit from the contents. (See Multimedia Appendix 1.)

Content Presentation

We described the content presentation in terms of type of output (ie, narrative or key point summaries or answers to clinical questions format), formal ontology of information, and output summary flexibility. We analysed whether the output included references, and if so, whether these were general, that is, suggestions of further sources on a particular topic, or specific, that is, they supported particular statements. We also explored whether, in addition to providing information, these summaries provided recommendations to practitioners, and if so, whether a formal grading system for the strength of the recommendations was used. Lastly, we sought whether the content of products included continuing medical education programmes or other educational resources and whether a plain language information document or handout had been specifically developed for patients. See Multimedia Appendix 1.

Breadth and Volume

We sought to describe the breadth of the medical conditions considered in terms of areas covered by the summaries (ie, general information, epidemiology, aetiology, physiopathology, diagnosis, treatment, follow up, and prognosis). As we were not able to identify a reliable measure of database volume (ie, comprehensiveness), we estimated the number of diseases covered by analyzing whether a random sample of chapters of the *International Classification of Diseases, Tenth Revision (ICD-10)* was represented in the product. This provided a rough proxy assessment of the comprehensiveness of each product (ie, its external validity). Of the 22 *ICD-10* chapters, 4 (20%) were randomly selected. These were: "Certain infectious and parasitic diseases," "Diseases of the skin and subcutaneous tissue," "Diseases of the genitourinary system," and "External causes of morbidity and mortality." We assessed whether sections (blocks) of diseases and conditions in these *ICD-10* chapters were covered in each EBP point-of-care summary [17].

In addition, we reported whether summary providers included information on topics other than medical conditions (eg, medical procedures and legal issues) and more complex technologies, such as electronic medical records, drug databases, and calculators.

Editorial Quality

To evaluate the methodological quality of the editorial process, we selected specific indicators of transparency: authorship, peer reviewing procedure, updating, disclosure of authors' conflicts of interest, and commercial support of content development. To create an indicator of editorial quality, points were assigned: 3 points were assigned if the dimension was judged "adequate," 1 point if judged "unclear," and 0 points if judged "not adequate" or "not reported." See Multimedia Appendix 2.

Evidence-based Methodology

To obtain information on the evidence-based approach to content development of each product, we specifically selected evidence-based methodology indicators. The indication of whether contents were based on a systematic literature search or surveillance aimed at identifying relevant, valid research evidence was considered of primary importance. The critical appraisal methodology was also judged, and we focused on the cumulative or discretionary approach to the evidence, reporting whether systematic reviews, particularly Cochrane reviews, were preferred over other types of publication. We also looked at the availability of a system to assess quality of evidence. Finally, if expert opinion was included in the content development, we analyzed whether this contribution could be easily recognized within the body of evidence. Similar to our method of scoring the quality of the editorial policy, we scored each indicator of the quality of the evidence-based approach: 3 points were assigned if the dimension was judged "adequate," 1 point if judged "unclear," and 0 points if judged "not adequate" or "not reported." See Multimedia Appendix 3.

Data Extraction

Data were extracted by two independent reviewers (authors RB and LT) who used an ad hoc predefined form. We obtained general features and information on the editorial policy and content development from a thorough analysis of the website pages that were freely available (ie, homepage, about us, editorial policy, and methodology description sections). When subscription to a product was not available at our institution, the free trial and sample topics were used to acquire further information on the content characteristics of the product and the type of output. We assumed that sample topics would likely provide users with the "best" of the product as these parts are often written with the most zeal and attention. When necessary, product editors were contacted by email. When we could not access the content, the products were excluded from the analysis. Disagreements were resolved by discussion between the reviewers and a referee (author LM).

We registered and stored within an electronic archive (December 2008) all the Web pages used to extract data.

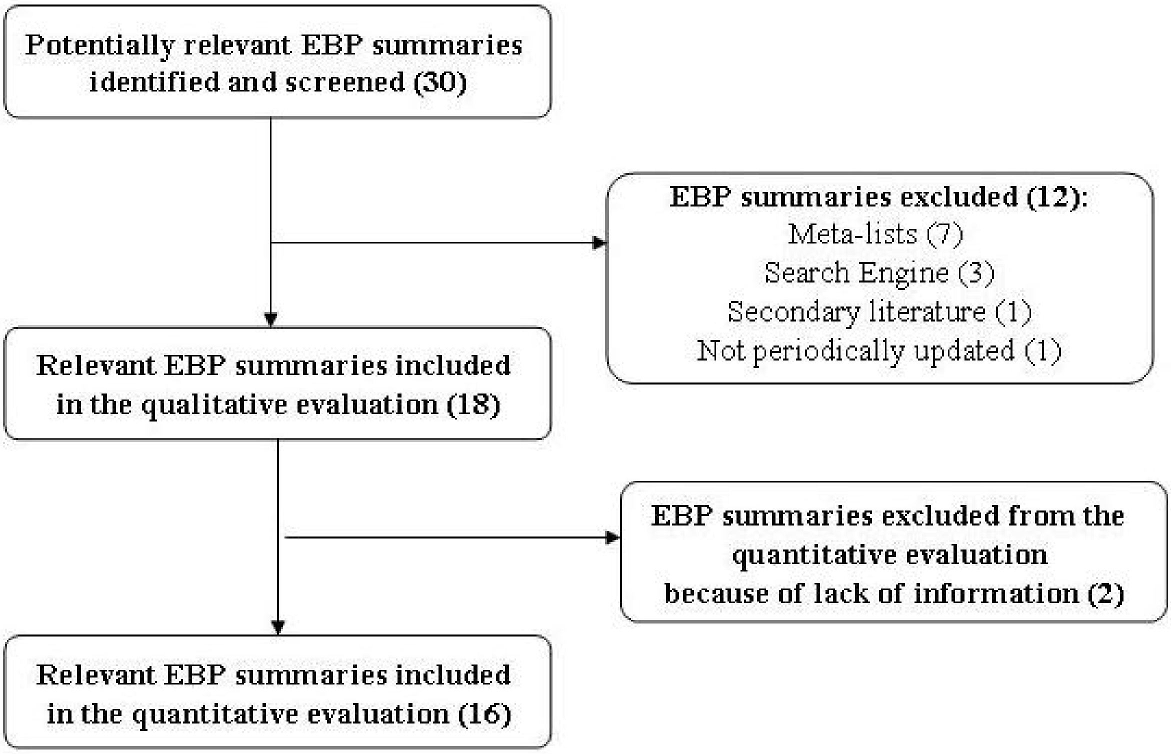
Analysis

Results are presented as median and interquartile ranges to describe the volume and quality indicator scores. The EBP point-of-care products were ranked on the basis of (1) the number of diseases covered (calculated as the number of diseases covered from those in a random sample of *ICD-10* chapters); (2) the editorial quality (defined on the basis of adherence to the items reported in Multimedia Appendix 2); and (3) the use of an evidence-based approach (defined on the basis of adherence to the items reported in Multimedia Appendix 3). The relationships between these factors were analyzed by applying the Spearman rank correlation coefficient.

Results

From January to December 2008 we screened 30 eligible EBP point-of-care summary providers (Figure 2). Of these, 12 were excluded (for details see Multimedia Appendix 4), and 18 met our inclusion criteria and were qualitatively evaluated. Two summary providers (ZynxEvidence and Health Gate) were excluded from the quantitative analysis because of a lack of information on the website general pages and unavailability of sample chapters; we attempted to acquire the missing information from vendors but received no answer.

Figure 2. Flow diagram of the EBP point-of-care summary providers included in the analysis



Qualitative Analysis

General characteristics and summary content presentation features are summarized in Tables 2and 3. In the EBP point-of-care summaries breadth, we found no variability in the areas of medical conditions covered (data not tabulated). With the exception of Clinical Evidence, all the summary providers reported general information, epidemiology, aetiology, physiopathology, diagnosis, treatment, follow-up and prognosis for each topic but they differed in terms of widening and length. Clinical Evidence focused mainly on treatment alternatives; diagnosis and testing were not systematically covered. Several summary providers presented topics other than medical conditions. For example, 5-Minute Clinical Consult, ACP Pier, DynaMed, eMedicine, EBM Guidelines, First Consult included information about medical procedures; ACP Pier, GP Notebook included, ethical and legal issues; and Dynamed, Harrison's Practice, Micromedex, and Pepid included drug information with summaries of product characteristics and pharmacokinetic interaction tables. Zynx Health presented complex content and integration with other technologies, such as electronic medical records while drug databases and calculators are distinctive of some other products, such as Micromedex and Pepid according to the shift from summary to systems described in the Haynes model [6].

Table 2. General characteristics of EBP point-of-care summary providers

Product Name (URL)	Year of Release	Vendor/ Publisher	Marketing Claim	Fee-based/ Open Access	Type of Subscription	Format	Annual Cost for Single User Account for year	Target Users
5-Minute Clinical Consult (www.5minuteconsult.com)	Not reported	Wolters Kluwer, Lippiccott Williams and Wilkins	Updated regularly for quick reference at the point of care.	Fee-based	Single user	Online, PDA, smartphone, print	US $89.90	Not reported
ACP Pier (www.acponline.org)	Not reported	American College of Physicians	Find authoritative, evidence-based guidance to improve clinical care	Open access to ACP members	Not Applicable	Online and PDA	Not Applicable	Internal medicine specialists
BestBETs (www.bestbets.org/)	1996	Department of Emergency Medicine, Manchester Royal Infirmary	… provide rapid evidence-based answers to real-life clinical questions, using a systematic approach to reviewing the literature.	Open access	Not Applicable	Online and print	Not Applicable	Emergency medicine specialists
CKS (www.cks.nhs.uk)	1998	NHS	Safe practical clinical answers- fast	Open access	Not applicable	Online and print	Not applicable	GPs, nurses, pharmacists, students; medical librarians
Clinical Evidence (www.clinicalevidence.bmj.com)	1999	BMJ Publishing group	The international source of the best available evidence on the effects of common clinical interventions	Fee-based	Single user, institutional, pay per view, season ticket	online, print (handbook), PDA	£137/€203/ US $260	GPs, specialists
DynaMed (www.ebscohost.com/dynamed/)	Not reported	EBSCO Publishing	Designed for use at the point-of-care, providing best available evidence and updated daily.	Fee-based	Single user, institutional	Online, PDA	US $350	GPs, specialists
eMedicine (www.emedicine.medscape.com/)	1996	WebMD-Medscape	Continually updated clinical reference…the most authoritative and accessible point-of-care medical reference available to physicians.	Open access	Not applicable	Online	Not applicable	GPs and other health care professionals.
eTG complete (www.tg.org.au)	1978	Therapeutic Guidelines Limited (Australia)	Therapeutic Guidelines…evidence in context	Fee-based	Single user, student subscription	Online, desktop, print, PDA	A$300	Not reported
EBM Guidelines (http://ebmg.wiley.com)	1989	Wiley Blackwell Interscience and Duodecim	Easy to use clinical guidelines supported by sound scientific evidence	Fee-based	Single user, institutional	Online, print, PDA	US $255	GPs
First Consult (www.mdconsult.com)	1997	Elsevier	Evidence-based answers for the point of care	Fee-based	Single user, institutional	Online, PDA	US $449 "Core + first consult"	GPs, specialists
GP Notebook (www.gpnotebook.co.uk)	1995	Oxbridge Solutions Ltd	A UK medical reference on the world wide web	Open Access	Not applicable	Online	Not applicable	GPs

Product Name (URL)	Year of Release	Vendor/ Publisher	Marketing Claim	Fee-based/ Open Access	Type of Subscription	Format	Annual Cost for Single User Account for year	Target Users
Harrison's Practice (www.harrisonspractice.com)	Not reported	Mc Graw Hill	Answers on demand at the point of care	Fee-based	Single user, institutional	online, PDA, wireless version	US $325	GPs, Internal Medicine Specialists
Health Gate (www.healthgate.com)	Not reported	HealthGate Data Corporation	The latest evidence-based clinical information	Fee-based	Not reported	Online	Not reported	Providers, payers, employers, and patients
Map of Medicine (www.mapofmedicine.com)	2001	Hearst Corporation	Support for clinical practice national, local and personal evidence-based content broad in scope	Open access to all NHS staff in England and Wales.	Not applicable	Online	Not applicable	GPs and other health professionals
Micromedex (www.micromedex.com)	Not reported	Thomson Reuters	Evidence-based answers to support your disease management and treatment decisions.	Fee-based	Not reported	Online, PDA	Contact for pricing	GPs, specialists, other health professionals. Medical school faculty and students, librarians
Pepid (www.pepid.com)	1994	Pepid LLC	The only "all-in-one" point-of-care medical reference tool available on the Internet	Fee-based	Single user, institutional	Online, PDA, Mobile Wireless	US $199.95 Primary Care Plus PCP	GPs, specialists
UpToDate (www.uptodate.com)	1992	UpToDate, Inc	UpToDate is an evidence-based, peer-reviewed information resource	Fee-based	single user institutional, patient subscription	Online, desktop, PDA	US $495	GPs, specialists
ZynxEvidence (www.zynxhealth.com/)	Not reported	Zynx Health Incorporated	Evidence-based health care. Informed decision. Improved care.	Fee-based	Not reported	Not reported	Not reported	GPs, specialists

Table 3. Content presentation of EBP point-of-care summary providers

	Output Presentation						Education		
Name	Type of Output	Formal Ontology	Summary Flexibility	References	Intent to Recommend	Strength of Recommendation Formal System	CME Programs	Other Educational Material	Patient Handout
5-Minute Clinical Consult	Key point summary	Yes	No	Yes, general	Yes	No	No	No	Yes
ACP Pier	Key point summary	Yes	Yes	Yes, specific	Yes	No	Yes	No	Yes
BestBETs	Answers to clinical questions	Yes	No	Yes, specific	No	No	No	Yes, methodology	No
CKS	Key point summary	Yes	Yes	Yes, general	Yes	No	No	No	Yes
Clinical Evidence	Narrative summaries on clinical questions	Yes	Yes	Yes, specific	No	No	Yes	Yes, statistics and methodology	Yes
DynaMed	Key point summary	Yes	No	Yes, specific	Yes	Yes	Yes	No	No
eMedicine	Book chapter-like summary	Yes	No	Yes, general	Yes	No	Yes	No	No
eTG complete	Book chapter-like summary	No	No	Yes, general	Yes	No	No	No	No
EBM Guidelines	Key point summary	Yes	No	Yes, specific	Yes	No	No	No	No
First Consult	Key point summaries	Yes	Yes	Yes, general	Yes	No	Yes	No	Yes
GP Notebook	Book chapter-like and key point summaries	No	No	Yes, general	No	No	Yes	No	No
Harrison's Practice	Key point summaries	Yes	No	Yes, general	Yes	No	Yes	No	No
Health Gate	No information	No information	No information	Yes, general	No information	No	No	No	Yes
Map Of Medicine	Clinical pathways	Yes	Yes	Yes, specific	Yes	No	No	No	No
Micromedex	Key point summaries	Yes	Yes	Yes, specific	Yes	Yes	No	No	No
Pepid	Key point summaries	Yes	No	No	Yes	No	No	Yes	No
UpToDate	Book chapter-like summaries	Yes	No	Yes, specific	Yes	Yes	Yes	No	Yes
ZynxEvidence	Key point summary	Yes	No	No information	Yes	No information	No	No	No

Quantitative Analysis

The EBP point-of-care summary volume based on four random samples of *ICD-10* chapter analysis is estimated in Figure 3. The median coverage volume was 80.6% (interquartile range: 68.9-84.2%). There were large differences among summaries, with DynaMed, eMedicine, and First Consult being the most comprehensive (88%) and eTG complete the least (45%).

Editorial policy quality and evidence-based methodology are summarized in Tables 4 and 5. The median scores were 8.0

(interquartile range 5.8-10.3) and 10.0 (interquartile range 1.0-12.8) on a 15-point scale.

EBP point-of-care summary provider scores were ranked according to volume, editorial, and EB methodology scores (see Multimedia Appendix 5). Table 4 shows the scores for each provider for editorial quality; Table 5 shows the scores for EBP methodology; and Figure 3 displays the results of the analysis of volume (ie, comprehensiveness).

Displayed together in Figure 4 are the EBP point-of-care summary provider rankings for volume, editorial quality and EB methodology. As is shown, DynaMed, EBM Guidelines, and UpToDate scored in the top quartile for two out of three variables and in the second quartile for the third of these variables. However, no association was found between the pairs of variables for each EBP point-of-care summary provider (Spearman rank correlations: editorial quality and volume, r = -0.001, P = .99; EB methodology and volume r = -0.19, P = .48; editorial and EB methodology r = 0.43, P = .09).

A brief presentation of these results is reported in Multimedia Appendix 6.

Table 4. Editorial quality of EBP point-of-care summary providers

Name	Authorship (Points)	Reviewing (Points)	Updating (Points)	Authors' Conflict of Interest (Points)	Commercial Support for Content Development (Points)	Editorial Quality Score
Clinical Evidence	Yes (3)	Yes (3)	Yes (3)	Yes, implemented and reported (3)	Not accepted (3)	15
UpToDate	Yes (3)	Yes (3)	Yes (3)	Yes, implemented and reported (3)	Not accepted (3)	15
eMedicine	Yes (3)	Yes (3)	Yes (3)	Yes, implemented and reported (3)	Accepted and disclosed (1)	13
DynaMed	Unclear (1)	Unclear (1)	Yes (3)	Yes, implemented and reported (3)	Not accepted (3)	11
eTG complete	Unclear (1)	Yes (3)	No (0)	Yes, implemented and reported (3)	Not accepted (3)	10
ACP Pier	Yes (3)	Yes (3)	Yes (3)	No information (0)	No information (0)	9
EBM Guidelines	Yes (3)	Yes (3)	Yes (3)	No information (0)	No information (0)	9
Pepid	Yes (3)	Yes (3)	Yes (3)	No information (0)	No information (0)	9
First Consult	Yes (3)	Unclear (1)	Yes (3)	No information (0)	No information (0)	7
BestBETs	Yes (3)	Yes (3)	No (0)	No information (0)	No information (0)	6
CKS	No (0)	Yes (3)	Yes (3)	No information (0)	No information (0)	6
Map Of Medicine	No (0)	Yes (3)	Yes (3)	No information (0)	No information (0)	6
Micromedex	No (0)	Yes (3)	Unclear (1)	Yes, implemented but not reported (1)	No information (0)	5
5-Minute Clinical Consult	Yes (3)	No (0)	Unclear (1)	No information (0)	No information (0)	4
GP Notebook	No (0)	Unclear (1)	Yes (3)	No information (0)	No information (0)	4
Harrison's Practice	No (0)	No (0)	Yes (3)	No information (0)	No information (0)	3

Table 5. Evidence-based methodology of EBP point-of-care summary providers

Name	Literature Search/ Literature Surveillance (Points)	Cumulative vs Discretionary Approach (Points)	Critical Appraisal (Points)	Formal Grading of Evidence (Points)	Cite Expert Opinion (Points)	Evidence-Based Methodology Score
BestBETs	Yes (3)	Yes (3)	Yes (3)	Yes (3)	Yes (3)	15
Clinical Evidence	Yes (3)	Yes (3)	Yes (3)	Yes (3)	Yes (3)	15
EBM Guidelines	Yes (3)	Yes (3)	Yes (3)	Yes (3)	Yes (3)	15
UpToDate	Yes (3)	Yes (3)	Yes (3)	Yes (3)	Yes (3)	15
DynaMed	Yes (3)	No (0)	Yes (3)	Yes (3)	Yes (3)	12
Map Of Medicine	Yes (3)	Yes (3)	Yes (3)	No (0)	Yes (3)	12
Micromedex	Yes (3)	Yes (3)	Unclear (1)	Yes (3)	Unclear (1)	11
ACP Pier	Yes (3)	No (0)	Yes (3)	Yes (3)	Unclear (1)	10
CKS	Yes (3)	Yes (3)	Unclear (1)	No (0)	Yes (3)	10
Pepid	Unclear (1)	Unclear (1)	No (0)	No (0)	No (0)	2
eMedicine	Unclear (1)	No (0)	No (0)	No (0)	No (0)	1
eTG complete	Unclear (1)	No (0)	No (0)	No (0)	No (0)	1
First Consult	Unclear (1)	No (0)	No (0)	No (0)	No (0)	1
GP Notebook	Unclear (1)	No (0)	No (0)	No (0)	No (0)	1
Harrison’s Practice	Unclear (1)	No (0)	No (0)	No (0)	No (0)	1
5-Minute Clinical Consult	No (0)	No (0)	No (0)	No (0)	No (0)	0

Figure 3. EBP point-of-care summary provider volume estimated on four random chapters of the ICD-10 classification

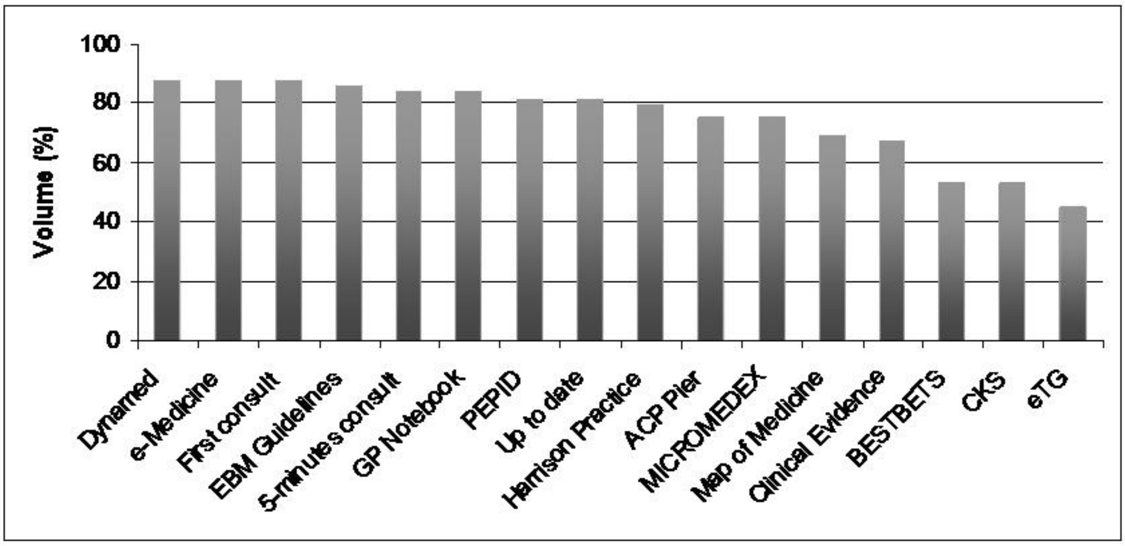
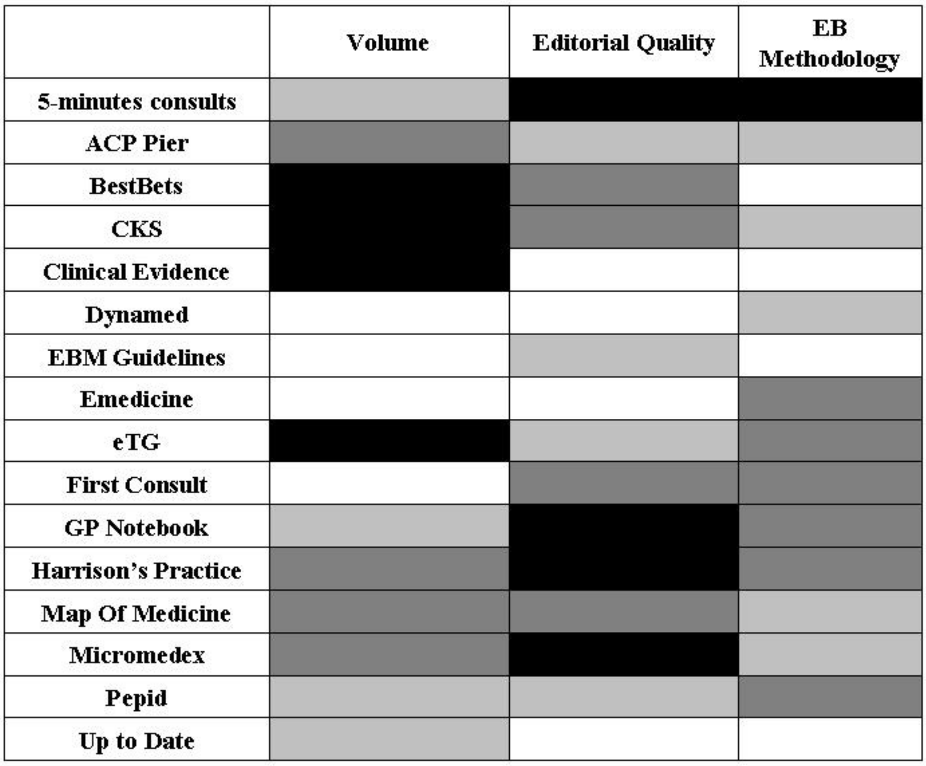


Figure 4. EBP point-of-care summary provider ranking for volume, editorial quality and evidence-based methodology. (Black represents the bottom quartile; dark grey represents the low intermediate quartile; light grey represent the high intermediate quartile; and white represents the top quartile.)



	Volume	Editorial Quality	EB Methodology
5-minutes consults	░	■	■
ACP Pier	▓	░	░
BestBets	■	▓	□
CKS	■	▓	░
Clinical Evidence	■	□	□
Dynamed	□	□	░
EBM Guidelines	□	░	□
Emedicine	□	□	▓
eTG	■	░	▓
First Consult	□	▓	▓
GP Notebook	░	■	▓
Harrison's Practice	▓	■	▓
Map Of Medicine	▓	▓	░
Micromedex	▓	■	░
Pepid	░	░	▓
Up to Date	░	□	□

Discussion

Summary of Key Findings

As of December 2008, we had found 18 EBP point-of-care summary providers. This suggests that several publishing groups and public health organizations are interested in investing time and resources into the development of these products. The overall characteristics of these products tended to vary, and evaluation of their quality is still in its infancy despite the emerging consensus that such information tools are professionally and scientifically essential [4]. Only a few products satisfied our criteria, with none excelling in all. Thus, at present, no clear set of dimensions for deciding among different products can be drawn. The choice of an information tool will depend on the properties of the resource and users' preferences according to the personal weight attached to different rankings.

Our Study in Context

One mainstay of evidence-based information mastery is the combination of tools that filter literature for relevance and validity and present summaries easily and in a quickly accessible form at the point of care [3]. Since doctors have significant information needs in their practice [18,19], an important question is whether all these products are reliable and really improve access to high-quality information. While many user-centred or experience/satisfaction analyses have been published [20-25], our evaluation aimed at providing an explicit way to assess the available products other than relying on potentially misleading marketing claims by vendors.

We developed a content validity scale using an evidence-based approach whenever possible. Desirable dimensions were included if there was evidence that not addressing that particular dimension would result in an increased risk of bias. Dimensions were also included where it was clear that information about that dimension was necessary to appraise the reliability of a point-of-care product. For some quality indicators, such as the literature retrieval process and updating, we borrowed our criteria from research on systematic review reporting methods [26,27], assuming that these also would apply to the further synthesized information tools that we included in our review. Other scale dimensions, such as authors' conflicts of interest and peer review, were based on peer-reviewed medical journals' policies, extensively debated during the past years [28-30]. Other dimensions that we measured, such as intent to recommend, were included because we judged them to be important, but these were not clearly based on prior research. Only 20% of the products that included recommendations formally graded the strength of the recommendations, whereas doing so is essential to assure transparency and reliability of recommendations [31].

Limitations of This Study

One of the limitations of our study stems from a lack of a clear definition of these products which could have led to a possible selection bias. We set eligibility criteria to select evidence-based summary products defined as portable and comprehensive [1] that Haynes et al would categorize as a summary [6]. Moreover, summary provider eligibility was independently evaluated by two authors. Our study is only a first attempt toward a more comprehensive assessment of this rapidly evolving field. The number of EBP point-of-care summary providers is increasing; in the first months of 2009 at least three vendors, the Journal of the American Medical Association (http://jamaevidence.com), the British Medical Journal (www.bestpractice.bmj.com) and the UK National Health Service (www.evidence.nhs.uk/) launched new point-of-care products. These new products were not included in our survey because they were launched outside the considered time frame.

The major limitation of our study was the arbitrariness of the scoring system. We chose a continuous scale instead of a classical star rating system to allow scores on individual categories to be correlated. Category scores have not been added to make an overall score. Scores allow readers to group EBP point-of-care summary providers according to quality and to detect top performers within categories. Our scoring system can be considered a preliminary approach to rating EBP point-of-care summary providers; other categories could be added.

We did not formally analyze website navigability and usability as this was beyond the scope of our study. Such an analysis might be valuable from the users' perspective because information on the Web can be communicated in many ways—such as diagrams, animations, and linked pages—which may improve comprehension. These analyses should be carefully interpreted as they suffer from the multiplicity bias as occurs when users are asked to compare known systems with new ones. EBP point-of-care summaries also largely differ according to the comprehensiveness of each topic. Choosing a random sample of *ICD-10* chapters as a proxy of the comprehensiveness of a summary may not necessarily be representative of what each provider offers. However, comprehensiveness is a crucial aspect of any information tool when used to answer clinical questions. Further research on the comprehensiveness of these information tools is needed.

Relationships Between Volume, Editorial Quality, Evidence-based Methodology

None of the associations we postulated turned out to be statistically significant. Thus, on the basis of the criteria we used, editorial quality, evidence-based methodology, and volume appear to be independent. For example, BestBETs scored among the worst on volume (comprehensiveness), with an intermediate score for editorial quality, and the highest score for evidence-based methodology. The search for associations between various desirable factors can be seen as "work in progress," suggesting that publishers have to balance these aspects, and achieving excellence in all three aspects is difficult.

Implications for Editorial/Publishing Groups

In the global trend for point-of-care products to inform clinical practice, there is room for improving the quality and increasing the coverage of diseases. Publishers should provide users (or purchasers in general) with transparent, easily accessible, and rigorously determined information regarding editorial processes and content development. Our assessment is intertwined with the quality of reporting. It is possible that publishers favored conciseness of information on their websites and omitted important editorial and methodological details. For instance a publisher may plan to disclose author conflicts of interest, but then does not report this key information on its website, thus diminishing the trustworthiness of its product.

Efforts have been made in the last two decades to improve the quality of reporting of the results of randomized controlled trials and systematic reviews [26,27,32]. However, there is still evidence that methods and reporting can be improved [33-35]. The experience obtained in the field of primary research can be applied to EBP point-of-care information summaries, considering that these point-of-care products are still in the early development. Important initiatives to improve the reporting of health care research, such as the EQUATOR Network [36,37] should also include initiatives to improve point-of-care products.

Implications for Clinicians

At present, clinicians who want to select an EBP point-of-care summary to use regularly need to find a balance among several desirable characteristics to inform their choice: according to our criteria, no product appears to be the best. Faced with a choice of summaries, one criterion should prevail. The judgement is complex because in addition to various desirable criteria, many other dimensions could be attractive and drive the choice, such as whether the summary can be used for continuing medical education, contains information addressed to patients, or can be integrated with more sophisticated technologies. Having access to high-quality and well-summarized evidence-based information will not answer all the questions that arise in the doctor-patient relationship, but these summaries help doctors to identify the best options in therapy, diagnosis, or prognosis for their patients. Even the most innovative information system must rely on sound evidence to improve clinical practice; the technology is only the vehicle to make the information accessible. Quality indicators that can be used to evaluate new EBP point-of-care summary providers can be valuable for clinicians, but these can also be useful for librarians, hospital managers, and policy makers who must choose the most appropriate point-of-care summaries to meet their needs.

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Conflicts of Interest

The Italian Cochrane Centre (ICC) was the recipient of grants from the Italian Drug Agency (AIFA) for the Italian translations of one of the products assessed (Clinical Evidence). The Italian Cochrane Centre is an entity of the Cochrane Collaboration, which forms a publishing partnership with Wiley-Blackwell to deliver The Cochrane Library through Wiley InterScience.

Authors' Contributions

Conception: Rita Banzi, Alessandro Liberati, Lorenzo Moja, Ivan Moschetti Design and protocol: Rita Banzi, Alessandro Liberati, Lorenzo Moja Data extraction: Rita Banzi, Ludovica Tagliabue Analysis and interpretation: Rita Banzi, Ludovica Tagliabue, Lorenzo Moja Drafting of article: Rita Banzi, Lorenzo Moja Critical review of the various versions of the manuscript: Ludovica Tagliabue and Alessandro Liberati Final approval of the article: Rita Banzi, Ludovica Tagliabue, Ivan Moschetti, Alessandro Liberati, Lorenzo Moja

Multimedia Appendix 1

Operational definitions adopted for this study

[PDF file (Adobe PDF File), 74 KB - jmir_v12i3e26_app1.pdf]

Multimedia Appendix 2

Instrument to measure editorial policy quality (max 15 points)

[PDF file (Adobe PDF File), 45 KB - jmir_v12i3e26_app2.pdf]

Multimedia Appendix 3

Instrument to measure editorial policy quality (max 15 points)

[PDF file (Adobe PDF File), 45 KB - jmir_v12i3e26_app3.pdf]

Multimedia Appendix 4

Online EBP information resources excluded and reasons

[PDF/PPT file (Adobe PDF File), 49 KB - jmir_v12i3e26_app4.pdf]

Multimedia Appendix 5

EBP point-of-care summary provider scores and ranks according to volume, editorial quality, and evidence-based methodology

[PDF/PPT file (Adobe PDF File), 57 KB - jmir_v12i3e26_app5.pdf]

Multimedia Appendix 6

A review of online evidence-based practice point-of-care information summary providers

[PPT file (Microsoft Powerpoint File), 232 KB - jmir_v12i3e26_app6.ppt]

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Abbreviations

EBP: evidence-based practice
ICD-10: International Classification of Diseases, Tenth Revision

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Original Paper

Exploring Virtual Worlds for Scenario-Based Repeated Team Training of Cardiopulmonary Resuscitation in Medical Students

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Abstract

Background: Contemporary learning technologies, such as massively multiplayer virtual worlds (MMVW), create new means for teaching and training. However, knowledge about the effectiveness of such training is incomplete, and there are no data regarding how students experience it. Cardiopulmonary resuscitation (CPR) is a field within medicine in high demand for new and effective training modalities.

Objective: In addition to finding a feasible way to implement CPR training, our aim was to investigate how a serious game setting in a virtual world using avatars would influence medical students' subjective experiences as well as their retention of knowledge.

Methods: An MMVW was refined and used in a study to train 12 medical students in CPR in 3-person teams in a repeated fashion 6 months apart. An exit questionnaire solicited reflections over their experiences. As the subjects trained in 4 CPR scenarios, measurements of self-efficacy, concentration, and mental strain were made in addition to measuring knowledge. Engagement modes and coping strategies were also studied. Parametric and nonparametric statistical analyses were carried out according to distribution of the data.

Results: The majority of the subjects reported that they had enjoyed the training, had found it to be suitable, and had learned something new, although several asked for more difficult and complex scenarios as well as a richer virtual environment. The mean values for knowledge dropped during the 6 months from 8.0/10 to 6.25/10 ($P = .002$). Self-efficacy increased from before to after each of the two training sessions, from 5.9/7 to 6.5/7 ($P = .01$) after the first and from 6.0/7 to 6.7/7 ($P = .03$) after the second. The mean perceived concentration value increased from 54.2/100 to 66.6/100 ($P = .006$), and in general the mental strain was found to be low to moderate (mean = 2.6/10).

Conclusions: Using scenario-based virtual world team training with avatars to train medical students in multi-person CPR was feasible and showed promising results. Although we found no evidence of stimulated recall of CPR procedures in our test-retest study, the subjects were enthusiastic and reported increased concentration during the training. We also found that subjects' self-efficacy had increased after the training. Despite the need for further studies, these findings imply several possible uses of MMVW technology for future emergency medical training.

(J Med Internet Res 2010;12(3):e38) doi:10.2196/jmir.1426

KEYWORDS

Cardiopulmonary resuscitation; concentration; educational technology; medical students; MMVW; avatars; patient simulation; self-efficacy

Introduction

Medical simulation is an effective instrument for training of technical as well as nontechnical skills [1-3]. Training in virtual reality, hosted online and accessed by personal computers, is an emerging learning technology that offers new possibilities. Serious games are intended to provide an engaging and self-reinforcing context in which to motivate and educate the users [4,5]. Multi-user computer environments make it possible to interact with other players in a massively multiplayer virtual world (MMVW) [6]. Heinrichs and coworkers have found MMVW training to be promising in the area of emergency medicine for repeated practice of uncommon, life-threatening trauma cases [7]; however, as Hansen points out in a review of the subject, more research concerning training outcomes is needed [8]. Further, the users' experiences of leisure gaming technology for explicit medical training purposes should be investigated.

We have used the teaching of cardiopulmonary resuscitation (CPR) as a model for a scenario-based MMVW training approach. For more than 40 years, attention has been focused on disseminating knowledge and skills in the field of CPR. It is believed that with a better-trained population, many lives could be saved by means of bystander CPR [9,10]. Concern also exists about the quality of current CPR training because of issues such as poor retention, lack of training in so-called nontechnical skills, and negative reactions to the training [11-17].

In this study, we explored initial effects on students using a virtual world for CPR training [18]. No systematic studies regarding the effect of stimulated recall on retention of knowledge and nontechnical skills have been reported. We concur with Kneebone [19], who has identified self-efficacy as an important feature of successful simulations in terms of learning and clinical outcomes, and we also suggest concentration and mental strain as important variables of learning and performance to be analyzed for the first time in CPR training [20-25]. We hypothesized that repeated team training of CPR in a virtual world would influence self-efficacy, concentration, and mental strain in medical students as well as enhance retention of knowledge.

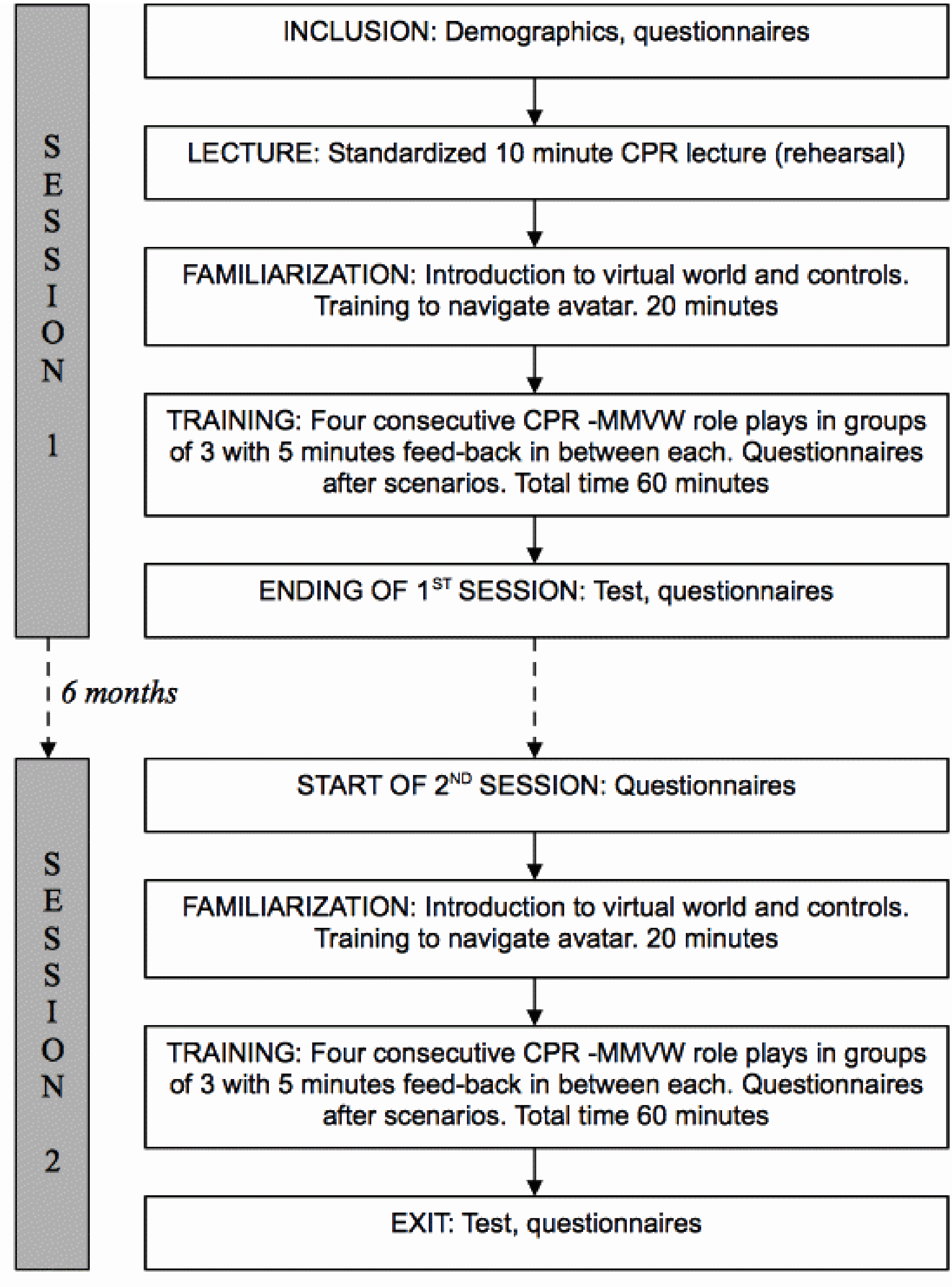
Methods

We enrolled 12 medical students attending the first year at Karolinska Institutet in a test-retest explorative study. The medical students participated voluntarily as study subjects. The students' experiences of the training were investigated using a questionnaire. Our effect measures of training were knowledge, self-efficacy, concentration, and mental strain. We controlled for engagement modes and coping strategies since students might relate differently to the virtual world as well as cope with events during training in different ways. These might in turn affect their performance and other subjective reactions differently during the two study sessions.

A test-retest design created an opportunity to follow retention and temporal changes of training effects. Based upon results from previous CPR studies [26], a 6-month interval between sessions was chosen. In order to control for expected differences between men and women both regarding computer interests and gaming preferences, we enrolled 50% of each sex. The study was approved by the regional ethics committee at Karolinska Institutet. Before entering the study, the subjects had received traditional CPR training, (bystander CPR [27]) during the previous 3 months as a component of their regular medical school curriculum.

A previously developed virtual world (Forterra Systems Inc, OLIVE, game development platform) with prehospital CPR training capabilities was implemented. In mixed groups of three, the subjects attended two structured two-hour sessions six months (185-204 days) apart. Figure 1 summarizes the content and extent of the training sessions.

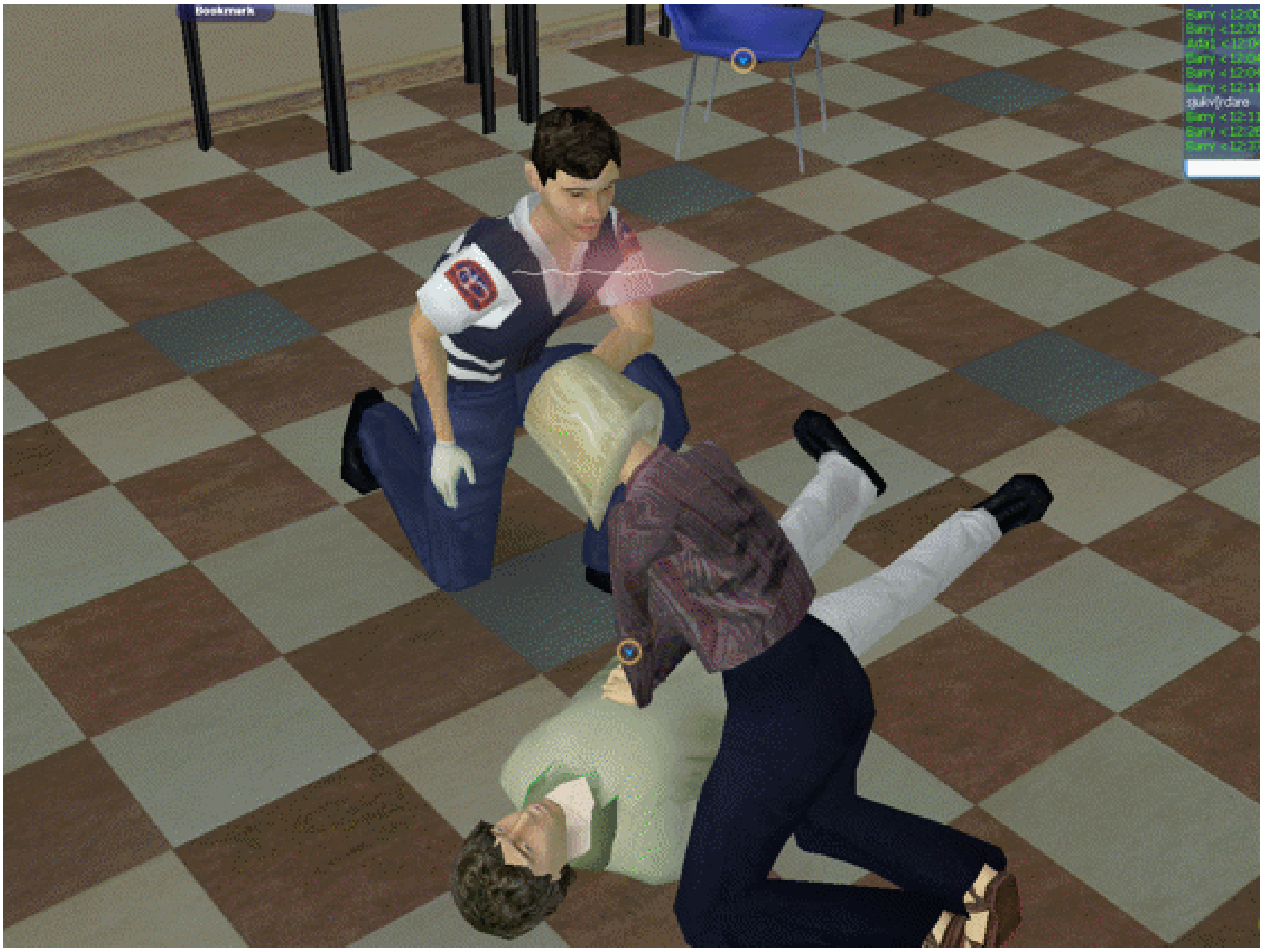
Figure 1. Design of the study in a test-retest manner



A short 10-minute lecture on adult basic life support adhered to 2005 guidelines from the European Resuscitation Council [27]. Besides focusing on when and how bystander CPR should be performed, other life support areas—precautions when performing out-of-hospital CPR and foreign body airway obstruction—were briefly covered. This presentation mainly served as a theoretical review of content covered during the previous conventional training. However, newer 2005 guidelines had, during the time that had elapsed, been fully implemented in Sweden. In the subsequent familiarization period, the subjects were acquainted with the interface features of the virtual world simulation. The interactions in the virtual world were controlled by the subjects using the computer keyboard, mouse, and headset. The subjects´ engagement modes were assessed before starting the scenarios using a validated 15-item questionnaire from which values for positive and negative engagement modes were calculated. This has previously been described in detail by Hedman et al [28]. In order to also control for different individual coping strategies during the two sessions, we administered a validated questionnaire described by Carver [29] before the scenarios, in which each of 21 items gave indications of a particular way of coping.

In the virtual world simulation, the subjects interacted in real time with each other, a victim, and paramedics, by use of their avatars. The trainees were instructed to approach a victim who had collapsed in the virtual world, take the correct diagnostic steps, and collaboratively perform the cognitive and procedural measures associated with bystander CPR. These included (1) moving to the victim, (2) checking the victim for consciousness, (3) declaring the victim unconscious, (4) checking the victim’s airway and breathing, (5) calling for help, (6) performing chest compressions and rescue breaths as stated by the CPR protocol, (7) relieving the rescuers, and (8) assisting the arriving paramedic and giving a brief report to him. Each group consisted of 3 medical students trained in 4 role plays (ie, scenarios). The first two scenarios occurred in a classroom followed by two scenarios that occurred outdoors in a parking lot. A screenshot from the classroom scenario is shown in Figure 2. The scenarios ended when a paramedic entered the virtual world and assisted the group. After each scenario, the trainees received classroom feedback from an instructor. The feedback focused on the bystander CPR protocol and how the actions performed in the scenario complied with the protocol. In general, the feedback sessions took 5 minutes or less.

Figure 2. Screenshot from scenario inside classroom



During the second session held six months later, the subjects received the same curriculum without the lecture. The virtual world scenarios were the same as in the first session. No subjects dropped out between the training sessions.

Demographic data of the study subjects are displayed in Table 1. The values shown are based on self-report at inclusion in the study. There were no significant differences between males and females.

Table 1. Demographics

	Total (n = 12)	Male (n = 6)	Female (n = 6)
Age, mean (SD)	22.6 (3.5)	23.2 (4.8)	22.0 (1.7)
Number with access to computer at home	12	6	6
Level of computer experience (0 to 3)[a] median (range)	2 (1-2)	2 (1-2)	2 (1-2)
Computer and video game use (0 to 5)[b] median (range)	1 (0-4)	3 (0-4)	1 (0-2)

[a] Level of computer experience was graded on a 0 to 3 Likert-type scale where 0 = none and 3 = very high.

[b] The use of computer and video games was graded on a 0 to 5 Likert-type scale where 0 = none, 1 = less than once a month, 2 = once every second week, 3 = once a week, 4 = several times every week, and 5 = every day.

In order to get information about the qualitative experiences from the virtual world training, a questionnaire was administered at the end of each session. The subjects were asked if they found the virtual world simulation to be realistic, easy to use, and useful in preparing them for future tasks. Subjects were asked to rank their answers on 5-grade Likert type scales where 1 = not at all and 5 = very much. Further, the subjects were asked to state the strengths and weaknesses of the training scenarios. The questions were open-ended, and the subjects could list as many examples as they wished. Lastly, the subjects were asked if they had learned anything new. Answers to this question were given as written free comments by the subject. These were then fragmentized into meaning-bearing entities, analyzed, classified, and categorized by the authors. If the same kind of answer was given several times by one subject, it was counted as only one occurrence to have it justly weighted.

Knowledge about the material covered by the lecture—adult basic life support (BLS)—was measured by a written examination using a 10-item questionnaire that was administered at the end of each session. Each question was followed by four true-or-false statements. The answer was considered correct if all four statements were correctly answered.

Perceived self-efficacy [20], as one affective component of learning [21], was self-assessed before and after each training session using a 5-item questionnaire where each item was rated on a 7-grade Likert-type scale. Self-efficacy was then calculated as the mean value of these items.

Concentration is a skill to selectively focus on relevant information while ignoring distractions and can be associated with this type of training [24,25]. Intense concentration is highly associated with the “flow experience”, defined as an internal state of total focus, involvement, and absorption in an ongoing task [22]. We used eight familiar items on concentration from previously validated instruments for assessing flow experience [22,28,30,31]. Concentration was measured immediately after the first, second, and forth scenario using a 0 to 100 visual analogue scale, and the concentration score was calculated as the mean of all items.

The mental strain during the training was measured by one question directly after the first, second, and forth scenario using a validated instrument, the Borg´s CR10 scale, in which subjects were asked to rate their mental strain on a scale of 0 to 10, where 0 = no mental strain at all and 10 = extremely high mental strain [23].

Repeated measurements analysis was used to analyze time dependent data, and regression analysis was used to evaluate the dependency between variables. Statistical comparisons to test differences between two groups were made by use of the Mann-Whitney U test or by use of the Student’s *t* test for uncorrelated means after validation for normal distribution by use of the Shapiro Wilk test. The within group analysis was made by use of pairwise Student’s *t* test for correlated means. Multiple comparisons of continuous data were performed by analysis of variance. The procedure proposed by Fisher was used to control for multiplicity [32,33]. In order to evaluate hypotheses of variables in contingency tables, the chi-square test was used or, in the case of small expected frequencies, Fisher's exact test. In addition, descriptive statistics and graphical methods were used to characterize the data. The study employed multiple hypotheses testing where each hypothesis was analyzed separately and the existence of patterns in and the consistency of the results were considered in the analysis. All analyses were carried out by use of SAS, version 9.1 (SAS Institute, Inc, Cary, NC, USA), and the 5% level of significance was considered. Data are presented as means (SD) or medians (range), depending on the type of distribution.

Results

Subjective Reflections

Results of subjects’ scoring of realism, ease of use, and usefulness in future work are presented in Table 2.

The first two questions were asked after both sessions, but there were no significant changes and the data are presented as mean values of both sessions. The questions on usefulness were only asked after session 2.

The subjects’ answers to the question pertaining to strengths and weaknesses of the simulated scenarios are summarized and presented in Table 3.

Table 2. Subjects' scoring on realism, ease of use and usefulness in future work

Question[a]	Female (n = 6) mean (SD)	Male (n = 6) mean (SD)
Did you find the simulations realistic?[b,d]	3.92 (0.29)	3.04 (0.75)
Did you find the computer program easy to use?[b]	3.88 (0.74)	4.17 (0.58)
How useful do you think these exercises would be for learning to react to a medical emergency?[c]	4.50 (0.55)	4.17 (0.41)
How useful do you think these simulation exercises would be for learning to work together as members of a health care team?[c]	4.67 (0.52)	4.00 (0.63)

[a] Scoring performed on 1 to 5 grade Likert-type scale where 1 = not at all and 5 = very much.

[b] Question asked after both sessions. Mean values are combined scores for both sessions. No significant changes were found over time

[c] Question asked only after session 2. See text for details.

[d] Difference between males and females statistically significant ($P < .05$, $t_{22} = 3.76$).

Table 3. The subjects' answers to the question pertaining to strengths and weaknesses of the simulated scenarios.

Answer Categories	Number of Statements in Category
Strengths	
Suitable and realistic environment	14
Good way to repeatedly practice	9
Necessary to adapt to changing circumstances	7
Easy and straightforward	4
Training teamwork aspects	2
Learning about own reactions	1
Weaknesses	
Tasks too easy, more options wanted	23
Lack of realism and environment not rich enough	9
Technical problems	2

In response to the question, “Have you learned anything new,” 11 subjects said yes and one subject said no. When asked in which field new learning had occurred, 8 of 12 subjects responded that new learning was mainly attributable to a newer version of CPR guidelines, 4 of 12 responded they had learned more about teamwork, and 4 of 12 said they had learned more about working under stress. When discussing how scenario-based team training in the virtual world was perceived, a typical comment was, ”I think that it is a good way of learning, which can attract a large group of experienced computer users more than other CPR education (with a manikin, although the manikin is needed to get the practical aspect).” Another reoccurring comment was a request for more “situations (with greater variation), preferably [with] people around, which increases stress and sense of reality.”

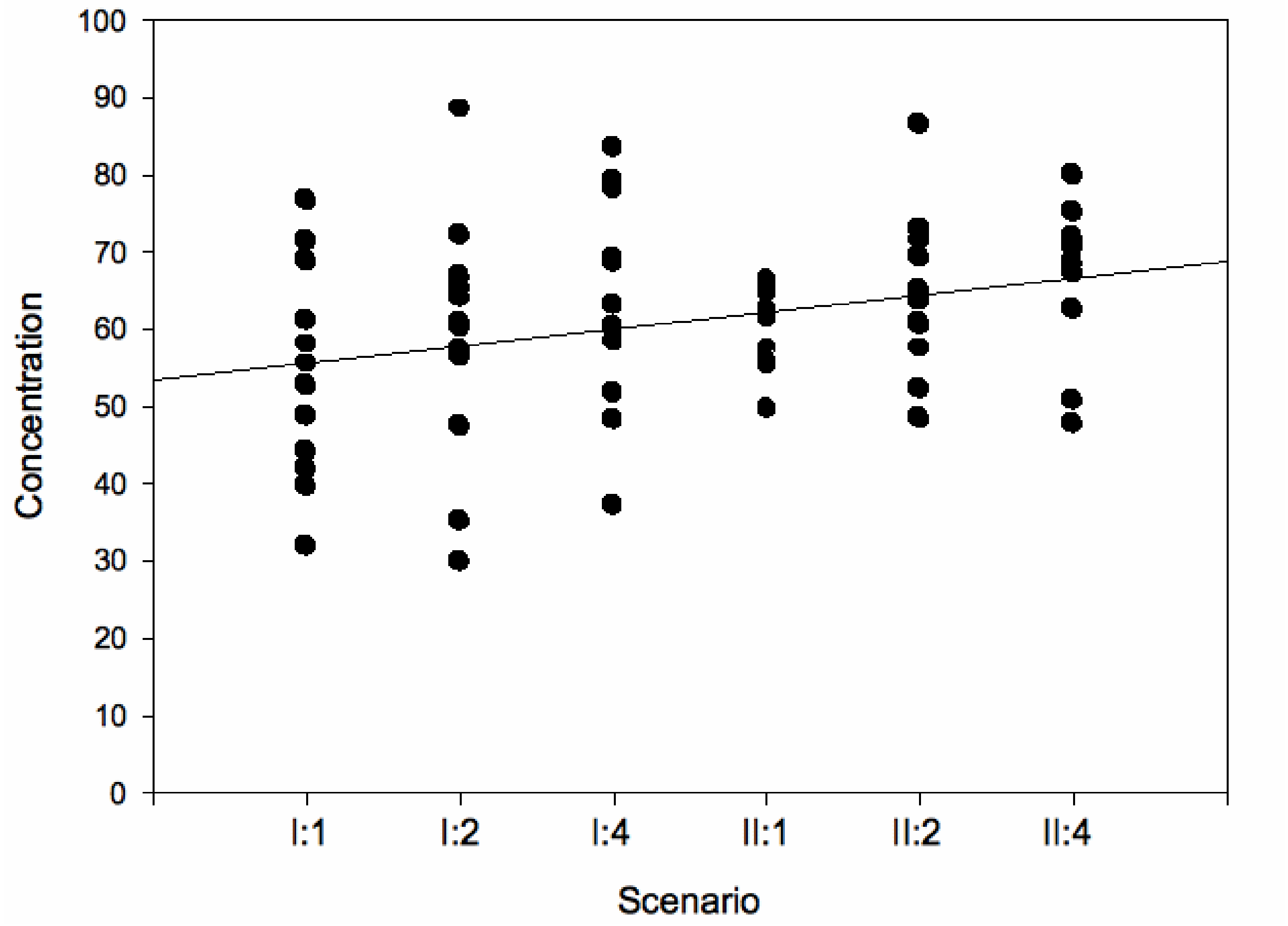
Other Individual Experiences and Strategies

Engagement modes and coping strategies were stable over time (data not shown). In Figure 3, box-plots illustrate self-efficacy at baseline and after training.

A significant increase was observed in self-efficacy for the whole group after the first session and also after the second session. Further, there was a statistically significant difference in self-efficacy between males and females before the training. The mean (SD) self-efficacy for female subjects was 5.47 (0.47); the corresponding value for male subjects was 6.20 (0.40) ($P = .015$). Thereafter, no difference in self-efficacy was observed between males and females. The change of concentration over time is shown in Figure 4.

Figure 3. Self-efficacy in the study group

Figure 4. Scatter plot depicting the individual score for concentration at each scenario



In the first session, the mean (SD) concentration value was 54.2 (13.7) during the first scenario. During the second scenario, it had increased to 58.7 (15.8), and during the fourth scenario, it reached 63.1 (15.6). In the second session, the corresponding values were 59.3 (5.1), 65.1 (10.4), and 66.6 (9.4) respectively (*P* = .006). For female subjects, mean (SD) concentration increased from 60.1 (10.6) to 71.4 (4.4), whereas for men, the increase was from 48.3 (14.8) to 61.8 (10.9). No significant changes in mental strain were noted over time either in the complete group or in any of the subgroups. However, over all scenarios, the mean (SD) mental strain value for men was 1.2 (0.7), significantly lower than for women whose mean (SD) mental strain value of all scenarios was 3.7 (1.7) (*P* < .001). No correlation between mental strain and gaming experience was found.

Knowledge

The mean (SD) results on the written examination was 8.0/10 (1.6) after the first session and 6.25/10 (1.5) after the second session. This 20 percent drop was statistically significant (*P* = .002).

Discussion

As, to our knowledge, very few examples of virtual world-based team training using avatars exist in the medical field, our objective was to understand how the use of this tool for CPR training was perceived by medical students. Despite leisure gaming being common and popular, it is debatable whether it can be useful in the field of serious games. An important finding was that the subjects, in general, felt positive about the virtual world training experience. Although all subjects had previously participated in traditional CPR training, a majority learned something new, and all were positive toward further virtual world training. Interestingly, the subjects rated the future potential and usefulness of this type of training highly. Although many of these findings must be regarded as context specific, it appeared that the major benefits from this type of training were in its usefulness to practice repeatedly in a scenario-based setting. The subjects found the training quite realistic, easy, and straightforward. Contrary to conventional CPR training curriculum, team aspects, probably important for real-life outcome, were introduced in this training. Also these measures seemed to be appreciated by the trainees. The weaknesses with the virtual world training were mainly related to the virtual environment itself; realism, increased diversity among the scenarios, and more challenging medical cases were asked for. Although there were several occurrences of technical imperfections, we found comments from only two subjects regarding technical problems.

The relatively high scores of self-efficacy found before the first training session, partly explained by recent conventional CPR training, increased to even higher scores after the training. After 6 months, the self-efficacy scores showed a numeric decrease that did not, however, reach statistical significance. After the second session, the scores increased again. We interpret this as an indication that virtual world scenario-based team training can be used effectively to rebuild confidence, if not competence. Despite the small sample size, it is important to note the differences between female and male subjects. The ratings for the female subgroup were in this aspect inferior, indicating less confidence, compared with those of the male subgroup during the whole study period.

Previous research has shown that effective training is correlated with a high degree of concentration [24,25]. During the first session, subjects' concentration was on a medium level and increased over time. This trend was also replicated in the second session. The reason for this could be due to subjects' clearer understanding of the tasks, their better control over how to maneuver in the virtual world, as well as their having fewer technical problems. However, increased ability to concentrate might also come from learning to work as a team, that is, as teamwork becomes smoother and the resuscitation process is perceived as more effective and rewarding, concentration increases. In the exit questionnaire, we noted that generally the scenarios were considered quite easy. However, it didn't appear as if the perceived easiness of the scenarios had any detrimental effects on concentration, although if the scenarios were better matched to expectations, it could be hypothesized that scores on concentration in general would be even higher. The higher score on concentration for the female subgroup might indicate a higher degree of involvement of females in these scenarios.

The experienced mental strain was in the medium or low range of the test scale. Mental strain can certainly be modified by the trainer, the expectations, and the setting of the training. High scores might be typical for the real world CPR situation, but generally too much mental strain might hamper learning. Interestingly, even with moderate mental strain, several subjects found the training to be useful in learning about their own reactions to stress. The difference between male and female subjects was obvious and persistent over time, indicating higher involvement in the task among the female subgroup during the scenarios. Although the level of previous gaming experience seemed to be higher in the male group, it is less likely that this fact contributed to the higher mental strain in the female subgroup, since no correlation between gaming experience and mental strain was found. Also, women in this study did not experience technical difficulties to a greater extent than men.

One intention in this study was to assess whether situated learning occurred. Therefore, the theoretical lecture on CPR allowed a common level of knowledge among the subjects to be set. The lecture was omitted in the second session. If situated learning did occur to any greater degree, we would expect the subjects to activate and retain this knowledge merely by repeated practice. We observed a significant decrease in knowledge of BLS between the test and retest. Assessing knowledge retention was possible by using the same quiz about information provided in a theoretical lecture. What this drop of knowledge actually reflected is debatable; the content of BLS is somewhat broader than bystander CPR, therefore, some aspects were not practiced in the virtual world. Hence, it could be argued that part of the knowledge that was tested was not actively sustained by training. One could also argue that this observation could reflect the lack of haptic chest compressions in MMVW simulation. Adding psychomotor activity, that is, simulated chest compressions, might increase the fidelity and enhance learning as well as recall of knowledge. In Sweden and many other countries, the established procedure of the resuscitation community is that annual training is warranted for professionals, and biannual training or less frequently for nonprofessionals. These long intervals may account for the poor efficacy of current training methods [34,35]. A potential solution may be to increase the sense of presence by adding a CPR manikin to the MMVW for a more engaging and integrated opportunity to practice and establish the routine.

These are clearly important aspects that are not specifically addressed in current CPR education and training. The reactions from the students also support further development of this tool as many in this group asked for more training options, technical possibilities, and different medical scenarios. Finally, the observation of lower confidence, reduced sense of self-efficacy, higher levels of concentration, and the greater mental strain experienced by females suggest the need for further studies of how different students learn resuscitation with this method. Further systematic studies with control groups are needed to understand the main reasons for such differences, that is, whether these are biological, cultural, or adaptive. We are unaware that these individual experiences have been evaluated with current manikin-based training methods. In order to better understand the nature of the experiences of trainees when using MMVW to learn CPR techniques, it would also be interesting to focus in depth on trainees' reactions and reflections. Another important area to be covered by future studies is how the trainers and stakeholders react to virtual world training. If this type of training is to be successfully implemented, it is of paramount importance that these groups find value in such alternative training methods.

Previously identified weaknesses in current CPR practice include stress, time constraints, lack of nontechnical skills among team members, uncertainty over the need to act, risk of inflicting harm, and lack of procedural competence. Virtual world training can address the majority of these problems. Most obviously, MMVW can be used to train the procedural competence, but the strictly physical aspects (eg, how to perform rescue breaths and chest compressions) cannot be trained with the current method. Hence, this type of virtual world training cannot stand alone to train people in CPR. Instead, it can be used to help students gain cognitive and team training skills, and therefore it can work as an adjunct to other manikin-based training.

Engagement modes and coping strategies were stable over time, and probably did not affect the students´ performance and other subjective reactions differently during the sessions.

To summarize, scenario-based virtual world team training of CPR using avatars seems to be engaging and elicits positive changes in students´ subjective experiences. The results demonstrate the potential of serious gaming technology as a new tool in medical education and training. Once the problem of the developmental costs of software has been solved, virtual worlds for training for medical emergencies might be easy to disseminate and be engaging, as well as enable new teaching strategies and pedagogic development.

Limitations

An obvious limitation of this study is its small sample size. However, the purpose was to perform a small exploratory study with a new training tool in an established learning context (medical school). The training effects might have been sensitive to factors other than training, such as technical difficulties, attitudes in the whole group towards this type of scenario-based simulator training, and previous computer and video game experiences. One way to partly control for this type of bias in the present study was the inclusion of the self-efficacy instrument and questions in the exit questionnaire. Our choice of the 6-month interval may have exceeded the capability of the subjects to recall accurately the details of CPR performance; shorter intervals may produce more favorable results.

Conclusions

Cardiopulmonary resuscitation is a critical competence that is necessary to disseminate in society in order to save lives. With a new emerging generation of health care staff accustomed to gaming technology since childhood, serious games for education and training have a great potential. Although more evaluations on the effectiveness and customizing of this technology are necessary, we have found supporting evidence for scenario-based virtual world training to be used to supplement and reinforce traditional education and training, in particular, to prolong retention of knowledge and procedural order. MMVW training using avatars offers several advantages since it is easily distributed, requires no specialized equipment, and may be carried out as distance training.

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Conflicts of Interest

None declared

Authors' Contributions

JC assisted in technology development, helped conceive the study, participated in study design and served as subject matter expert (emergency medicine), acquired and analyzed data, took part in data interpretation as well as drafted the manuscript. LH contributed substantially to study design, served as subject matter expert (psychological assessment), developed psychometric methods, interpreted data, and critically revised the manuscript. CM assisted with technical support (hardware and software), participated in data acquisition, and critically revised the manuscript. WLH assisted in technology development and the conception and design of the study and also took part in the critical revision of the manuscript. LFT conceived the study and participated in study design as well as interpreted data and critically revised the manuscript. All authors read and approved the final manuscript.

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Abbreviations

BLS: basic life support
CPR: cardiopulmonary resuscitation
MMVW: massively multiplayer virtual world
SUMMIT: Stanford University Medical Media and Information Technology

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Original Paper

Online Social and Professional Support for Smokers Trying to Quit: An Exploration of First Time Posts From 2562 Members

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Abstract

Background: Both intratreatment and extratreatment social support are associated with increased rates of smoking cessation. Internet-based social support groups have the capability of connecting widely dispersed groups of people trying to quit smoking, making social support available 24 hours a day, seven days a week, at minimal cost. However, to date there has been little research to guide development of this particular feature of Web-assisted tobacco interventions (WATIs).

Objective: Our objectives were to compare the characteristics of smokers who post in an online smoking cessation support group with smokers who do not post, conduct a qualitative analysis of discussion board content, and determine the time it takes for new users to receive feedback from existing members or moderators.

Methods: Data were collected from StopSmokingCenter.net version 5.0, a WATI equipped with an online social support network moderated by trained program health educators that was operational from November 6, 2004, to May 15, 2007. Demographic and smoking characteristics for both users and nonusers of the online social support network were analyzed, and qualitative analyses were conducted to explore themes in message content. Posting patterns and their frequency were also analyzed.

Results: During the study period, 16,764 individuals registered; of these, 70% (11,723) reported being American. The mean age of registrants was 38.9 years and 65% (10,965) were female. The mean number of cigarettes smoked was 20.6 per day. The mean score for the 41% (6849) of users who completed the Fagerström Test for Nicotine Dependence was 5.6. Of all registered members, 15% (2562) made at least one post in the online social support network; 25% of first posts received a response from another member within 12 minutes, 50% within 29 minutes. The most frequent first posts were from recent quitters who were struggling with their quit attempts, and most responses were from members who had quit for a month or more. Differences in demographic and smoking characteristics between members who posted on the support group board at least once and those who did not post were statistically but not clinically significant.

Conclusions: Peer responses to new users were rapid, indicating that online social support networks may be particularly beneficial to smokers requiring more immediate assistance with their cessation attempt. This function may be especially advantageous for relapse prevention. Accessing this kind of rapid in-person support from a professional would take an inordinate amount of time and money. Further research regarding the effectiveness of WATIs with online social support networks is required to better understand the contribution of this feature to cessation, for both active users (posters) and passive users ("lurkers") alike.

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KEYWORDS

Internet; social support; addiction; treatment; tobacco; WATI

Introduction

Extensive evidence exists to prove the effectiveness of several traditional behavioral interventions for smoking cessation, including brief or intensive advice, individual or group counseling, tailored self-help, and telephone quitlines [1,2]. As access to the Internet continues to expand globally and an increasing number of individuals turn to the Internet to search for health information [3], a growing number of individuals are likely to seek help on the Internet with quitting smoking in place of or as an adjuvant to more traditional forms of treatment. The wide reach of these Internet-based interventions thus provides an opportunity to impact tobacco use at a population level [4]. A review of several randomized controlled trials concluded that tailored, interactive, Internet-based interventions significantly increase abstinence rates compared with untailored written or Web-based materials, and their effectiveness appears to be similar to intensive face-to-face counseling [5]. However, insufficient evidence and considerable heterogeneity in design at present prevent any reliable conclusions or recommendations regarding the effectiveness of Web-assisted tobacco interventions (WATIs) to be made [1,5]. Thus, further research is necessary to characterize the different features of WATIs and how they are experienced by users in order to determine for whom and by what mechanisms WATIs may be effective.

Online Social Support for Health

Based on evidence from traditional behavioral interventions, current cessation guidelines recommend that all smoking cessation interventions incorporate an element of social support [1]. Meta-analytic findings indicate that providing either intratreatment or extratreatment social support significantly increases the odds of smoking abstinence at follow-up (OR = 1.3, 95% CI = 1.1-1.6 and OR = 1.5, 95% CI = 1.1-2.1, respectively) [1]. Access to the Internet affords the possibility to connect individuals worldwide 24 hours a day, seven days a week, at minimal cost, eliminating barriers to in-person group participation due to factors such as childcare, disability, and employment.

Cutrona and Suhr [6] developed a coding scheme that classifies social support behavior under two broad categories: “nurturant” and “action facilitating.” Nurturant types of social support help the person cope with the situation without necessarily solving the problem. Subcategories include “emotional support” (eg, “I know how you feel. The crankiness was the worst part for me too, but it does pass”), “esteem support” (eg, “don’t let that slip get you down, I know you can do it”), and “social network support” (eg, “I am glad you are part of this support group, and we are here to help you”). Action facilitating social support, on the other hand, is usually subcategorized into “informational support” that intends to help solve the problem causing stress (eg, “you can drink a glass of water when you have a craving”) or “tangible support” (eg, “I will send you a book on smoking cessation medications and the name of an excellent specialist”). Several content analyses of posts on online communities for health conditions such as irritable bowel syndrome [7], Huntington’s disease [8], and HIV/AIDS [9], have utilized Cutrona and Suhr’s [6] coding scheme and identified that all five subtypes of social support are evident in posts, with informational and emotional support most frequently offered [7,8,9]. However, Coursaris and Liu [9] noted that not all post content fit into this social support framework, and thematic analysis identified an additional three themes that were seen as facilitating social support: sharing personal experiences, expressing gratitude, and offering congratulations.

In the addictions field, there have been very few published studies that have examined the content of posts to online social support groups. In a study of AlcoholHelpCentre.net (AHC) [10], analyses of 474 posts made by registered problem drinkers revealed that the most common themes were providing encouragement and suggestions to other forum members and expressing gratitude for support received. Of the 155 registered members of AHC, 32% made at least one post on the forum, and those who posted did not differ significantly on any demographic characteristics compared with those who did not post.

To date there has only been one published qualitative analysis of posts to an online smoking cessation forum, part of the primarily French-language website, www.Stop-tabac.ch, a nonprofit WATI [11]. Burri [11] analyzed all 1033 messages posted in April 2005 by 97 ex-smokers who had quit smoking within the past 6 months. The most frequent theme identified among posts was providing emotional support and encouragement, followed by personal stories and opinions, congratulations to quitters, commonplace remarks often not related to tobacco, and expressing gratitude to other forum members. Discussing smoking cessation medications, giving practical advice and tips, and asking for information or emotional support were among the least common themes.

However, a number of features of the study by Burri and colleagues [11] limited its generalizability to other online support groups for smoking cessation. The forum was not moderated by a professional, and members were segregated according to their “stage of change” [12]. Therefore, the findings only reflected the experiences of recent quitters in the “action” stage, who comprised the sample. Segregation by stage of change may have prevented these members from observing or communicating with other members at different stages, and other online support boards that do not share this design may exhibit differences in interactions between members.

Current Study

The purpose of the current study was to explore seeking and providing social support on a moderated online smoking cessation support group board. In particular, we sought to answer the following research questions: (1) Are there any differences in demographic or smoking-related characteristics that differentiate smokers who choose to post on an online smoking cessation discussion board and those who do not choose to post? (2) What topics prompt someone to make a first post on a smoking cessation discussion board, and do specific topics prompt members to post more quickly after joining an online community? (3) Are any topics more frequently or more quickly responded to by other members of an online support group? The current paper attempts to answer these questions using data collected from the English language StopSmokingCenter.net

(SSC), version 5.0, a free-access WATI with both a self-help behavior change program and an online social network moderated by trained health educators.

Methods

Description of the Program

Version 1.0 of the SSC was officially launched on September 28, 2000. Since launch, the program has been updated five times, with the most recent version of the SSC (6.1) released on January 1, 2008 (see Figure 1). At the time of data collection, the life cycle of version 5.0 had been longer than version 6.0 and 6.1 and thus provided a greater quantity of data for analysis; therefore, data for the current study were collected from the lifecycle of SSC version 5.0, which lasted from November 6, 2004, through May 15, 2007 (the study period). Version 6.1 differs from version 5.0 in the information architecture (IA) of the program's behavior change program. Version 5.0 was based on tunnel IA design, which guided users through a strict, step-by-step series of interactive exercises.Version 6.1 of SSC utilizes a free-form matrix IA design, which allows users to freely explore all program elements and self select interactive exercises, information, and tools. The decision to modify the program from the tunnel IA design to the free-form IA design was based on current literature outlining how individuals utilize eHealth programs [13] and results from usability testing at the Centre for Global eHealth Innovation in Toronto, Ontario. Recent evidence indicates that the free-form IA design increases usability [14]. However, it is important to note that version 5.0 utilized the same support group software as version 6.1 of the SSC, and users of version 5.0 were permitted to post in the support group at any time following program registration, as in version 6.1. Therefore, although there are differences in version 6.1 in access to behavior change exercises, information, and tools, access to the support group of the program was the same in version 5.0 as in version 6.1.

Figure 1. Screenshot of StopSmokingCenter.net 6.1 home page

All aboard for a warm and wet train ride to ....
Hot SiO2
March 11 2010 10:51 AM

Tuesday pledge
memie
March 11 2010 10:03 AM

11 Month's Down the Drain
Jan58
March 10 2010 11:20 PM

- I want to quit smoking in the next 6 months
- I've recently tried to quit but I've slipped
- I've quit smoking and I'm looking for some help to stay smoke free
- I don't want to quit smoking

Welcome to the Stop Smoking Center 6.1!

Are you concerned about your smoking? Are you trying to quit or are you thinking about quitting? Signing up is free and easy and gives you access to lots of tools and information:

- Create your own personalized quit program
- Connect with other quitters who have been where you are
- Opt in to receive email and text messages
- Set your quit date and start counting down!

If you're just looking for more information you can also read about the effects of smoking, benefits of quitting, common questions about quitting and the effects of second hand smoke.

Sign up now to get started. New accounts are given on a first come, first serve basis. Evolution Health Systems Inc. donates 10 free memberships each day, available to the first 10 visitors. If you would still like to use the tools and features, we offer links to our community partners who also offer the SSC program.

You do not have to purchase any products to use this free program. Please remember that this program is not to replace the advice of a healthcare professional.

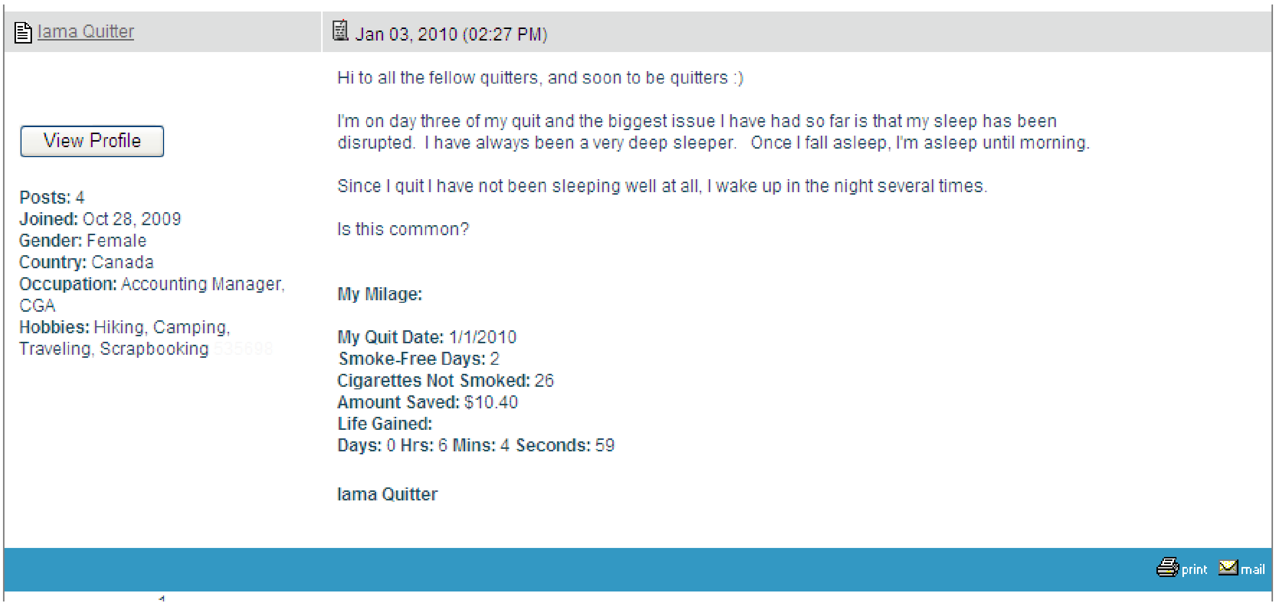
This program is for educational purposes and is not to replace the advice of your family physician or other health care provider. © 2000-2010 Evolution Health Systems Inc.

There were no fees to access the program; however, to participate and post messages in the program, registrants must have agreed to abide with a user agreement and consented to the use of their anonymous data for research purposes. The program does not sell, advertise, or promote any products, and user data were not sold to any third party. Registration enabled a unique ID number to be assigned to each member and allowed for tailored information to be provided to the member. Following registration, a unique password was sent to the member's email address. The unique password permitted the member access to all of the program's tools and services.

Following registration, members were able to use all of the tools within the tailored quit program, participate in the online social support group, email questions to the program's trained moderators (health educators), receive inspirational emails, and chat with other members via the program's Quitting Buddies Instant Messaging program. If a health care professional or a researcher registered with the program for review purposes, they were asked to endorse a second checkbox to indicate their health care professional or researcher status and their data were discarded from the database. Unregistered visitors had the ability to view and search all posts and all message threads within the program's support group. However, to participate in discussions or use other features of the program, registration was required.

Once members endorsed the user agreement and accessed their tailored program, they had the additional ability to upload specific information to their personal profile, which could be displayed as part of their support group post(s). The personal profile was optional, but if used, personal profile information was then in the public domain and could be viewed by other members as well as by users who had not registered, known as "lurkers." Members could provide within their profile an avatar or uploaded image as well as personal information including their sex, age, country of origin, occupation, and hobbies. Members could also add a tagline or signature to their posts and could select to display all, some, or none of their personal profile. In addition to optional personal profile information, members' usernames, dates they joined SSC (registered), and numbers of posts to date were automatically displayed in their support group posts (see Figure 2).

Figure 2. Screenshot of a sample StopSmokingCenter.net 6.1 support group post



Iama Quitter

Jan 03, 2010 (02:27 PM)

Hi to all the fellow quitters, and soon to be quitters :)

I'm on day three of my quit and the biggest issue I have had so far is that my sleep has been disrupted. I have always been a very deep sleeper. Once I fall asleep, I'm asleep until morning.

Since I quit I have not been sleeping well at all, I wake up in the night several times.

Is this common?

Posts: 4
Joined: Oct 28, 2009
Gender: Female
Country: Canada
Occupation: Accounting Manager, CGA
Hobbies: Hiking, Camping, Traveling, Scrapbooking 535698

My Milage:

My Quit Date: 1/1/2010
Smoke-Free Days: 2
Cigarettes Not Smoked: 26
Amount Saved: $10.40
Life Gained:
Days: 0 **Hrs:** 6 **Mins:** 4 **Seconds:** 59

Iama Quitter

All posts made within the support group boards were published instantaneously but were reviewed by the program's health educators via WebTriage. WebTriage enabled health educators to review, approve, edit, or delete posts (see Cunningham et al [10] for more details). Health educators could also communicate directly with members via email to ensure appropriate behavior and edit or delete member posts. All program health educators were paid employees of Evolution Health Systems Inc and were trained to only give brief, behavioral advice and were instructed to not provide one-on-one counseling, discuss specific instances of medication use, or provide psychiatric advice.

Ethical Considerations

All members, having completed the registration process, consented to the use of their anonymous data for research purposes. During registration, an explanation was provided to participants as to how their information would be used and how privacy would be maintained. Registration or log-in was not required to access the support group boards, therefore all posts were in the public domain. To further protect member privacy, anonymity was promoted and potential members were encouraged at registration to use free email services such as Hotmail, Yahoo! Mail, or Gmail. The current study was approved by the Research Ethics Board at the Centre for Addiction and Mental Health (#456/2007).

Measures and Data Collection

Data collected during the study period were extracted from the program's customized structured query language (SQL) server database. Information on demographics (age, gender, and country of residence) and smoking behavior (number of years smoked and number of cigarettes smoked per day) collected at registration was extracted.

One of the exercises members had the option of completing following registration was the Fagerström Test for Nicotine Dependence (FTND) [15], a widely used self-report measure of nicotine dependence. The FTND is composed of six items including questions assessing number of cigarettes smoked per day, time to first cigarette in the morning, smoking when ill, and difficulties refraining from smoking where prohibited. High levels of nicotine dependence are classified by scores of 6 or higher. The coefficient alpha for the current sample was .63, similar to the value reported by the scale developers (alpha =

.61) [15]. Scores were extracted for all members who opted to complete the FTND.

Information regarding quit status was not requested at the time of registration. However, the majority of posts on the support group boards contained information regarding quit status. In addition to content posted (eg, “I’ve been smoke-free for 3 days now”), the optional “My Quit Date” exercise allowed members to automatically append quit date information onto each post as part of their signature (eg, quit date, number of smoke-free days) (see Figure 2). Using both of these sources of information, all first posts were coded for the quit status of the member who posted. Similarly, the content of first replies to first posts was coded to determine the quit status of the member who posted the reply.

For each member, date and time values were extracted from the SQL server database for (1) completion of the registration process, (2) first post, where applicable, and (3) first reply to first post, where applicable. This allowed for calculation of time elapsed (in hours) between registration and first post and between first post and first reply. In addition, the content of all first posts and first replies was extracted for qualitative analysis.

Data Analysis

The content of all first posts was analyzed using content analysis. Themes were identified using an inductive approach grounded in the data as opposed to a deductive approach guided by existing theory and/or predetermined categories or themes. The fourth author (DP), an employee of Evolution Health Systems Inc and a fourth year nursing student, coded the content of each post and identified a list of themes. Many posts contained more than a single theme.

Background information (ie, demographic and smoking variables) and themes for first posts were entered into a database for analysis. Chi-square and *t* tests were computed to compare groups on categorical and continuous variables, respectively. Time to first post and time to reply variable distributions were significantly skewed and kurtotic; therefore, nonparametric Mann-Whitney U tests and Kruskal-Wallis tests were conducted to determine whether time to post or reply varied by absence or presence of a theme or a member’s quit status, respectively. Medians and ranges are reported in place of means and standard deviations for nonnormally distributed variables. Statistical analyses were conducted with SPSS version 15.0 (SPSS Inc, Chicago, IL). In light of the large sample size and number of comparisons being made, significance was set at the more stringent level of $P < .01$ to reduce type I error.

Results

Demographic and Smoking Characteristics

During the study period 16,764 smokers (“members”) had registered with SSC version 5.0. Of these 16,764 registrants, 15.3% (2562) made at least one post to the support group boards (“posters”), while 84.7% (14,202) did not post (“nonposters”). (See Table 1 for demographic characteristics of posters and nonposters.) The average smoker who registered with SSC was 39 years old, had smoked for approximately 20 years, smoked a pack a day, and had a moderate to high level of nicotine dependence. The majority of smokers were female. Although, there were no clinically significant differences between posters and nonposters, the completion rate of the FTND was almost double among posters compared with nonposters. This likely reflected greater engagement in the process of smoking cessation by those who posted.

Table 1. Demographic and smoking characteristics of registered members of StopSmokingCenter.net version 5.0 (November 6, 2004, through May 15, 2007)

	All Registered Members	Posted On Support Group Boards	Did Not Post On Support Group Boards	*P* Value[a]
Demographic Characteristics	(n = 16,764)	(n = 2562)	(n = 14,202)	
Female, % (n)	65.4 (10,965)	70.1 (1795)	64.6 (9170)	< .001
Age (years), mean (SD)	38.9 (11.3)	40.4 (10.8)	38.7 (11.3)	< .001
Country of residence				< .001
United States, % (n)	69.9 (11,723)	73.5 (1882)	69.3 (9841)	
Canada, % (n)	12.6 (2104)	12.3 (315)	12.6 (1789)	
United Kingdom, % (n)	7.1 (1191)	6.2 (159)	7.3 (1032)	
Other, % (n)	10.4 (1746)	8.0 (206)	10.8 (1540)	
Smoking characteristics				
Years smoked, mean (SD)	19.9 (11.2)	21.6 (11.0)	19.5 (11.2)	< .001
Cigarettes per day, mean (SD)	20.6 (10.6)	22.2 (10.9)	20.4 (10.5)	< .001
Completed FTND, % (n)	41.0 (6849)	66.7 (1708)	36.2 (5141)	< .001
FTND score[b], mean (SD)	5.6 (2.3)	5.8 (2.2)	5.5 (2.3)	< .001
High level of nicotine dependence (FTND score > 6)[b], % (n)	54.9 (3759)	58.3 (996)	53.7 (2763)	< .001

[a] Differences in demographic and smoking characteristics are statistically significant, but are not clinically significant.

[b] Based on subsample that completed the FTND (n = 6849)

First Posts to Online Support Group

There were 2562 first posts to the online support group. A complete list of the most relevant first post coding themes—overall and according to quit status—is presented within Table 2. The most common theme that emerged overall was seeking support or advice with quitting.

Table 2. Themes in first posts to support group by members of StopSmokingCenter.net version 5.0 (November 6, 2004, through May 15, 2007)

		Quit Status			
	Total[a] (n = 2562)	Not Quit (n = 637)	Quit ≤ 1 month (n = 1401)	Quit > 1 month (n = 228)	*P* Value[b]
Theme of First Post	% (n)	% (n)	% (n)	% (n)	
Struggling with quitting and seeking support or advice	28.0 (717)	17.4 (111)	34.6 (485)	32.9 (75)	< .001
Responding to another member’s post or comment	17.6 (451)	7.4 (47)	16.8 (236)	32.5 (47)	< .001
Question or comment about cravings or triggers	15.3 (391)	10.2 (65)	19.5 (273)	11.0 (25)	< .001
Question or comment about withdrawal symptoms or postcessation weight gain	16.1 (413)	5.7 (36)	20.7 (290)	23.2 (53)	< .001
Discussing need to quit for own health or the health of others	13.6 (348)	22.1 (141)	12.8 (179)	6.1 (14)	< .001
Sharing a tip or strategy about quitting	6.8 (174)	0.5 (3)	6.5 (91)	20.2 (46)	< .001
Had a slip or relapse	6.2 (158)	5.8 (37)	6.7 (94)	4.8 (11)	.47
Question or comment about nicotine replacement therapy or other quit aid	4.5 (115)	5.2 (33)	3.5 (49)	6.6 (15)	.04
Encouraged to quit by family member or friends	3.7 (95)	5.0 (32)	3.6 (51)	1.8 (4)	.07
Joining in a “stats parade” or “rally cry” to celebrate achievement (eg, number of days smoke free)	1.7 (44)	0 (0)	1.8 (25)	5.3 (12)	< .001
Expressing a desire to quit	1.2 (32)	2.2 (14)	1.3 (18)	0 (0)	.04
Financial motivation to quit	1.1 (29)	2.0 (13)	1.1 (16)	0 (0)	.048
Having technical difficulty with the website	0.7 (19)	0.3 (2)	0.6 (8)	0.4 (1)	.74
Surprised or concerned about how easy the first few days had been	0.2 (6)	0 (0)	0.4 (6)	0 (0)	.16
Told to quit by health care professional	0.2 (6)	0.3 (2)	0.2 (3)	0 (0)	.68

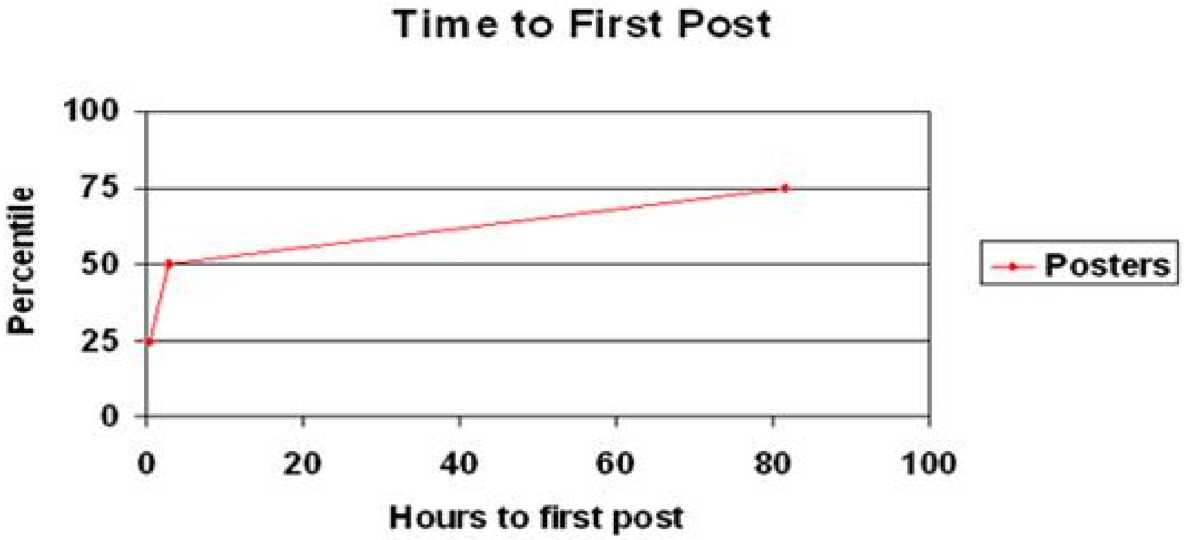
[a] Total includes members whose quit status could not be determined.

[b] Based on subsample with quit status information available (n = 2266)

Approximately 54.7% (1401/2562) of members who posted a message on the support group boards had recently quit smoking (ie, ≤ 1 month prior), 8.9% (228/2562) had quit more than 1 month previously, and 24.9.% (637/2562) had not quit smoking yet but had set a future quit date or expressed a desire to quit. Quit status could not be ascertained for 11.6% (296/2562) of support group posters.

Considering the necessary steps to register, navigate to the support group, and write a personal message, it is interesting to note that 25% of all first posts to the support group occurred within 20 minutes after registration, 50% of first posts occurred within 3 hours of registration, and 75% of first posts occurred within 81 hours of registration (see Figure 3).

Figure 3. Time to first post on support group by members of StopSmokingCenter.net version 5.0 (November 6, 2004, through May 15, 2007)



Presence (versus absence) of the theme discussing the need to quit for one's own health or the health of others was associated with a faster time to post (median 1.0 hours, range 0 - 13,030 vs median 4.7 hours, range 0-17,524; Mann-Whitney U = 300,598; $P < .001$). In contrast, presence of several themes associated with providing support to others were associated with a slower time to first post, namely: responding to another member's post or comment (median 29.3 hours, range 0-13,827 vs median 1.7 hours, range 0-17,524; U = 323,156, $P < .001$); sharing a tip or strategy about quitting (median 72.0 hours, range 0-15,638 vs median 2.3 hours, range 0-17,524; U = 123,133, $P < .001$); and joining in a "stats parade" or "rally cry" (median 71.3 hours, range 0-11,161 vs median 2.8 hours, range 0-17,524; U = 35,080, $P < .001$) whereby members join in celebration and congratulations of another member's achievements (eg, number of days smoke-free). Stats parades and rally cries could have occurred regularly (eg, every Friday) or spontaneously.

Time to first post varied significantly by quit status (Kruskal-Wallis H_2= 118.2, $P < .001$). Follow-up post-hoc Mann-Whitney U tests revealed that members that had not quit (median 0.9 hours, range 0-8,448) posted sooner than members who had quit for less than one month (median 10.0 hours, range 0-17,089; U = 348,520, $P < .001$), or more than one month (median 178.6 hours; range 0-17,518; U = 41,143, $P < .001$). Members who had quit less than one month previously were also faster to post compared with members who had quit for more than thirty days (U = 111,611, $P < .001$).

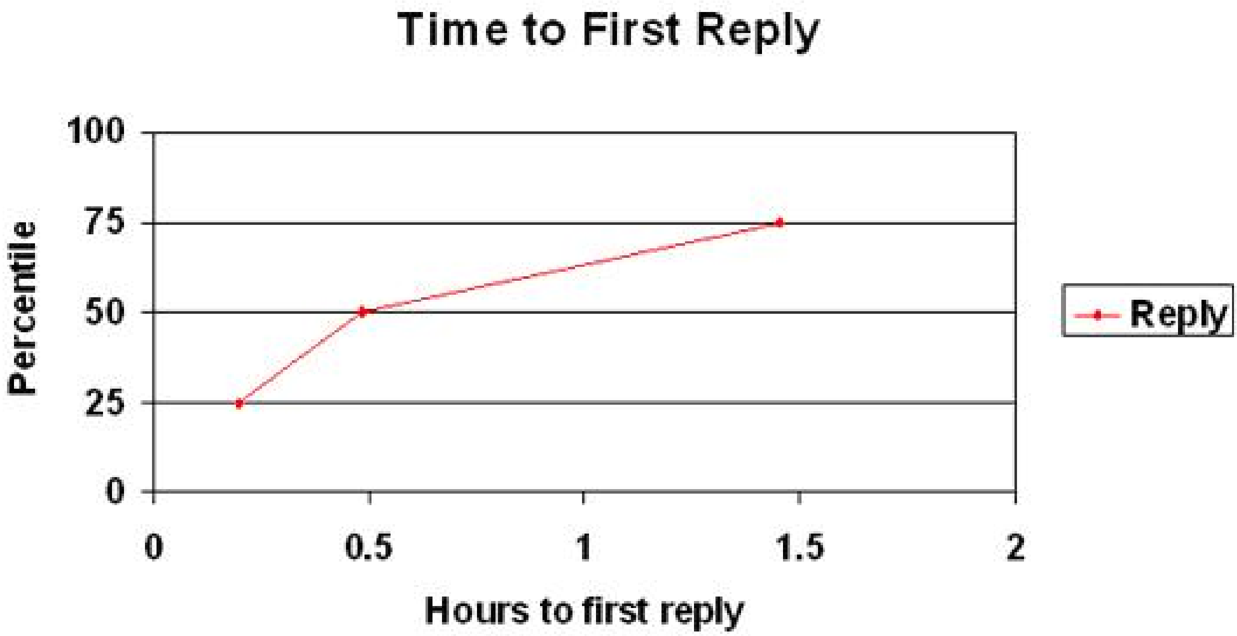
First Replies

A total of 79.5% (2036/2562) of replies to first posts were from other members. An additional 15.6% (399/2562) of replies were from health educators. Only 2.7% (68/2562) of posts did not receive a response. The remaining 2.3% (59/2562) of "replies" were made by the same member who originally posted (eg, adding more information or "bumping" their post) and were excluded from further analyses.

Almost half (48.5% or 33/68) of all posts that did not receive a reply from either another member or moderator had been posted in response to another member's thread. The second most prevalent theme among posts that did not receive a reply was sharing a tip or strategy about quitting (23.5% or 16/68). Both of these themes were significantly more prevalent among posts that did not receive a reply than among posts that did receive a reply at the $P < .001$ level ($\chi^2_1 = 46.62$ and $\chi^2_1 = 30.31$, respectively). No other first post themes were significantly associated with a greater or lower likelihood of receiving a reply or not. Examining responses from members only (ie, excluding moderator responses), no theme was associated with a lower likelihood of receiving a response when it was present versus absent within a first post. However, first posts that were joining in a "stats parade" or "rally cry" were significantly more likely to receive a reply from another member (2.3% vs 19.0%; χ^2_1= 7.92, $P = .005$) compared with posts that did not contain this theme.

Replies from other support group members were quick, with 25% of first posts receiving a reply within 12 minutes, 50% within 29 minutes, and 75% within 1 hour and 30 minutes (see Figure 4). Time to reply to first posts from moderators was very similar in length, with 25% received within 14 minutes, 50% within 33 minutes, and 75% within 1 hour and 27 minutes.

Figure 4. Time to first reply to first post from a support group member of StopSmokingCenter.net version 5.0 (November 6, 2004, through May 15, 2007)



Struggling and seeking support or advice was the only theme associated with a faster time to reply from another support group member (median 0.4 hours, range 0-8622 vs median 0.5 hours, range 0-1,386; U = 378,756, *P* <.001). Themes associated with a slower time to reply by other support group members when they were present (versus absent) within a first post were responding to another member's post or comment (median 0.9 hours, range 0-1386 vs median 0.4 hours, range 0-8,622; U = 245,691, *P* < .001) and sharing a tip or strategy about quitting (median 0.8 hours, range 0-567 vs median 0.5 hours, range 0-8622; U = 105,534, *P* < .001) .

The majority of replies were made by members who had quit, 35.0% (713/2036) by members who had quit within the past month, 49.0% (997/2036) by members who had quit for more than 1 month but less than 1 year, and 6.6% (135/2036) by members who had quit for more than one year. Only 1.4% (28/2036) of members who posted a first reply had not quit. Quit status could not be determined for 8.0% (163/2036) of response posts. Quit status of members who posted a reply was not related to the themes of the first posts replied to. The quit status of members who replied was also not associated with the length of time to post a reply (H_3= 3.86, *P* = .28).

Discussion

Findings from the current study revealed that 15% of members of an online smoking cessation program chose to make a post on the support group boards. First posts were made relatively quickly—50% within three hours—and members most frequently conveyed that they were seeking support and advice. Provision of support was prompt, with 50% receiving a reply within 29 minutes. Responses were even faster when posts communicated that a member was seeking support, revealing that the support group board did function to provide members with an immediate source of support not available with most traditional interventions. While first posts were most often made by recent quitters or those planning to quit, those who had quit for a month or longer were more likely to reply and provide support to other members.

Principal Results

Only a small minority of StopSmokingCenter.net members chose to actively participate on the support group boards by posting at least one message, suggesting that other self-help quit program components may have been more appealing. However, an additional unknown number of members may have benefited sufficiently from lurking and reading posts alone. More than half of lurkers on online discussion board communities report that "just reading/browsing is enough" as a reason for not posting [16]. Research has shown that lurkers gain many of the same benefits of online support groups as those who actively post, including developing a strong sense of community [17]. For example, a recent study of Dutch online support groups for breast cancer, fibromyalgia, and arthritis found no difference between lurkers and posters across a range of self-reported empowering outcomes such as being better informed, increased optimism and control, enhanced self-esteem, increased acceptance of the disease, and feeling more confident about treatment [18]. The only exception was that posters reported a greater enhancement of their social well-being compared with lurkers. Together these findings suggest that more individuals may utilize and benefit from online discussion boards than can be judged by examining the frequency of posts and number of individuals posting. The absence of substantive differences between posters and nonposters further supports the possibility that existing content on discussion boards could potentially have also met the needs of those who did not post.

In contrast, An and colleagues [19] found that active (ie, posting) but not passive (ie, reading) online community engagement was associated with increased smoking abstinence rates among WATI users at 6-month follow-up. Path analysis revealed that the association between active online community engagement and abstinence was accounted for in large part by increased use of interactive quitting tools and one-to-one messaging. Whether these findings indicated that active online community engagement promoted engagement with other features of the Web-based program, or vice versa, could not be determined. Nevertheless, these findings suggested that posting was associated with overall engagement with the Web-based program, which other research has established as a predictor of subsequent smoking cessation outcome [20]. Clearly, additional research is necessary to examine and compare the experiences of lurkers and posters on support boards, including the impact on smoking cessation outcomes.

Similar to findings from Stop-tabach.ch [11], more than half of the posters on the support group boards were recent quitters, and another quarter were in the preparation stages to quit. This suggests that people may require more support during the early stages of their quit process then during other times in their quit process. Because the quit status of smokers who did not post could not be determined in both studies, it is not clear whether or not nonposters or lurkers are at the same stage in the quit process as posters or if smokers are more likely to lurk at one stage and post at another. Smokers who were planning to quit were quicker to make a first post after registration, and discussing the need to quit for health reasons was also associated with a faster time to first post, suggesting a more immediate need for support for those who desire or are planning to quit.

Seeking support and advice was the most common theme identified in first posts among both recent and longer term quitters. Although less prevalent than among those who had quit, seeking support and advice was the second most common theme among members planning to quit. Thus, it is evident that one of the most common reasons that prompted a member to make a first post on the support group board was to seek help.

In addition to seeking support, several themes among first posts also revealed that provision of support to other members also prompted members to make a first post. Providing support was more evident among those who had already quit, particularly members who had quit for more than one month. Consistent with this was the finding that almost half of all replies to first posts were made by members who had quit for more than one month but less than one year, while only 1% of those who posted the first reply to a first post had not yet quit. Thus, it appears that members who had more experience with the quit process may have been more comfortable or inclined to provide advice or support to other members, providing posters a response from someone they could identify with while allowing the responder to model their behavior and reinforce their own commitment to quitting by articulating a response. Moreover, these posts and exchanges also allowed for vicarious learning by all viewers of the posts. Taken together, these findings reflect principles of social cognitive theory models in action [21]. Whether members who had quit for longer were more inclined to provide a particular type of support (eg, informational or emotional) was not examined in the current study but may have differed.

Despite the fact that those providing support were slower to make their first post, replies from other support group members were quite rapid. This demonstrates the almost immediate support that smokers can receive online, a significant advantage over several other types of more traditional supports. This feature may be particularly relevant for relapse prevention. However, particular features of first posts—date of registration, number of posts to date, and introductions (eg, “I’m new here”)—may trigger a more prompt response and may not be reflective of the timing of responses for all posts.

Replies to first posts were primarily from other support group members rather than health educators, and only 2.7% of posts did not receive a response. Almost three-quarters of posts that did not receive a reply from another member or moderator had been posted in response to another member’s thread or were sharing a tip or strategy about quitting. These types of messages may have been less likely to have been seeking a response, especially given that not all first posts began a new discussion thread. In fact, first posts that conveyed that the member was struggling and seeking support or advice received a significantly faster reply, while posts that were responding to another member’s post or comment or sharing a tip or strategy about quitting received slower replies. This suggests that other members responded to the needs of those who were seeking support and they received it faster.

Limitations

One limitation of the current study was that the content of first posts was analyzed by one coder and resources were not available to determine interrater reliability with a second coder. Future research would benefit from including a second coder to enhance and verify the reliability of findings.

It is important to keep in mind when interpreting results of the current study that they reflect the content and timing of first posts and first replies and may not be generalizable to later (second, third, etc) posts or replies. Members that are more active on the discussion boards and go on to post second, third, or more posts may differ from those who are less active in posting on discussion boards. Furthermore, as smokers become more active on discussion boards, their posts may vary over time on several factors, including content and timing.

The support group analyzed in this paper has been operating for almost a decade, and the tone and style of messaging that has evolved in this particular support group, as well as the design of the broader behavioral program it is embedded within, may not be representative of other support groups, eHealth interventions, or WATIs. As well, the population who used the program were self-selected and found the program through their independent search initiatives and may not be representative of all smokers who have used WATIs or online support groups.

Conclusions

When considering the most common themes of first posts, as well as the relatively short time to first post, the SSC support group may be regarded as a peer-to-peer social support tool for those who are struggling with quitting, particularly recent quitters, who require immediate support. Responses to first posts were timely and would have otherwise required the smoker to make an appointment to see a professional or track down a quit buddy. This provides smokers an opportunity to seek timely help which, if effective, may avoid a relapse back to smoking. Based on these findings, WATI developers and researchers may be inclined to create content and tools such as relapse prevention support and resources that appeal to this specific population. Further, as the program analyzed in this study was not advertised and the population was self-selected, there may be a large number of recent quitters who are seeking these types of services and would benefit from health promotion efforts that alert them to the availability of these types of programs.

Acknowledgments

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Conflicts of Interest

Peter Selby received funds from Schering Canada to provide buprenorphine training and received honoraria for consultant work, grant funding, advisory board and/or lectureships from: Johnson & Johnson Consumer Health Care Canada; Pfizer Inc, Canada; Sanofi-Synthelabo, Canada; GSK, Canada; Genpharm and Prempharm, Canada; CTI; Health Canada; Smoke Free Ontario; and Canadian Institutes of Health Research (CIHR). Funding was in compliance with the Canadian Medical Association (CMA) and the Canadian Psychiatric Association (CPA) guidelines/recommendations for interaction with the pharmaceutical industry. Peter Selby and John Cunningham have acted as paid consultants to Evolution Health Systems Inc, the owner of the StopSmokingCenter.net and WebTriage software platforms. Trevor van Mierlo is the CEO of Evolution Health Systems Inc. Danielle Parent is a health educator for Evolution Health Systems Inc. Sabrina Voci has no interests to declare. No tobacco industry funds were received by any of the authors.

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Abbreviations

FTND: Fagerström Test for Nicotine Dependence
IA: information architecture
SSC: StopSmokingCenter.net
SQL: structured query language
WATI: Web-assisted tobacco intervention

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Original Paper

Patient-Centered Design of an Information Management Module for a Personally Controlled Health Record

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Abstract

Background: The development of health information technologies should be informed by iterative experiments in which qualitative and quantitative methodologies provide a deeper understanding of the abilities, needs, and goals of the target audience for a personal health application.

Objective: Our objective was to create an interface for parents of children with attention-deficit hyperactivity/disorder (ADHD) to enter disease-specific information to facilitate data entry with minimal task burden.

Methods: We developed an ADHD-specific personal health application to support data entry into a personally controlled health record (PCHR) using a three-step, iterative process: (1) a needs analysis by conducting focus groups with parents of children with ADHD and an heuristic evaluation of a prerelease version of a PCHR, (2) usability testing of an initial prototype personal health application following a “think aloud” protocol, (3) performance testing of a revised prototype, and (4) finalizing the design and functionality of the ADHD personal health application. Study populations for the three studies (focus groups and two usability testing studies) were recruited from organizations in the greater Boston area. Study eligibility included being an English- or Spanish-speaking parent who was the primary caretaker of a school-age child with ADHD. We determined subjects’ health literacy using the Test of Functional Health Literacy in Adults (TOFHLA). We assessed subjects’ task burden using the National Aeronautics and Space Administration **(**NASA) Task Load Index. To assess the impact of factors associated with the time spent entering data, we calculated Pearson correlation coefficients (r) between time on task and both task burden and subject characteristics. We conducted t tests to determine if time on task was associated with successful task completion.

Results: The focus groups included three cohorts: 4 Spanish-speaking parents with diverse health literacy, 4 English-speaking parents with lower health literacy, and 7 English-speaking parents with higher health literacy. Both the initial usability testing cohort (n = 10) and the performance-testing cohort (n = 7) included parents of diverse health literacy and ethnicity. In performance testing, the prototype PCHRs captured patient-specific data with a mean time on task of 11.9 minutes (SD 6.5). Task burden experienced during data entry was not associated with successful task completion (P = .92). Subjects’ past computer experience was highly correlated with time on task (r = .86, P = .01), but not with task burden (r = .18, P = .69). The ADHD personal health application was finalized in response to these results by (1) simplifying the visual environment, (2) including items to support users limited by health literacy or technology experience, and (3) populating the application’s welcome screen with pictures of culturally diverse families to establish a personal family-oriented look and feel.

Conclusions: Our patient-centered design process produced a usable ADHD-specific personal health application that minimizes the burden of data entry.

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KEYWORDS

Attention deficit disorder with hyperactivity; patient-centered care; personal health record; computerized medical record systems; user-computer interface; comprehension; questionnaires; software design

Introduction

Pediatric chronic disease management requires timely and effective information exchange between health providers and parents of affected children. Parents' reporting of health data is the first and most elemental information task in a series of collaborative steps between a parent and a pediatric health provider that result in health-promoting actions. Attention-deficit/hyperactivity disorder (ADHD) is an archetypal pediatric chronic disease where parents' ability to communicate information to health providers directly impacts management [1,2]. Optimal disease control requires medication dose titration to optimize behavior control with mitigation of side effects—a process that is difficult for practices and populations to make operational [3].

While the classic model of office-based and paper-driven information exchange with the physician as the locus of control often fails to gather data needed for ADHD care [3], electronic health information technologies offer innovative alternatives. A personally controlled health record (PCHR) [4,5] provides an electronic mechanism for patient-driven data capture and communication with health providers [6,7]. Although such PCHRs are endorsed for their potential to impact chronic disease management [8,9], examples of the functionality and effectiveness of products are limited. The user interface of a well-designed personal health application should provide a mechanism for the collection and organization of information from patients with a range of health literacy and technology skills, while maintaining the capacity to codify answers and communicate them in a standardized fashion to clinician-controlled electronic medical record systems.

Successful implementation of a technology depends on a match between the system design and the users' expectations and abilities. It has long been recognized that employing a user-centered design and development process is essential for ensuring a quality user experience [10-12]. Technology quality has been defined by the ease of learning, overall workload requirements of task completion, error avoidance and reduction, and meeting predetermined performance metrics [11,12]. The degree to which a given system maps to the knowledge and ability of the user determines the quality of that technology experience. By employing a user-centered development process, the likelihood of achieving a successful technology-to-user match is increased significantly.

In the current study, we limited our design focus to the tasks surrounding parents' one time data entry of a child's current ADHD status, assuming that any long-term success of a patient-driven technology requires a successful first experience for parents, as has been show in usability research in e-commerce [13,14]. The focus of our formative design process and iterative usability testing was on parents' needs, expectations, and performance [15,16]. The goals for development were (1) to create a Web-based interface for parents of children with ADHD to enter disease-specific information, (2) to implement a universal design with a visual layout, navigational cues, and workflow that is usable by parents across a range of health literacy and technology skills, and (3) to create an interface to facilitate data entry with minimal task burden.

Methods

Prototype Development

Over many decades, a technology development process has emerged to address the needs of the user. The first stage in this process is a needs assessment in which users' goals and expectations of the task are determined, typically through observations, interviews, and focus groups [10,17-19] before being articulated as specific user requirements. Next, various design prototypes are explored to identify the optimum implementation of a given requirement. This is accomplished through a series of prototypes and participatory walk-throughs with actual or intended users [11,17]. Finally, the implemented design is tested to assess the degree of match with the users' mental models, error prevention and recovery, and overall learning and workload requirements [12,20]. Employing a user-centered development strategy significantly increases the likelihood of a successful technology implementation.

To achieve the first step in information management to inform ADHD care—getting accurate data from parental reporters via an interface that imposed minimal task burden—we followed an iterative three-step development process. First, we concurrently performed a user-centered needs analysis using focus groups and a heuristic evaluation [21] of the main menu and medication data entry pages of a prerelease version of a PCHR before any ADHD-specific application had been created. During this phase, a three-person panel composed of a clinical informatician, usability specialist, and software engineer developed the requirements used to create the application. The discussions and final consensus for the panel's decisions were informed by the formative data gathered through heuristic review and focus groups. From this work, a preliminary prototype was developed, which we then tested following a "think aloud" protocol with parents of diverse health literacy and technology skills to explore how parents experienced data entry tasks. Redesign based on this usability experiment produced a second prototype with which we completed performance tests with a different cohort of parents focused on time on task, the task experience (as measured by the National Aeronautical and Space Administration [NASA] Task Load Index), and parents' success in completing specific data entry tasks. Results from the performance test were used to finalize the design of the ADHD data entry tool.

Study Population

Three subcohorts of subjects for the three studies detailed below (ie, focus groups, initial usability testing, and performance testing) were recruited by a research associate from a broad coalition of organizations in the greater Boston area, including the Children's Hospital Neighborhood Partnership and the Pediatric Practice Organization at Children's. Study eligibility required being an English- or Spanish-speaking parent or guardian of a school-age child (5 to 18 years of age) reported to carry a diagnosis of hyperactivity, impulsivity, or attention-deficit/hyperactivity disorder (ADHD). Parents had to have confirmed they were the child's primary caretaker responsible for communicating with the child's primary care physician and school. For the usability testing, these inclusion criteria were further restricted to require the index child to have been currently taking a stimulant medication for at least 2 months.

Subjects' health literacy level was determined based on parents' completion of the brief Test of Functional Health Literacy in Adults (TOFHLA) [22,23]. We defined lower health literacy as TOFHLA scores of 80 or less. We assumed that subjects would be (1) knowledgeable about the child's medical history and recent behavior and (2) motivated reporters.

Baseline Needs Analysis

Needs Assessment: Parents as Information Providers

The following 3 focus groups of parents were assembled from the study population (see above): (1) four English-speaking parents with lower health literacy and/or lower educational achievement (high school education or less), (2) seven English-speaking parents with at least a college education and higher health literacy, and (3) four Spanish-speaking parents with diverse health literacy. Experienced moderators (authors BL and RB) followed focus group scripts to encourage discussion of (1) words used in ADHD care, (2) medications, (3) forms that parents are asked to fill out, (4) use of computers to input health data, and (5) parents' preferences and ideas for how behavioral data and medication data might be displayed using preliminary design sketches as examples. Our process was consistent with the methods espoused by Gibbs [24].

For analysis of the focus group data, we employed a variation on content analyses [20] commonly used in the social sciences, such as grounded theory [25] and narrative explanatory model [26] methodologies. We first assembled and reviewed the collected data (ie, audio recordings, notes, and transcripts) generated for each focus group. Data for each group session were examined to identify majority opinions, dissenting opinions, examples, and anecdotes from the 5 topic areas that framed the discussion for that particular group. Summative opinions and recurring terms were then compared across the 3 focus groups to identify any difference in the pattern of collected data. A group of 3 individuals (the 2 moderators and the observer for the sessions) discussed the data and arrived at consensus for what findings represented a uniform result or a difference based on language or health literacy. The consensus findings were then separately reviewed by the first author to confirm their validity against the interview transcripts. No formal reliability measures were employed during the analysis of this qualitative data.

We offer the following demonstration of how the categorization of the focus group results informed the development of the initial prototype. Asked to explain the term "impulsive," parents uniformly gave a consistent description. In contrast, presented the term "inattentive," parents with lower health literacy stated "argumentative" and "provocative" were similar to "inattentive," while parents with higher health literacy stated that "can't focus" was similar to "inattentive." This discrepancy in the interpretation of a core ADHD symptom reinforced the need for the interface to use language familiar to all users.

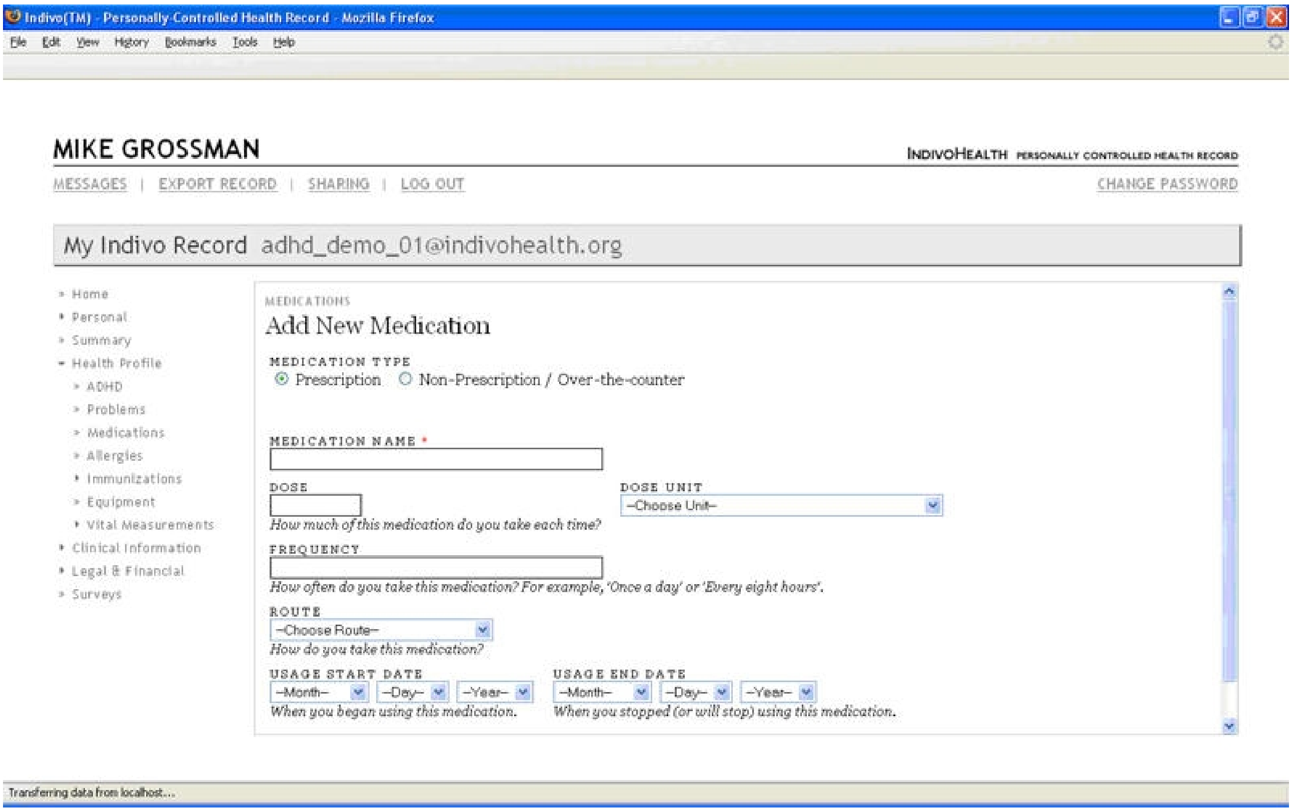
Heuristic Evaluation

Specific displays for the user-interface (the viewer) of a prerelease version of the Indivo platform were analyzed by a single physician-informatician trained in human factors and information design. The main menu page and the medication data entry page were examined from the perspective of a parent who would engage the system for the first time with the intent of initiating documentation/tracking/management for ADHD. The informatician examined each display for its information density, structure, semantics, and navigational cues with the intent of discovering opportunities to improve how the system would support culturally diverse parents with a range of skills in the areas of technology and health literacy.

Initial Prototype: Design and Architecture

In response to the finding of the needs assessment and heuristic evaluation, detailed in the "Results" section, the prototype was developed within a prerelease version of Indivo, an open-source PCHR with strong security features and robust interoperability for data exchange between electronic health data sources [4,15]. To create the capacity for childhood ADHD clinical information management within Indivo, we initiated the development of a personal health application to support patient-driven data entry as a critical first step in designing an information management system that would demonstrate value longitudinally.

Figure 1. Screenshot from medication entry screen of the prerelease Indivo user-interface used in the heuristic analysis



My Indivo Record adhd_demo_01@indivohealth.org

MEDICATIONS

Add New Medication

MEDICATION TYPE
● Prescription ○ Non-Prescription / Over-the-counter

MEDICATION NAME *

DOSE
How much of this medication do you take each time?

DOSE UNIT
–Choose Unit–

FREQUENCY
How often do you take this medication? For example, 'Once a day' or 'Every eight hours'.

ROUTE
–Choose Route–
How do you take this medication?

USAGE START DATE
–Month– –Day– –Year–
When you began using this medication.

USAGE END DATE
–Month– –Day– –Year–
When you stopped (or will stop) using this medication.

Initial Usability Testing

Cognitive Walk-through Protocol

The initial prototype was tested in July 2007 at the Bentley Design and Usability Center (Bentley University, Waltham, MA, USA) using a cognitive walk-through protocol in which subjects were "instructed to verbalize their thoughts as they perform a particular experimental task" [27]. A trained facilitator led each subject through the protocol using a standard script that invited participants to enter data about their child's ADHD medications and behaviors beginning with the phrase, "I will ask you to perform several tasks using the computer to enter information about your child." (The full script of the test is available in Multimedia Appendix 1). During testing, we collected observations made about usability issues such as how subjects chose to enter data (eg, typed medication names as free text or selected from a drop-down list). While using the initial prototype, subjects were invited to describe their reactions to it [20,27]. For example, subjects entering data might ask themselves, "Am I receiving adequate confirmation of my actions?" The facilitator further explored subjects' emotional responses and opinions generated by entering data. To expose problems that would otherwise not be captured, subjects were asked to explain comment or intents of initiated actions. Collected data included audiovisual recording of users' verbal reactions and facial expressions, and on-screen mouse movements. Each testing session was conducted individually and lasted approximately 1.5 hours.

Using well-accepted social science analytic methods [28], we analyzed and summarized the collected data (ie, video recordings, notes, and NASA index ratings) to identify the usability issues and their causes, which included areas of confusion, unfamiliar or ambiguous terminology, lack of consistency across screens, navigation issues, and the like. After the multidisciplinary team analyzed the rich qualitative data generated by following the think-aloud protocol during the initial usability tests, the team prioritized the findings before generating recommendations for revising the personal health application. Subjects' computer experience was determined by subjects' reports and observations made by investigators during testing sessions [22,23], which was then categorized as high, moderate, or low (ie, does not use computers).

Initial Prototype Redesign

In response to comments from initial user testing (see "Results" section and Table 3, which summarizes the changes made to the initial prototype in response to the identified problems), the prototype was refined before it underwent performance testing. Of note, the medication module was significantly redesigned with specific attention to semantics around dose and frequency (see Figure 2).

Figure 2. Screenshot from the medication module of the revised prototype used in the performance testing of the ADHD personal health application

Medication: Bupropion Form: tablet Strength: 100 mg Frequency: Once a day

How many tablets does Mike take?

Performance-Based Usability Tests Using the Second Prototype

We conducted a series of performance tests of the redesigned prototype with 7 subjects, none of whom had been involved in the initial think-aloud testing. Subjects in the performance tests had a range of health literacy, education, and computer experience (see Table 1 for subject characteristics).

During performance tests, the facilitator introduced the general task to the parent following a script that introduced the performance test to parents reminding them of the general purpose of the reporting tool and that they would complete the task independent of help from the observer in the room (see Multimedia Appendix 2). To minimize contamination of performance data, facilitators did not intervene or assist subjects in task completion. Subjects were observed until they said they had completed all task steps or had reached task failure and had no desire to continue. Performance testing lasted 1.5 hours during which audio-visual recording similar to the think-aloud test was maintained. The primary outcomes assessed included successful task completion, the task completion time, and the NASA Task Load Index, an established measure of task burden [29].

As participants in performance testing did not think aloud (unlike the initial usability tests), analyses relied primarily on task success and failure data as well as observed areas of confusion. To determine if time on task was linearly associated with NASA Task Load Index scores or subject characteristics (ie, previous computer experience), we calculated Pearson product-moment correlation coefficients. We conducted *t* tests to determine if time on task was associated with successful task completion.

Results

Baseline Needs Analysis

Needs Assessment

We found that parents attached a range of descriptors to ADHD as a condition. Some descriptors were specific to the formal medical definition (eg, hyper, disorganized, and hard to control), while others addressed comorbid conditions (eg, anxious, angry, and fixation on certain topics).

Parents were shown alternative presentation formats for a behavioral questionnaire with 55 items. Formats displayed included one question per screen, groups of questions, and a longer list that would require scrolling. This questionnaire included the previously validated Vanderbilt Parent Assessment Scale, [30] which collects data on ADHD behaviors necessary for medication-related management decisions. Overall, participants preferred questions presented as one long list, and cited the efficiency of that approach. Of note, only one parent in the lower education, lower health literacy group preferred the one-question-per-screen approach.

Parents were shown two approaches for selection of a medication name: (1) a text box that captured spelling and sounded features of entered letters that would match to a medication name, and (2) a vertically-oriented alphabetical list of all prescription ADHD medications with an index of horizontal letters and a scroll bar to facilitate rapid localization of a given medication name. Parents endorsed the list for selecting medications, recognizing that the names were already spelled-out correctly. Parents also recognized the value of the dynamic text box that could react to the likely name being entered.

Heuristic Evaluation

The information-sharing goal for the parent was to provide (or confirm) enough information on behaviors, current medication use, and potential side effects to allow for inferences regarding disease control and potential management options. The main menu display emphasized storage and retrieval of information at the summative level but did not show a clear roadmap for data entry. Users challenged by health literacy or technology experience would ask, “Where do I start?” and “What can I do with each of these labels in the index?”

The view of the main menu of the prerelease Indivo displayed the label “medication” in the left index; selecting the “add new medication” function led to a single screen with 7 data elements (either text box or drop-down menu) awaiting data entry (Figure 1). The accuracy of the data entered into the text box depended on the users’ keyboard-specific skills, medical knowledge, and comprehension of the labels. For example, prior research with parents identified the concept of “dose” as problematic and subject to multiple interpretations [31].

Needs Analysis

The focus groups and heuristic evaluation each confirmed the need for a disease-specific personal health application that provides a tailored data entry environment for the parent of a child with ADHD. Table 1 summarizes the main design features of the initial prototype proposed for an ADHD personal health application based on issues identified during the needs analysis. Given the importance of accurate capture of dose-specific information on ADHD medications, a structured and hierarchical approach to entry of data in this domain was designed in which data entry began with name and then moved to form, then strength, then frequency/dose, and lastly to review and edit (see Figure 3 for dose screen). Successful navigation and data entry required users to recognize and interact with drop-down menus and scroll bars using a mouse and/or keyboard.

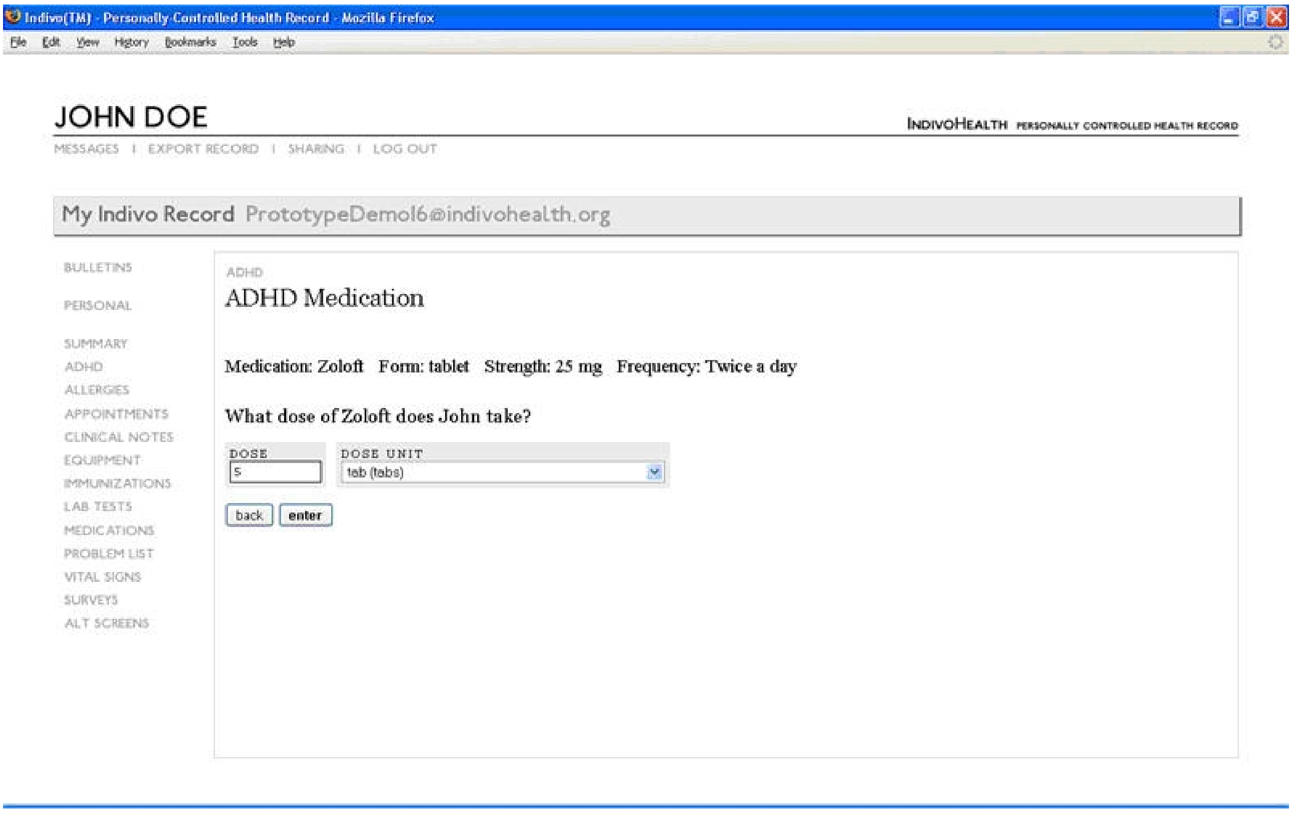
Table 1. Summary of baseline needs analyses and heuristic evaluation linked to design of initial prototype of the ADHD personal health application

Identified Problem or Challenge	Findings of Needs Analysis and Heuristic Evaluation	Design Features Embedded Within Initial Prototype
How will the interface support an action-oriented task experience?	• The interface will need to provide location and direction to the task experience.[a] • The interface will need to match parents’ goals for the ADHD personal health application.[a]	• Immediately display a main menu page that summarizes tasks. • Provide an “introduction” step that explains the tasks that follow. • Number the steps in order.
How can the interface best support data entry for medications?	• Choosing from a list reduces concern about spelling.[b] • A drop-down menu approach to details specific to form and strength will require a stepwise process of data entry.[a] • Limit medical jargon during data entry process[a]	• At medication name entry, offer choice of using either dynamic text box or alphabetical list. • Provide stepwise data entry for each attribute of a medication. • Use of bread crumb display on-screen of previously selected attributes for a medication supports stepwise data entry.
How can a survey on behavior be displayed while simultaneously supporting users’ understanding and limiting missing data?	• Having all questions on one screen makes it easier to review answers from previous items.[b] • A limited number of questions per screen facilitates reading. [b]	• Display all survey items on one screen with scroll bar for navigation. • Embed an audio file for each question in the survey to augment comprehension.

[a] Finding from the heuristic evaluation

[b] Result of focus group sessions

Figure 3. Screenshot from the medication module of the initial prototype of the ADHD personal health application tested following a think aloud protocol



ADHD Medication

Medication: Zoloft Form: tablet Strength: 25 mg Frequency: Twice a day

What dose of Zoloft does John take?

DOSE: 5

DOSE UNIT: tab (tabs)

Cognitive Walk-through Usability Testing Results

The 10 participants in the cognitive walk-through testing had TOFHLA scores ranging from 79 to 100 (see Table 2). Of the 2 subjects with TOFHLA scores less than or equal to 81 and low computer experience, 1 had not graduated from high school (see Table 2) and neither had used the Internet to find health-related information.

Table 2. Characteristics of subjects in both usability testing sessions

Subject ID	Education	Race/Ethnicity[a]	Health Literacy (TOFHLA Score)	Computer Experience
Cognitive walk-through testing				
CW-1	College, some	Black	98	Moderate
CW-2	College graduate	Mixed	94	Moderate
CW-3	High school, some	Black	81	Low
CW-4	Post-college degree	White	100	High
CW-5	College, some	Black	100	High
CW-6	High school graduate	Mixed	98	Moderate
CW-7	College, some	Black	100	High
CW-8	High school graduate	White	100	High
CW-9	High school graduate	White	98	High
CW-10	High school graduate	Mixed	79	Low
Performance testing				
PT-1	High school graduate	White	98	Moderate
PT-2	College graduate	White	100	High
PT-3	Graduate school degree	White	98	Moderate
PT-4	College graduate	Black	98	High
PT-5	College, some	White	96	High
PT-6	Grade school, some	Black	80	Low
PT-7	College, some	Mixed	98	High

[a] Subjects’ race/ethnicity was determined by self-report concordant with NIH policy *NOT-OD-01-053*.

[b] This assessment is a combination of subjects’ reports of past experience and observations made by examiners during usability testing.

Overall Impressions

Subjects’ overall reaction to the concept of the personal health application was positive, as emphasized by CW-1: “I think it’s awesome! It would save time by entering information before the visit; the doctor would be better prepared.” All subjects found the progression of data entry tasks intuitive, and most liked the feedback they received after completing each step. Problems identified during the usability tests are presented in Table 3. While most found the homepage easy to use, two felt it was visually unpleasant (eg, “bland,” and “clinical”). The purpose of the computer system was unclear to some (ie, they did not know whether it was to get or give information). Some subjects felt there should be a help button on the menu.

Medication Module

Subjects endorsed the concept of a medication summary page. Notably, 8 of 10 subjects failed the medication data entry task for which success required a parent to enter all attributes of the medicine (ie, name, form, strength, dose, and frequency), review the summarized data on-screen, and endorse it as correct. The attributes of dose and frequency created the most confusion. For example, a subject with higher health literacy and with moderate computer experience (CW-1) remarked: “I don’t understand…what [does] it mean by ‘dose?’” before leaving the field blank. While entering data on dose, a well-educated subject with higher health literacy and high computer experience (CW-5) commented: “Oh, wait a minute…two doses (shakes head)…two tablets; go back (smiles)…one tablet twice a day; there you go (smiles while laughing).” Of note, two parents (CW2 and CW8) entered both name and strength information (ie, Concerta 27 mg) into the dynamic text search box, which caused an error in returned matches and ultimate frustration for subjects.

Participants were divided about whether they preferred the dynamic text box or the alphabetized list. A subject with lower health literacy, little computer experience, and no high school degree (CW-3*)* noted: “You know how some people can’t really spell the names of the medications? I would like to see the list because you would be able to say, ‘yeah, that’s the medicine.’” Terminology about medication strength introduced confusion for users—the drop-down list for combination medicines displayed two numbers that represented the strength of each component and was not intuitive. For example, a well-educated subject with higher health literacy and high computer experience (CW-9) noted: “I am not a pharmacist; how am I supposed to know what 10/2.5 is?”

Table 3. Summary of problems identified in usability testing and solutions incorporated into second prototype of the ADHD personal health application

Identified Problem	Severity Description/Reason	Design Features Embedded Within the Second Prototype
Purpose of system unclear	Moderate with regard to satisfaction with user experience	Revised introductory video to better explain system
Visually bland	Minor in short term for testing purposes, more significant for actual use in field	No changes for performance prototype
Confusion with meaning of dose and frequency	Severe in that total daily dose exposure cannot be calculated	Revised semantics in plainer language
Entry of too much detail into dynamic search creates errors	Severe in that medication name is primary branch point for all other details	Limited algorithmic matching to first five alphabetical characters entered
Navigation within behavioral survey problematic	Moderate with regard to increased frustration and potential for missing data	Behavioral survey with simplified layout and introductory video explaining navigational features
Confusion with terminology in behavioral survey	Moderate with regard to potential inaccuracies in responses	Text-specific help feature added

Performance-Based Usability Testing Results

Table 2 describes the relatively diverse group of 7 subjects who participated in the performance tests. Similar to the initial usability testing, most participants liked using the redesigned prototype. For example, subject PT-2 commented: “It’s very simple and extremely easy to use.”

Task Completion

Of the 7 subjects, 5 successfully completed all 3 data entry tasks; subject PT-6 failed all three tasks, and PT-2 failed the behavioral symptom task but successfully completed the other two tasks. An example of the importance of providing users feedback about completing an interaction task, PT-2 stated: “It was just confusing, because it doesn’t say ‘thank you for completing the above three steps; you’re finished.’ You are just sort of wondering, ‘Did I miss a question?’” In addition to having lower health literacy, less than high school education, and low computer experience (see Table 1), PT-6’s poor performance was influenced by poor screen-scrolling skills that resulted in his not viewing all the questions.

Time Requirement

The mean of all 7 subjects’ total time on task was 11.9 minutes (SD 6.5 minutes, range 7 to 26 minutes, median 9 minutes), with the subject who failed all 3 tasks (PT-6) having the longest time on task (26 minutes) and the subject who failed 1 task (PT-6) having the shortest time on task (7 minutes). Users’ previous computer experience was highly correlated with their time on task ($r = .86$, $P = .01$). For the 5 subjects who successfully finished all 3 data entry tasks, the mean task completion time (TCT) was 8.8 minutes (SD 1.5, range 7 to 11 minutes, median 9 minutes).

Completing the behavioral module took subjects the most time. After restricting analyses to those who completed each task, the mean TCT for the behavioral task was 5.5 minutes (median 4 minutes, range 2 to 5 minutes) compared with the medication module’s mean completion time of 2.2 minutes (median 3 minutes, range 1 to 5 minutes) and the side-effect module’s mean of .72 minutes (median 1 minute, range 0 to 1 minute).

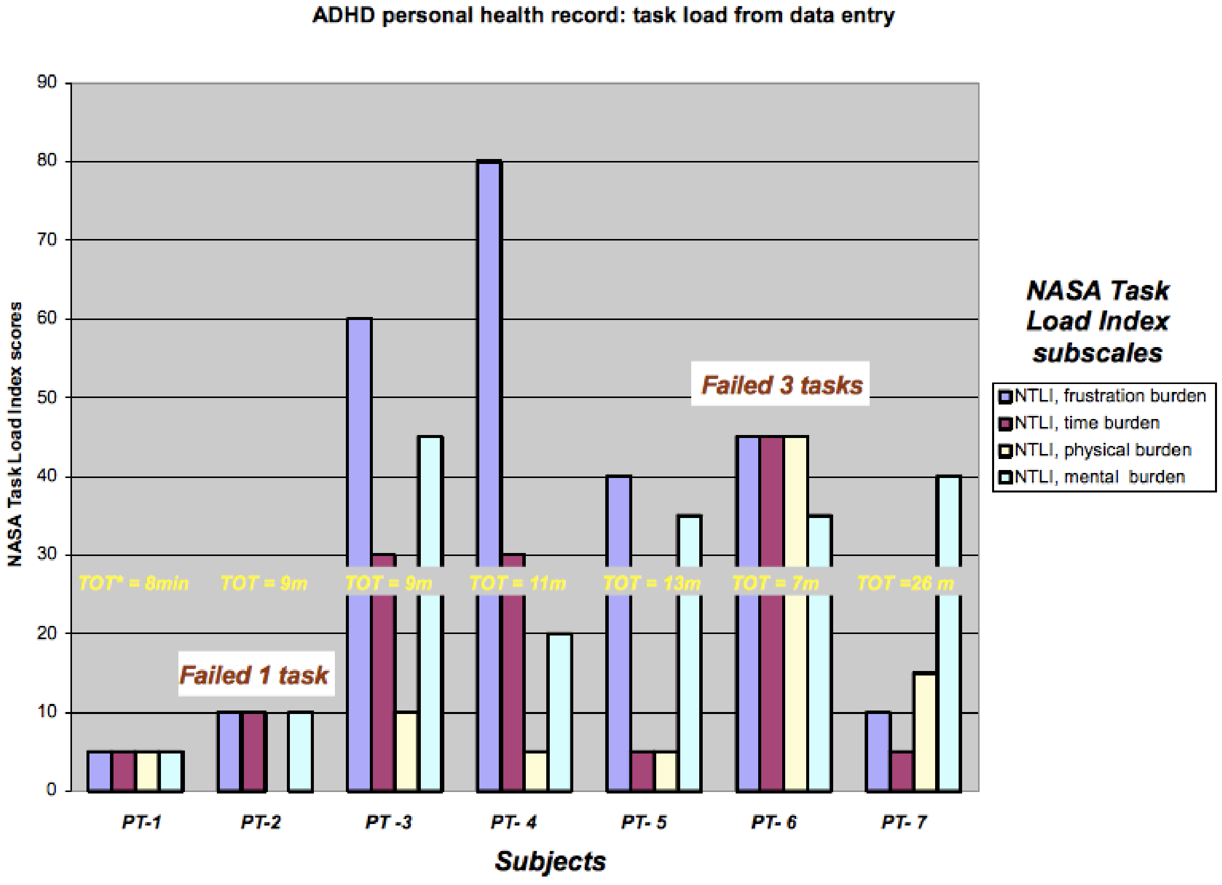
Time on task was not associated with successfully completing all 3 tasks ($P = .27$), but subjects who successfully completed the behavioral module trended toward having briefer time on task (mean 3.6 minutes) than the 2 who didn’t complete this task (mean 10 minutes, $P = .07$). The amount of time subjects reported having spent on completing the 3 tasks (as measured by the temporal subsection of the NASA Task Load Index) was correlated with the actual time they spent on the 3 tasks ($r = .74$, $P = .06$).

Task Burden

The aggregate NASA Task Load Index score was not associated with successfully completing all 3 tasks ($P = .92$), nor were scores on the effort and frustration NASA Task Load Index subscales associated with successfully completing all 3 tasks ($P = .36$ and $P = .67$, respectively) . Similarly, users’ previous computer experience was not correlated with their total NASA Task Load Index score ($r = .18$).

Figure 4 presents the task burden experienced by subjects during data entry. Subjects’ responses confirmed the low physical task burden of using the computer even for the individual who did not master the mechanics of the mouse. Although some subjects experienced high frustration, their scores on the frustration subsection of the NASA Task Load Index were not correlated with time demands of the interface (ie, time on task) ($r = .19$, $P = .69$). The two users with the highest frustration scores were college-educated and had high health literacy, with one having high and the other moderate computer experience. No clear differences were evident for median task scores between subjects who did or did not successfully complete all 3 tasks.

Figure 4. Task burden experienced and time on task (TOT) spent by subjects while they attempting to complete the 3 tasks during the performance testing of the revised prototype of the ADHD personal health application



Final ADHD Personally Controlled Application Interface

The final version of the ADHD personal health application, which was finalized in response to the performance testing results, simplified and personalized the visual environment (see Multimedia Appendix 3). A panel of pictures showing children and multicultural family units reinforces the pediatric perspective. A line of colored rectangles creates a link across the main menu into the submenu pages. A help button is overtly visible to the user in both the left navigation menu and the top menu on-screen. The main menu presents users an initial message of what task steps are needed as well as confirmation of when a task step has been completed by virtue of a blue circle adjacent to each step changing to a green check mark. To support complete and accurate data entry, a series of solutions are embedded in the final design. In the behavior module, questions skipped by the user in the initial process of answering are redisplayed to encourage completion of each one. To address errors due to specifying dose, semantics around dose-units were further simplified by asking "how many" for solid-based medications and "how much" for liquid-based medications. Dose units are inferred based on the specified form and strength at an earlier point in the hierarchical process of discovery.

The final version of the ADHD personal health application includes items to support a potential user who is limited by health literacy or technology experience. These include brief videos that demonstrate key features (workflow and tasks) and give hints on navigation (eg, scroll bar use). The items in the behavior module and the medication names are presented with links to audio files. In addition, in the behavior module, alternative text language can be activated by moving the mouse over the terms. The skills that a user must employ (and that are consistent with minimal Web navigation) are to (1) find letters on the keyboard and/or use the mouse to direct the on-screen arrow to the desired location and then click on a given selection, (2) recognize the scroll bar as a tool for navigation, and (3) recognize that a drop-down menu will show potential responses for a given item.

Discussion

By employing a patient-centered design process, we have successfully developed a gateway for the parent of a child with ADHD to populate a PCHR with data to drive symptom monitoring and clinical decision making. Our universal design approach creates a single solution for display and user-interaction with the software endorsing users' values for colocating, viewing, and updating health information [32]. Our medication module allows for a parent to provide information on prescribed medications across multiple levels of granularity in order to codify the child's total daily medication exposure and the timing of doses. Consistent with literature [33], some participants with limited computer skills struggled while using the application; our usability testing suggested that successful data entry by users with limited technology experience may require embedding a brief tutorial in navigation and mouse-directed interactions within the final version of the personal health application.

The final design for the ADHD personal health application successfully matches parents' expectations while entering data essential to evidence-based treatment decisions. While the drop-down menu creates an important opportunity for controlled vocabulary, the choices offered to users must match up to their own knowledge and practices to ensure accurate responses. Consistent with existing literature [34,35], the study populations of both the focus groups and usability testing met our assumptions about parents' needs and practices (ie, parents are knowledgeable, observant, and motivated reporters about their children). As we hoped, the redesigned personal health application prototype met subjects' expectations. Synergy between users' expectations of a technology and their actual experience is relevant to sustained user-engagement with a technology over time.

Usability testing of the ADHD personal health application revealed that parents who were not familiar with the mouse and had not previously "scrolled" on a Web page were at a significant disadvantage. We do not believe this finding compromises the success of our universal design, as the profile of users for an electronic personal health application will necessarily be engaged in a Web browser experience and thus have basic scrolling and point-click skills. Importantly, our final design embeds multiple mechanisms to support health literacy demands, including alternative text explanations as well as audio files that allow for content to be heard as well as read on-screen.

The final design of the ADHD personal health application ensures maximal completeness and accuracy of parent-entered data. The success of a personal health application in promoting the quality of care delivered for ADHD requires that sufficient and correct information is communicated to the system. The ADHD personal health application is currently being tested as part of a clinical trial comparing paper-based data entry to a computer-based mechanism with this application at its core.

We believe our solution addresses a difficult-to-solve tension between the expectations of a highly educated, technologically proficient parent and a parent who possesses limited knowledge or skill in either the health or technology domains. There is danger in a design appearing "too simple" and, therefore, being perceived by some users as less valuable or less valid as medically oriented software. It was interesting to note that users who voiced frustration during testing of the prototype were more often highly educated parents whose expectations for speed, style, or functionality were not met. However, these expectations were not core to the exchange of data so were not judged to impact the overall task burden for the ADHD personal health application.

The ADHD personal health application does not employ channels such as telephony or objects such as scannable forms used by others in the direct capture of medical data from patients [36-38]. Our goal was to tightly couple the Web-based PCHR construct to the input of data while preserving the ability to flexibly display a range of question types and deploy adjunctive features to assist with accuracy in data capture. Existing systems such as telephone-linked communications, shown to engage and capture valid data from a diverse patient population via structured telephone-based communication, currently do not link to a PCHR entity that allows patients to electronically view/update/reuse previously collected data. Although scannable forms provide a familiar "paper-and-pen" approach for users, constraints on efficient display of items, the potential for incomplete data from users, and the inability to support user's constrained by reading comprehension make these forms a less than ideal solution.

Limitations

The success of our personal health application development should be considered a preliminary result. Although our usability testing was rigorous, our sample size was small and nonrepresentative. Performance testing in a usability lab cannot avoid some artificiality in the experience, and, therefore, our parents' report of task burden is a proxy for what might be reported from a data entry experience at home with stress and noise associated with a full and busy household. As our testing examined a one-time data entry experience, we cannot report on usability issues related to longitudinal engagement with a PCHR where iterative data entry is required, as long-term use can be affected by complex factors unrelated to the interface.

Conclusions

Informed by a patient-centered formative process that included measurement of the task experience, we successfully developed a usable patient-centered ADHD-specific personal health application with minimal task burden for parents to enter data about their child with ADHD. This work confirmed the value of iterative usability testing for assessment and improvement of eHealth prototypes where the users' interactive experiences are critical to the product's success. Any eHealth technologies that intend to provide patient-centered solutions require a design/re-design process that centers on the voice of the patient.

Acknowledgments

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Conflicts of Interest

In 2007, Children’s Hospital Boston entered into a one-year contract with the nonprofit entity Dossia to support the use of Indivo—an open source, freely available PCHR developed by the Children’s Hospital Informatics Program—by the employees of the Dossia founding companies. The core PCHR software produced under this contract is made freely available as part of the open source code base of Indivo. Dr Mandl received support from Children’s Hospital Boston to provide advice or technical expertise informing the joint work between Children’s Hospital Boston and Dossia as well as other Indivo deployments. The advice is nonexclusive and unrestricted. There are no other conflicts of interest.

Multimedia Appendix 1

Usability test script

[PDF file (Adobe PDF File), 102 KB - jmir_v12i3e36_app1.pdf]

Multimedia Appendix 2

Tasks assessed during performance testing

[PDF file (Adobe PDF File), 57 KB - jmir_v12i3e36_app2.pdf]

Multimedia Appendix 3

Screenshots of the final ADHD PCHR interface

[PPT file (Microsoft Powerpoint File), 1382 KB - jmir_v12i3e36_app3.ppt]

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Abbreviations

ADHD: attention-deficit/hyperactivity disorder
PCHR: personally controlled health record
TCT: task completion time
TOFHLA: Test of Functional Health Literacy in Adults
TOT: time on task

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Original Paper

Usability Testing of an Online Self-management Program for Adolescents With Juvenile Idiopathic Arthritis

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Abstract

Background: A new bilingual (English and French) Internet-based self-management program, Teens Taking Charge: Managing Arthritis Online, for adolescents with arthritis and their parents was developed following a needs assessment.

Objectives: This study explored the usability (user performance and satisfaction) of the self-management program for youth with juvenile idiopathic arthritis (JIA) and their parents to refine the health portal prototype.

Methods: A qualitative study design with semi-structured, audio taped interviews and observation by a trained observer was undertaken with two iterative cycles to determine the usability (ease of use, efficiency, errors, and user satisfaction) of the user interface and content areas of the intervention. A purposive sample of English-speaking (n = 11; mean age = 15.4, standard deviation [SD] 1.7) and French-speaking (n = 8; mean age = 16.0, SD 1.2) adolescents with JIA and one of their respective parents/caregivers were recruited from 2 Canadian tertiary care centers. Descriptive statistics and simple content analyses were used to organize data into categories that reflected the emerging usability themes.

Results: All of the participants had access to a computer/Internet at home; however, adolescents were more comfortable using the computer/Internet than their parents. Adolescents and parents provided similar as well as differing suggestions on how the website user interface could be improved in terms of its usability (navigation; presentation and control usage errors; format and layout; as well as areas for further content development). There were no major differences in usability issues between English- and French-speaking participants. Minor changes to the website user interface were made and tested in a second cycle of participants. No further usability problems were identified in the second iterative cycle of testing. Teens and parents responded positively to the appearance and theme of the website (ie, promoting self-management) and felt that it was easy to navigate, use, and understand. Participants felt that the content was appropriate and geared to meet the unique needs of adolescents with JIA and their parents as well as English- and French-speaking families. Many participants responded that the interactive features (discussion board, stories of hope, and video clips of youth with JIA) made them feel supported and “not alone” in their illness.

Conclusions: We describe the usability testing of a self-management health portal designed for English- and French-speaking youth with arthritis and their parents, which uncovered several usability issues. Usability testing is a crucial step in the development of self-management health portals to ensure that the various end users (youth and parents) have the ability to access, understand, and use health-related information and services that are delivered via the Internet and that they are delivered in an efficient, effective, satisfying, and culturally competent manner.

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KEYWORDS

Juvenile idiopathic arthritis; Internet; usability testing; self-management; adolescent

Introduction

Juvenile idiopathic arthritis (JIA) is the most common rheumatic disease in childhood [1]. JIA can negatively impact all aspects of health-related quality of life (HRQOL) [2]. Disease management is often complex, involving diverse multifaceted therapies over long periods of time that require frequent monitoring. As children mature, they are expected to assume increasing responsibility for disease management concomitant with their growing independence and autonomy [3]. However, adolescents’ acceptance of and ability to implement this increasing responsibility is not always optimal, thereby often reducing the potential benefits of treatment and adversely impacting HRQOL [4]. In the absence of cure, improving HRQOL through better disease self-management becomes critical [3].

Self-management interventions typically encompass educational strategies designed to achieve optimal patient knowledge, understanding, beliefs, and skill acquisition as well as to provide meaningful social support [5]. However, the vast majority of adolescents with JIA do not receive comprehensive disease education linked with self-management strategies due to (1) difficulty accessing these services (eg, no services available in many geographic areas, language barriers, or long-wait times), (2) limited availability of trained professionals (eg, psychologists and nurses) especially in rural and remote areas, and (3) costs (eg, time away from school for students or time away from work for parents) associated with these therapies [6,7]. There is a clear need for developing alternative and acceptable ways to deliver self-management therapies to youth with JIA and their families.

With emerging interactive and communication technologies (eg, eHealth), new media for the delivery of health interventions are now available [8]. The Internet has emerged as one of the top health information resources and mode of social communication for youth and is, therefore, ideally suited to the provision of online health care services to adolescents [9]. Internet interventions are treatments based on effective face-to-face interventions (eg, cognitive-behavioral therapies and psycho-education) that are transformed for delivery via the Internet with the goal of improved health outcomes, such as symptom reduction. Usually, such interventions are highly structured, self-guided or partly self-guided, tailored to the user’s needs, and interactive [8]. While this is a burgeoning field, the Internet remains a relatively new medium for delivery of health care for children [10]. Formal evaluations of the impact of Internet health interventions on health outcomes, level of resource utilization, and user satisfaction have lagged far behind their development [11]. Furthermore, there is a paucity of high quality multilingual Internet health information at an appropriate reading level for youth with JIA and their parents, and no Internet-based self-management program for youth with JIA exists [12].

We developed the Teens Taking Charge: Managing Arthritis Online treatment program. This program is a multi-component, interactive Internet-based program consisting of JIA-specific education, self-management strategies, and social support (in the form of a discussion board and video clips) designed for youth with JIA and their parents that is available in English and French. This program was developed and evaluated using a sequential phased approach consisting of program development, usability testing, and outcome evaluation [13]. In Phase 1, the content of the Internet program was developed based on a needs assessment of adolescents with JIA and their parents [14]. In Phase 2, formative evaluation of the usability of the Internet program was tested and is the focus of this paper. In Phase 3, the feasibility of the intervention was recently evaluated in a pilot randomized controlled trial prior to conducting a large-scale multicentered trial to determine the program’s effectiveness [15].

Usability testing is a critical step in the development of Internet interventions and solicits end-user feedback to learn what works, what doesn't, and where gaps in information or functionality exist using iterative cycles to refine the prototype [16,17]. These factors may impact the frequency of use, understanding, and the likelihood that a user will implement the recommendations [8,16,17]. Usability testing can also help determine the appropriateness of the website interface and content [18], especially when it is designed for different audiences (eg, youth and parents) and delivered in different languages. The usability of the Teens Taking Charge: Managing Arthritis Online treatment program was assessed in terms of user performance (ease of use, ease of learning, errors, and efficiency) and satisfaction with content, user interface, and functionality of the program.

Methods

Patient Selection

Adolescent/parent dyads were recruited from 2 large rheumatology clinics in university-affiliated pediatric tertiary care centers. Dyads were eligible to participate if (1) the adolescents were 12 to 18 years of age, (2) the adolescent had been diagnosed with JIA by a rheumatologist, and (3) both adolescent and parent were able to speak and read English or French as their primary language. Adolescents were excluded if they had major cognitive impairments or comorbid medical or psychiatric illnesses that may have impacted their ability to understand and use the Internet program. Eligible patients listed on the participating hospitals' rheumatology database registries were sent a study information letter inviting them to participate. This method was supplemented by convenience sampling of patients attending a regularly scheduled clinic visit to achieve a heterogeneous sample in terms of age and disease severity. The study was approved by research ethics boards at both sites.

Study Design and Procedures

A qualitative usability testing approach with semistructured, audio taped interviews and observation by a trained observer was undertaken, with iterative cycles to determine the usability of the Internet intervention and to further refine the prototype [16,17]. This design approach was based on the concept of a ‘‘hermeneutical circle’’ as described by Snodgrass and Coyne [19], which is an iterative process of implementing a design, learning and understanding from discussion and feedback, and making subsequent design refinements. This iterative rapid design development approach concentrated on testing the user-interface with a focus on user performance and satisfaction.

After giving informed consent, participants were asked to complete a general information questionnaire that included questions about demographic characteristics and level of comfort with computers and the Internet. A health information questionnaire was completed by a research assistant to gather additional demographic and disease-related data from the patient's chart (duration of illness, disease subtype and the rheumatologist's global assessment of the patient's disease severity rated on 10-cm visual analogue scale) [20]. Adolescents and their parents then participated in separate 30- to 45-minute semistructured usability testing interviews in a quiet room with computer and Internet access. Participants were given a brief explanation of the online program by the research assistant. The sessions were audio taped and participants were asked to "think aloud" as they worked through a "live" version of the program. Participants were guided to move through a standardized list of features in each of the 12 modules, which included content, graphics, video clips, interactive components, animations, and the discussion forum, while commenting on any difficulties they had. It was anticipated that participants would be able to move through all of these tasks during the usability interview (ie, within 40 minutes). The research assistant also recorded the length of the sessions and made field notes about any problems encountered during the sessions (eg, tracking participant navigation errors and program errors) as well as ease of use and learning. At the end of the session, participants were asked a series of questions using a semistructured interview guide to ascertain user satisfaction and suggestions for improving the program (See Multimedia Appendix 1). Interviews were conducted in two iterative cycles, one cycle per site. Following the first iterative cycle with English-speaking participants, changes were made to the user interface screens based on problems identified from the content analysis of the taped interviews and field notes. The revised user interface was then evaluated in a second iterative cycle with French-speaking participants.

Internet Self-management Program

The Internet program is a 12-module interactive multi-component treatment protocol that consists of JIA-specific education (eg, common problems associated with treatment and disease), self-management strategies (eg, how to deal with pain and stress), and social support (eg, monitored discussion boards and narratives in the form of written stories and video clips of adolescents with JIA). There are two modules specifically for parents to help them promote healthy teens' behaviors. The program content was developed by a team of experts from across Canada, written at a grade 6 to7 reading level, and geared to the needs identified by adolescents and their parents [14]. The Teens Taking Charge: Managing Arthritis Online treatment program is composed of 310 content pages (approximately 156459 words), flash files (animations), images, videos, forums (separate adolescent and parent discussion boards, surveys, and interactive forms (eg, weekly knowledge quizzes). The entire program was translated into French using forward and backward translation as well as being reviewed by Francophone medical experts. The video clips of teens for the French site were recorded with Francophone adolescents and their parents in Montreal to ensure they were culturally competent.

In the website architecture, four applications are integrated together to provide the experience of a single website to the users. These applications include (1) the content application for both English and French, which is delivered by the AboutKidsHealth.ca content management system; (2) the forums application, which provides a framework for creating and managing discussion forums for the users; (3) the survey application, which provides support for creating, managing, and gathering survey questions and responses; and (4) the custom application, which provides management of interactive questions. Each of the applications has its own database model where data are managed and stored. Security and restriction of the program are based on the ASP.NET membership model and ensure that only authenticated users with the allowed permission (ie, role) are able to view the allowed content and to participate in the private forums. The membership model works across several applications and accommodates a single sign-on process so users do not have to sign in to every application and thus can move across the applications seamlessly. Users get the best experience of the Teens Taking Charge: Managing Arthritis Online treatment program with Internet Explorer 6/7 and Flash player 9+ on a Windows XP/Vista platform. The given computer requirements ensure that users are able to view the animation and video streams within the site and as well view the embedded interactive forms, which are delivered via an AJAX interface that captures the responses to a database. The AJAX interface reduces the number of clicks and pages to keep the user experience intuitive. Please see Multimedia Appendix 2 for an overview of the Teens Taking Charge: Managing Arthritis Online progam.

Data Analysis

The quantitative data from the questionnaires was analyzed using SAS version 9.1.3 [21] to determine measures of central tendency and the distribution of values. Interviews were audio taped and transcribed verbatim. The French interviews were transcribed directly into English by two bilingual transcriptionists. Field notes taken during the interviews were also transcribed and included in the analytic process. Simple content analysis was performed after each iterative cycle, with categories emerging form the usability research questions (ie, learnability, efficiency, errors, and satisfaction) and frequencies calculated [22]. Initially, the English (iterative cycle 1) and French (iterative cycle 2) interviews were analyzed separately. Minor modifications to the website were made based on the first iterative cycle of testing and were subsequently evaluated in the second cycle of testing. No further modifications to the prototype were made based on the second iterative cycle of testing. The data from these two cycles were similar and provided a strong source of triangulation for the developing themes. To ensure anonymity, all participants were identified by pseudonyms, and quotes were identified by participant type (adolescent = A; parent = P) [23].

Results

Sample Selection and Participant Characteristics

Patients meeting the study criteria who attended clinics from August 22 through October 2, 2008, were invited to participate in this study at the two sites. Of the 20 eligible English-speaking dyads, 11 (55%) agreed to participate, and of the 23 French-speaking dyads, 8 (39%) agreed to participate. The mean age of the sample of adolescents was 15.7 years (SD 1.5), and 14 (74%) were female. Of the 19 adolescents, 15 (79 %) were in high school. The mean duration of illness was 6.99 years (SD 5.03, range 0.3 - 15.2 years). The most common disease onset subtype was polyarticular arthritis with 7 of the 19 adolescents (37%) having this diagnosis; the average disease severity rating was 0.92 out of 10 (SD 1.5, range 0 - 4.9). Of the participating adolescents, 100% had a computer at home, and 100% were comfortable using a computer. These findings are in accordance with recent data that 88% of 15-year-old Canadian students have at least one computer at home and are comfortable using the computer/Internet [24]. Thirteen of the 19 parents/caregivers were female (63%), 10 of the 19 parents/caregivers (53%) were aged 40 to 49 years, and 9 (47%) responded that their highest level of education was high school. The numbers, means, and standard deviations for demographic and disease-related characteristics of the adolescent sample by usability testing phase are shown in Table 1. Participants' comfort level with and use of computers and the Internet are described in Table 2.

Table 1. Characteristics of the adolescents from interative cycles 1 and 2 (n = 19)

Characteristic	Iterative Cycle 1 English (n = 11)	Iterative Cycle 2 French (n = 8)
Mean age (SD) in years	13.6 (2.03)	16 (1.23)
Gender		
Male, n (%)	3 (27%)	2 (25%)
Female, n (%)	8 (73%)	6 (75%)
JIA onset subtype		
Oligoarthritis, n (%)	1(9%)	2 (25%)
Polyarthritis (RF -), n (%)	4 (36%)	3 (38%)
Polyarthritis (RF +), n (%)	2 (18%)	0
Psoriatic arthritis, n (%)	1 (9%)	0
Enthesitis related, n (%)	1 (9%)	1(13%)
Systemic, n (%)	0	2(25%)
Unknown, n (%)	2(18%)	0
Mean (SD) duration of illness in years	7.23 (4.45)	6.65(6.05)
Current grade		
Public school, n (%)	2 (18%)	0
High school, n (%)	8 (73%)	7 (88%)
University, n (%)	1 (9%)	1 (12%)

Table 2. Information about use of the computer by adolescents and their parents

	Adolescents		Parents	
	English (n = 11)	French (n = 8)	English (n = 11)	French (n = 8)
Characteristic	n (%)	n (%)	n (%)	n (%)
Computer at home				
Yes	11 (100)	8 (100)	11 (100)	8 (100)
No	0	0	0	0
Internet at home				
Yes	11 (100)	8 (100)	11 (100)	8 (100)
No	0	0	0	0
Computer at school/work				
Yes	9 (82)	5 (63)	9 (82)	6 (75)
No	1 (18)	3 (37)	1 (18)	2 (25)
Hours spent on computer each week				
≤ 5 hours	1 (9)	3 (37)	3 (27)	3 (37)
> 5 hours	10 (91)	5 (63)	8 (73)	5 (63)
Hours spent on Internet each week				
≤ 5 hours	4 (36)	3 (37)	7 (64)	5 (63)
> 5 hours	7 (64)	5 (63)	4 (36)	3 (37)
Comfort level on computer				
Not at all comfortable	0	0	0	1 (12)
A little comfortable	0	0	2 (18)	0
Comfortable	2 (18)	0	4 (36)	2 (25)
Very comfortable	9 (82)	8 (100)	5 (45)	5 (63)
Comfort level on Internet				
Not at all comfortable	0	0	0	1 (12)
A little comfortable	0	0	2 (18)	0
Comfortable	2 (18)	0	4 (36)	2 (25)
Very comfortable	9 (82)	8 (100)	5 (45)	5 (63)

User Performance

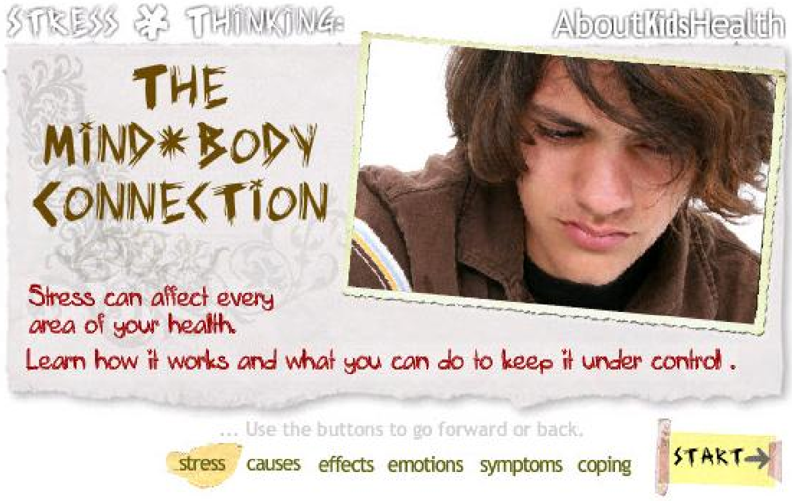
User performance was measured in terms of (1) ease at which the user could navigate through the site, (2) ease of learning in terms of how fast a user who has never seen the user interface before could learn it sufficiently well to accomplish basic tasks, and (3) the frequency and severity of errors. Overall the participants rated the Teens Taking Charge: Managing Arthritis Online health portal as easy to use. All of the adolescents were able to navigate through the site with little to no guidance, whereas 5 of the 19 parents (27%) required several minutes to orientate themselves to the site before confidently navigating the interface. In terms of ease of learning, all participants were able to accomplish the standardized set of basic tasks in 35 minutes or less, as was predicted.

During the usability testing, three types of errors were observed: navigation errors, presentation errors, and control usage problems. Navigation errors were defined as failures to locate functions, excessive keystrokes, or failures to follow recommended screen flow. There were minimal navigation errors with 10% of adolescents and 21% of parents experiencing one. All navigation errors encountered were easily recovered from and were considered to be minor. No changes were made based on these findings. Presentation errors were defined as failures to locate and properly act upon desired information or selection errors due to labeling ambiguities. These were found to be concentrated in the medication module. Presentation errors were encountered by 58% of parents and 26% of adolescents on the homepage of the medication module, which were coded as fatal errors. Users found the labeling on the medication homepage by classification of medication type to be unclear and were unable to navigate to the information they wanted about their/their child's particular arthritis medication(s). This page was changed by adding a list of generic medications grouped by their drug classification with direct links to each medication discussed in that section to enhance user performance (See Figures 1 and 2 for before and after screen shots of medication homepage). Following this change, this presentation error did not occur in iterative cycle 2 testing with French-speaking participants. Control usage errors were defined as improper tool bar or entry field usage. In iterative cycle 1, 42% of adolescents and 26% of parents were unable to identify controls to stop, start, or advance the functional features on the “stress and thinking animation” and video clips at the start of each module, which were coded as fatal errors. These were changed and retested in iterative cycle 2 with no further control usage errors arising. See Figure 3 for an example of the “stress and thinking” animation controls following usability testing. There were no differences between French and English participants in the types of errors found.

Figure 1. Example of medication homepage before usability testing

Figure 2. Example of changes to medication homepage following iterative cycle1 testing

Figure 3. Example of a “stress and thinking” click through animation



Stress can affect every area of your health.
Learn how it works and what you can do to keep it under control.

... Use the buttons to go forward or back.

User Satisfaction

In terms of satisfaction with the Teens Taking Charge: Managing Arthritis Online health portal, adolescents and their parents perceived that their satisfaction with the site was based on the overall design aesthetics of the user interface, content, functionality and features, and opportunities for social support. There were minor differences within these categories by participant (adolescent versus parent/caregiver) and language.

Design Aesthetics

The overall design aesthetics of the website were felt to be a critical factor from the perspective of the end users that helped to enhance engagement and motivation to use the site. Four subthemes were identified under the broad theme of design aesthetics including layout, navigation, visual assets, and visual appeal. Differences were found between both adolescents and parents and French and English participants. Adolescents wanted the large amounts of text “chunked up” and broken up with visual assets (graphics, animations, illustrations), while parents did not mind having large amounts of text to scroll through. Similarly, 42% of parents indicated that they would like a larger font; however, only 15% of adolescents cited this as a problem. Furthermore, 16% of both French adolescents and parents suggested adding labels to the medical diagrams, where this was not an issue with English participants. Finally, all the participants felt that the most important information on each page should be at the top of the page, otherwise teens will not scroll down to find it. See Table 3 for a summary of issues and changes made to the design aesthetics.

Content

All of the participants commented positively on the content of the program including the text, images, and multimedia components. Four subthemes were identified under the broad theme of content including completeness, understandability, quality and credibility, and relevance. For the most part, participants were satisfied with the completeness of content; however, 21% of adolescents and 32% of parents suggested additional content. The most common suggestion for additional content was for videos or photos to show teens how to do the various exercises. However, due to budgetary and time constraints we were not able to add these. Additionally, 89% of adolescents and 95% of parents felt that the content was relevant, and 74% of adolescents and 79% of parents rated the content as trustworthy. The site was created with a focus on understandability and all text was developed at a grade 6 to7 reading level. Participants expressed appreciation for this consideration and generally found the information, language level, and explanation of medical terminology (in a glossary of words) to be helpful in furthering their understanding of topics that were either unclear, new to them, or both. French grammar errors were found by 20% of French adolescents and 5% of French parents. These errors were corrected following usability testing. See Table 4 for a summary of comments and changes made with regard to website content.

Functionality and Features

Functionality and features refers to the adaptive and interactive features of the website. These included a glossary of terms, relaxation audio clips, printable PDF information forms for teachers, click-through animations (ie, how we feel pain, how antiinflammatory medications work, stress, and thinking), videos of teens with arthritis, interactive questions (weekly knowledge quizzes), a journal for keeping track of symptoms and weekly goals, and a discussion board with an “Ask an Expert” feature where participants could send an email question to a designated health care professional. Participants unanimously felt that these adaptive and interactive features allowed for an increased level of personalization of the website content to meet the individual needs of the users and were all good features of the website. They also commented that these features would help to enhance motivation and engagement with the program.

Table 3. Summary of user satisfaction with design aesthetics and changes made to the site

Design Aesthetics	Examples of Comments by Adolescents	Examples of Comments by Parents	Subsequent Changes Made to the Site Based on Comments
Layout: the compilation and placement of text and graphics on each page	“I really like the layout. I really like how it looks; I find it easy to go through everything.” (A05) “It’s good because it is…visually broken up so it doesn’t seem like a big block of text, but it’s still giving you everything you need to know.” (A04) “Yeah, if they just moved this part up [session goals] and they could do like half above the video and then they would know to like keep going after the video.” (A10)	“I don’t think it is too much. I am always of the opinion....the more information for me the better.” (P08) “Like this, it looks like a lot of stuff to read, and I probably, as a teenager…wouldn’t take the time to read it.” (P11) “I’m not sure how important these bottom links are…but if they are, I would bring them up…that is the only thing because you don’t really see them.” (P01)	- Moved session outlines to appear before the video clip at the start of each module - Moved the discussion forum, “Ask an Expert”, and “My Journal” tool bar from the bottom to top of the page - chunked up the text more in the teen introduction module
Visual assets: the illustrations, graphics, and animations in the website	“Oh, I liked the animation [about] taking drugs, and what arthritis is because it showed me what happens and I didn’t know that”(A11) “Alright, the only thing is that if you hadn’t told me I wouldn’t have seen the next and back buttons [stress animation].” (A01)	“They don’t know what’s happening because they never see their x-rays, that’s a great idea. ”(P04) “I don’t think it [x-ray image] is necessarily clear, for someone who has medical knowledge, yes it works. But otherwise it is difficult.” (P03F)	-Labeled the images of the normal x-rays and MRIs more clearly so users could better understand the differences between images of diseased and normal joints. -Highlighted the control buttons more clearly on the stress and thinking animation so users could stop it if they wanted to.
Visual appeal: the overall look and feel of the website	“User friendly and inviting. I liked everything. It’s very jolly; it doesn’t look too scientifical.”(A04) I’d have to say it would be these pictures…as soon as–like when I walked in, right, I saw that, and I’m like, ‘wow, that’s fairly depressing’…like I look at her and she doesn’t look happy…she doesn’t look like she’s gotten over this.” (A11)	“Oh. I think its dynamite. I really can’t say enough positive things about it. It’s very impressive.” (P08) “Here, for example, I find that [font] hard to read. Maybe make it a bit bigger.” (P06)	-Photo of teen was replaced on the homepage with a more upbeat looking teen. -Not able to increase font as the health portal needed to conform to the hosting site’s (AboutKidsHealth.ca) design suite which features a 12pt Trebuchet, Arial, sans-serif font.
Navigation: the ability of the end user to easily move around the site to find the information they were interested in	“Everything that came up was really well labeled, and you know what you were going to be reading, and you could choose because everything was broken down.” (A04) “It’s pretty simple…it’s easy to find what you want to look at.” (A05)	“It—it works like every kind of website where you’re looking stuff up. You know it’s really simple.” (P03) “I know, um, the napr—what the naproxen is that she takes. But I wouldn’t have a clue where to look under Avara, or methotrexate... like I wouldn’t even know which one of those it is. So, I think…if you could list some of them like examples, or something.” (P05)	- The medication section was changed as per the user performance section.

Table 4. Summary of user satisfaction with website content and changes made to the site

Content	Examples of Comments by Adolescents	Examples of Comments by Parents	Subsequent Changes Made to the Site Based on Comments
Completeness: the extent to which the website content contained all desired information	"It's all here. It's all on one site. You don't have to travel for one thing, and then travel for the next thing…It has all the information that you need basically." (A02F)	"So I think it could possibly be a good one-stop kind of place to go, as opposed to, you know, the times I've had to sit down for hours and go to a million different sites looking for different little bits of things." (P08)	-Participants recommended adding videos of how to do the suggested exercises; however, due to budgetary and time constraints, we were not able to add the exercise videos.
Understandability: the aspects of the content of the website such as readability (reading level), use of plain language, translation of material into French, and explanation of medical terminology	"No, that's another good thing. They are not huge words that are going to take me forever to look up and then go back on it." (A09)	"I liked the way things were explained. It was simple and easy to understand." (P10)	-During the 2nd iterative cycle, French-speaking participants identified some minor grammatical errors in the translation of the English content that were corrected following the second cycle of testing. These minor changes were checked with the bilingual medical expert.
Quality and credibility: the extent to which the participants perceived the content to be accurate and trustworthy	"I find it reassuring that it's not coming from 1984, and I know that it is current and up to date." (A06F)	"The volume of credible information in an easy to access package is really impressive. I love that." (P03)	-No changes were suggested.
Relevance: applicability of the content of the site to the needs of teens with JIA and their caregivers	"Yeah, I think that the stress and the relaxation, I think I would use that a lot because half the time I don't even know what to do when I am in pain or anything, right?...Right, and I know that when I am stressed out my arthritis does get worse." (A05F)	"This is bang on, with what we deal with constantly." (P10)	-No changes were suggested.

Sociability

Sociability refers to the ability of the Internet program to support social interactions among participants. The site featured 2 discussion boards, one for teens and one for parents, video clips of teens talking about ways they have learned to manage their arthritis, in addition to written stories of hope submitted by teens with JIA. All of the participants commented that these features of the site would help to ease feelings of hopelessness and particularly isolation. However, while almost all teens (95%) indicated that they would like to use the discussion forum to chat with other teens; less than one-half (42%) of parents felt they would use a parent discussion forum. Many teens commented that they did not know another teen with arthritis and that the interactive features (discussion board, stories of hope, video clips of teens with JIA) made them feel supported and "not alone" in their illness.

Desire to Use Program in the Future

Overall, the program was well received, and 84% of all participants expressed a desire to use the program in the future. Most participants felt the program would have been especially helpful when they were first diagnosed with JIA. Adolescents and caregivers also liked that the site was geared toward the promotion of self-management skills to reduce symptoms, improve quality of life, and promote transition to adult health care services.

Discussion

This study assessed the user performance and satisfaction with a new health portal designed to help youth with arthritis learn how to better manage their chronic health condition. This health portal is unique in that it was developed for two different end-user groups (youth and their parents) and in two languages (English and French). Testing uncovered user performance errors (minor navigator and major presentation and control usage errors) as well as areas to enhance user satisfaction. Adolescents and parents provided ideas on how the website user-interface could be improved in terms of its usability (navigation, design format and layout, and content). Changes were made to the health portal that corrected the errors uncovered and improved user satisfaction. Formative usability testing was a crucial step to help ensure the relevance of the content and that the website was easy to use and learn, efficient to complete, and acceptable to youth and their parents. The results of this study also provide a model for formative evaluation of other online interventions for delivery of chronic disease self-management, especially those that target different end users and are provided in multiple languages.

This study also highlights the value of conducting usability testing prior to wide scale outcome assessment (ie, a randomized controlled trial to test effectiveness of the program) and/or implementation to ensure that the end product is usable and acceptable to the end users (youth and parents), and is culturally competent when targeting different languages. While there is increased attention regarding the need for health care professionals to provide face-to-face culturally competent care, there is little research examining how to provide culturally competent health interventions delivered over the Internet. Culturally competent care is defined as the ability to effectively work within the cultural context of the client [25]. While only a few differences were found in this study between French- and English-speaking users, it remains imperative that we evaluate the usability of health portals to ensure they include linguistically and culturally appropriate advice, written information, graphics, and other interactive features [26]. Further research is needed to define what is meant by culturally competent Internet-based interventions and how to evaluate these aspects of usability in formative evaluations given the ethnically diverse populations that are affected by this chronic illness.

Furthermore, these types of interventions have typically been developed by health care professionals (ie, a top down approach) with little input from the end users during intervention development. This is particularly important given the proliferation of Internet-based interventions and the resources currently being invested in health-related websites by governments worldwide [27]. Many of these interventions are often of poor quality and of unknown effectiveness [28]. For example, during the development of our website we undertook a descriptive study to determine the quality and content of English language Internet information about JIA from the perspectives of consumers and health care professionals [12]. Most sites targeted parents, and none were specifically developed for youth with JIA. The overall quality of website information was fair, with a moderate level of accuracy; however, the material was written well above the recommended grade level (6 to 8) indicating that the material was difficult to read. Participants in this study commented on the quality and comprehensiveness of the content as well as on the ease of use and the ease of learning the program. Therefore, it is essential that the end users be actively involved in the development and testing of these health portals.

Usability testing also uncovered some differences by end user. However, little is known about how user traits, which refer to user characteristics such as computer proficiency and demographic and disease characteristics, may affect the use of these health portals [29]. As an example, a study by Jesdanun suggested that among people with chronic diseases, being older and less educated were two traits linked to lower Internet usage [30]. Future studies might investigate user traits that predict usability and treatment outcomes with Internet-based health interventions.

A few potential limitations of our study need to be addressed. First, the study was conducted in two tertiary pediatric care centers and the sample was relatively small, which could be considered a threat to the generalizability of the results. However, with a representative sample of end users, typically involving as few as five participants per cycle, the majority of usability problems and issues can be identified. It has been estimated that a single initial cycle of design/evaluation/redesign can lead to as much as a 10-fold reduction in usability problems [18,31]. Second, while several frameworks have been proposed for evaluating information and communication technologies in health care, there is no consensus on the best approach to use [15,29]. However, the rigor of this study was enhanced by using analyst triangulation (ie, using several researchers to analyze the data). Third, the sample was too small to allow us to examine whether factors related to participants (eg, age, gender, and grade level), disease (severity and duration of disease), or experience (access to and comfort with computers and the Internet) were related to the usability of the Internet program. Future work in this area is needed to determine how these user trait characteristics impact usability and outcome assessment. Finally, due to financial and time constraints we were unable to make all of the suggested changes to the health portal prototype.

This study provides strong initial support for the usability of the Teens Taking Charge: Managing Arthritis Online treatment program for youth with JIA. Findings from this study were used to refine the website prototype prior to conducting a pilot randomized controlled trial to determine the feasibility of the Internet-based self-management program for teens with JIA. If effective in improving health outcomes, this program could be used as a template for other pediatric chronic illness interventions as the psychosocial challenges facing adolescents with JIA are generalizable to all youth with chronic illnesses. Furthermore, the Internet may be critical to improving the accessibility and acceptability of self-management programs for the large population of youth with chronic health conditions that are not able to receive these treatments in their local communities. Usability testing during the formative phase of developing Internet-based treatments is a crucial step in ensuring that these interventions are effective and acceptable to youth with chronic health conditions and their parents.

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Conflicts of Interest

None declared

Multimedia Appendix 1

Teens Taking Charge: Managing Arthritis Online semi-structured interview guide

[PDF file (Adobe PDF File), 53 KB - jmir_v12i3e30_app1.doc]

Multimedia Appendix 2

Overview of the Teens Taking Charge: Managing Arthritis Online program

[PPT file (Microsoft Powerpoint File), 1,843 KB - jmir_v12i3e30_app2.pptx]

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Abbreviations

HRQOL: health-related quality of life
JIA: juvenile idiopathic arthritis

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Original Paper

Information-Seeking at a Caregiving Website: A Qualitative Analysis

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Abstract

Background: The Internet is widely used for health information, yet little is known about the online activity of family caregivers of elders, a rapidly growing group. In order to better understand the online information-seeking activity of “e-caregivers” and other visitors at a caregiving website, we undertook a qualitative analysis of survey data from a website marketed as a comprehensive resource for adults caring for aging parents.

Objective: The objectives were to better understand what types of information are sought by those visiting a website focused on elder-care issues and to identify overarching themes that might inform future development of Internet resources related to caregiving and aging.

Methods: From March 2008 to March 2009, a 5-question pop-up survey was offered 9662 times and completed 2161 times. For 1838 respondents, included was a free text answer to the question "What were you looking for?” and 1467 offered relevant and detailed responses. The survey also asked about satisfaction with the site, gender of the respondent, and relationship to the individual being cared for. Content analysis was used to develop a coding dictionary, to code responses into information-seeking categories, and to identify overarching themes.

Results: Of the respondents (76% of whom were female), 50% indicated they were caring for parents, 17% for themselves only, and 31% for others. Over half (57%) reported finding what they were looking for, and 46% stated they were extremely likely to recommend the website. Frequently mentioned information-seeking categories included “health information,” “practical caregiving,” and “support.” Respondents also requested information related to housing, legal, insurance, and financial issues. Many responses referred to multiple comorbid conditions and complex caregiving situations. Overarching themes included (1) a desire for assistance with a wide range of practical skills and information and (2) help interpreting symptoms and behavior, such as knowing what life impacts to expect over the course of a health condition or treatment.

Conclusion: Visitors to a website targeting adults caring for aging parents reported seeking both general information on caregiving and specific assistance with the complex custodial, medical, emotional, and financial aspects of caregiving. Visitors requested both information to build caregiving skills as well as assistance in interpreting and knowing what to expect from symptoms, health conditions, and changes in behavior and relationships. Many desired communication with and support from other caregivers. Health care providers and eHealth developers should expect that many caregivers of elders are using the Internet as a resource. Further research and development is needed to fully realize the Internet’s potential for education and support of caregivers.

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KEYWORDS

Caregivers; Internet; consumer health information

Introduction

While the Internet is one of the most widely used resources for health information [1,2], its role in providing consumer information specifically related to the health care and living needs of frail elders (and other dependent adults) remains less well understood. Relatively few older Americans use the Internet regularly [3]. One 2004 survey found that only 31% of respondents older than 65 years had ever gone online, and only 8% said they obtained “a lot” of health information online [4]. Nonetheless, in recent years websites providing elder-focused consumer health information have become more common [5]. This may be partly due to a realization that, although the elderly are often not themselves online users, their needs for care may prompt their caregivers to search the Internet for information [6]. For instance, a recent Pew report found that about half of all online health inquiries are on the behalf of another person [1].

The number of elderly people in America is rapidly growing, with the number of those aged 85 and over projected to more than triple by 2040 [7]. However, as noted in *Retooling for an Aging America*, a 2008 Institute of Medicine (IOM) report [8], the nation is not well prepared to meet the complex medical and social needs of a growing frail population. To address this pressing public health issue, the IOM’s key findings included a recommendation that the United States “better prepare informal caregivers to tend to the needs of aging family members and friends” [9]. Currently, an estimated 30 to 40 million Americans provide unpaid care to relatives and friends, the value of which has been estimated at $375 billion [10-13]. Caregivers are often integral to facilitating medical and personal care for frail elders [11,14,15]. Yet, this “shadow workforce in the geriatric care system” continues to feel inadequately informed, prepared, and supported [16]. Societal trends indicate that use of the Internet to meet information needs will almost certainly continue to increase. It is clear that developing a better understanding of “e-caregivers” will be necessary if the resources and capabilities of eHealth are to be properly leveraged to best serve the elderly, the disabled, and the millions who care for them.

Although other scholars have used the term “e-patient” to refer to “both those who seek online guidance for their own ailments and the friends and family members who go online on their behalf” [17], in this paper we will use the term “e-caregiver” to refer to those online seeking guidance related to helping another person with their medical care or personal care.

To date, little has been published regarding who these e-caregivers are and what they are seeking to learn or obtain through the Internet. While some empirical evidence exists that documents caregivers’ use of Internet health care resources, especially for specific conditions such as cancer and stroke [18-20], the online information seeking of caregivers in the broader context of frail and vulnerable adults has hardly been studied. In particular, although two studies used caregiver focus groups to elicit suggestions regarding potential eHealth applications [21,22], this work has not yet been followed by more detailed observational analyses of what caregivers may be actually seeking when they turn to the Internet, which must be better understood if eHealth resources are to be properly developed and refined.

The existing literature on caregiving does describe many facets of the preInternet caregiver experience, and this work could be used to inform the expansion of caregiver studies to the realm of eHealth. Frameworks of caregiver needs have been proposed, almost always tailored to the context of specific diseases and conditions. For instance, in a study of information and service needs in dementia, Edelman et al organized caregiver (and care recipient) concerns into 4 main domains: care, coping, medical, and services [23]. Other authors have roughly categorized caregiver needs as being informational (about illness, services, and what to expect), instrumental (related to building caregiving skills), and emotional (related to support and coping) [24-26]. While these conceptual frameworks can provide a foundation for understanding the needs of caregivers who seek information online, they are limited in two important respects. First, they were not developed from the perspective of caregiving for the frail elder, a context in which multiple complex medical and psychosocial conditions (including the possibility of dementia prior to a clear diagnosis) are the norm, as are evolving caregiver responsibilities. Second, these frameworks predate the dominance of the Internet for information seeking, which is producing significant cultural shifts in information behavior and health behavior [27] and, hence, might influence the types of caregivers who seek help and the domains of needs that are expressed.

To help address these gaps in the understanding of e-caregivers and their needs, we conducted a qualitative analysis of over 2000 responses to a Web-based survey conducted in 2008 and 2009 as part of routine research and development at Caring.com, a website created to provide support and informational resources to adults caring for aging parents. Our goal was to understand what types of information were being sought, especially to explore whether new domains should be considered for the existing conceptual models. Through qualitative analysis, we also sought to explore overarching themes that cut across the specific information-seeking categories.

Methods

Study Design and Sample

Our study consisted of a secondary analysis of responses to a five-question Web-based survey. Data were obtained from Caring.com, a website launched in November 2007 and designed to function as a comprehensive resource for adults caring for aging parents. The website provides informational articles about common medical problems affecting seniors, articles on caregiver well-being and managing difficult family dynamics, information on housing options for elders, as well as blogs, discussion forums, and postings of answers by experts in health and eldercare to visitors' questions. To conceive of the major sections of the website, the founders relied both on their own personal experiences struggling to help aging parents, as well as on their professional experience working with Babycenter.com, a successful and well-established website for expectant parents and people with small children. The vast majority of Caring.com's content is original and written by the company's health writers, and users are not required to pay any fees (although free registration with the site is encouraged, and sometimes required to access certain features). During the study period, Caring.com was supported by venture capital funds, with a plan for the company to eventually support itself through revenue from those wishing to advertise eldercare services and supplies. Caring.com's editorial policy forbids advertisers from participating in the creation of the written content.

The survey had been implemented for the purpose of quality improvement and was available via Caring.com's website for 12 calendar months, beginning in March 2008. The survey was offered to users of the site via a pop-up invitation to help improve Caring.com. Those who agreed to participate were redirected to a Zoomerang survey that presented five items, four with multiple choice response sets, and one open-ended question. The specific questions were: (1) How likely is that you would recommend Caring.com to a friend or relative? (scored 0 to 10 where 10 = extremely likely) (2) What were you looking for when you came to the Caring.com website? (3) Did you find what you were looking for? (4) Who are you caring for? and (5) What is your gender? For the open-ended question (What were you looking for?), the survey provided space for unlimited free text responses. A more detailed description of the survey, in accordance with the checklist for reporting results of Internet e-surveys (CHERRIES) guidelines [28], is provided in Multimedia Appendix 1.

We collected all survey data available from the time of the survey's launch in March 2008 (approximately five months following the website's launch) until the website closed the survey in March 2009. At the time the survey became live, the website was attracting approximately 6500 visits per week. By March 2009, the site traffic had increased to approximately 75,000 visits per week. At this time, the survey had been viewed 9662 times and was submitted 2161 times (22.4% participation rate), of which 1838 responses included an answer to the free-text question "What were you looking for?"

The raw data were imported into Microsoft Excel 2007 (Microsoft, Redmond, WA) and into StataMP version 10.0 (StataCorp, College Station, TX), which we used to compile descriptive statistics. Use of the data for this project was approved as exempt by the University of California, San Francisco Committee on Human Research, and by the San Francisco Veterans Affairs (VA) Medical Center Committee on Research and Development.

Respondent Characteristics

Descriptive statistics were used to describe those respondents included and excluded from content analysis of the free-text question. We also tabulated the survey results by response to the question "Who are you caring for?" Respondents had indicated one or more of the following choices: parent(s), grandparent(s), spouse, sibling(s), self, other older loved one(s), and other. This resulted in 69 different combinations of care recipients, and hence, these answers were recoded into the following 4 respondent types: those caring for parents (those who indicated parent(s), whether or not any other care recipient was also indicated); those caring for self only; all other caregiving situations; and unknown (for those who did not choose any of the options).

Analysis of Free Text Responses

The 1838 free-text responses to the question "What were you looking for?" were analyzed using content coding. Initially, all free text answers were reviewed by one of the investigators (LK) to identify themes and patterns among the responses and to construct a preliminary coding manual. Based on the preliminary review of the data, we excluded 371 respondents from further analysis because their free-text answers were irrelevant to the purpose of the website (eg, "weather"), indicated an unintentional visit to the site (ie, "got here by accident," or "nothing"), or were too nonspecific to be categorized (eg, "an article" or "not sure"). This left us with 1467 free-text responses to further classify into information-seeking categories. Although we initially considered excluding responses from those who reported caring for themselves only, we chose to include them in our analysis as we felt there was value in understanding what information a noncaregiver might be seeking at a caregiving website.

We refined the coding manual by having two investigators (LK and SK) apply the preliminary category codes to a sample of data (1000 responses) followed by discussion and further refinement of the categories and their criteria. Table 1 shows the final categories and the defining criteria for each. The nine categories were: health information, practical caregiving, behavioral, support, legal/financial/insurance, housing/living situations, driving, unspecified need for help/information, and "other." The "other" category was used to capture responses that were explicit and specific but unique and not able to be grouped within another category.

Table 1. Information-seeking category codes based on content analysis

Category	Free-Text Reponses Indicated Respondent Looking for:	Examples
Health information	Information about diseases, medical condition, health care	"Dementia," "health tips"
Practical caregiving	Information about how to provide care to another person	"Tips on bathing," "Alzheimer's care"
Help/information, nonspecific	Information and/or help, without further specification	"Info to help my aging parents"
Legal/financial/insurance	Information about legal matters, financial issues, or health insurance	"Long-term care insurance," "estate tax info"
Behavioral	Help addressing behavioral, psychological, and relationship issues	"Ways to understand what they say without causing an argument"
Support	Emotional support from other site participants and/or help coping with stress	"Someone to relate to," "support group and answers"
Housing/living situations	Information about housing, placement, parent moving in	"Nursing home," "whether my mother should move in"
Driving	Information about elders and driving	"How to take the keys away"
Other	Specific information that doesn't fall into any other domain	"Emergency pendants," "how to write a eulogy"
Excluded	Text shows only vague interest, is uninterpretable, or seems not at all relevant to site	"Just looking," "opinions," "the weather"

Following the development of refined codes, both investigators classified the content of the 1467 free text answers according to the primary category represented in the text. An initial assessment of interrater agreement for the two investigators was 83% indicating good interrater reliability. To generate the final counts within each category, coding discrepancies were resolved through discussion with a third researcher (RS). The category counts were summarized by caregiver type (ie, parent, self, all other, and unknown).

In a final step, we selected four of the frequently coded categories where the responses were of sufficient length to allow further interpretation. These responses were reviewed, using inductive content analysis [29], to provide a deeper and more nuanced understanding of the responses and to identify overarching themes that occurred across all of the categories.

Results

Respondent Characteristics

Of the 2161 submitted surveys, 1838 (85%) provided free-text answers to the question “What were you looking for?” Of the free-text answers, 1467 of 1838 (80%) contained sufficient detail relevant to caregiving to be considered for interpretation and thus inclusion in the content analysis. Characteristics of the respondents included in the content analysis, compared with those not included, are presented in Table 2. Excluded respondents were more likely to be male, were less likely to be caring for parents, were less likely to report finding what they were looking for, and were less likely to say that they would recommend the site to others.

Table 2. Respondent characteristics

Respondent Characteristic/Response	Included[a] n = 1467		Excluded[a] n = 694		Total n= 2161	
	n	%	n	%	n	%
Gender						
Female	1,115	76%	462	67%	1,577	73%
Male	339	23%	201	29%	540	25%
Missing	13	1%	31	4%	44	2%
Who caring for						
Parent(s) or parent(s) and other(s)	739	50%	246	35%	985	46%
Self only	249	17%	162	23%	411	19%
Other caregiving situations	450	31%	236	34%	686	32%
Missing	29	2%	50	7%	79	4%
Information found?						
Yes	831	57%	302	44%	1,133	52%
No	91	6%	53	8%	144	7%
Unsure	538	37%	301	43%	839	39%
Missing	7	0%	38	5%	45	2%
Mean recommendation score	8.1		7.0		7.7	
95% confidence interval (CI)	7.9 - 8.2		6.8 - 7.3		7.6 - 7.8	

[a] Included in or excluded from the content analysis (included if respondent provided a sufficiently detailed and relevant response to "What were you looking for?")

Who Respondents Reported They Were Caring For

Respondent characteristics varied somewhat by who the respondent reported caring for, as shown in Table 3. Those caring for parents were more likely to be female and to have indicated that they had found the information they were looking for on the site. This group also had the highest mean score on the scale indicating likelihood of recommending the site to others.

Table 3. Respondent characteristics by whom they reported caring for, for content analysis sample

Characteristic/Response	Caring for Parents n = 739 % of n	Caring for Self Only n = 249 % of n	Other Caregiving Situation n = 450 % of n	Unknown Caregiving Situation n = 29 % of n	All n = 1467 % of n
Gender					
Female	79.6%	67.5%	75.6%	65.5%	76.0%
Male	19.6%	31.7%	24.0%	24.1%	23.1%
Missing	0.8%	0.8%	0.4%	10.3%	0.9%
Information found?					
Yes	60.0%	51.8%	54.2%	51.7%	56.7%
No	3.4%	11.7%	7.8%	6.9%	6.2%
Unsure	36.3%	36.1%	37.6%	37.9%	36.7%
Missing	0.4%	0.4%	0.4%	3.5%	0.5%
Mean recommendation score	8.4	7.6	7.9	6.7	8.1
95% CI	8.2 - 8.5	7.3 - 8.0	7.7 - 8.2	5.4 - 8.0	7.9 - 8.2

Information-Seeking Categories

Responses to the question “What were you looking for?” were coded into 9 specific categories through content analysis. Frequency counts of information-seeking domains (by who the respondent reported caring for) are presented in Table 4. Among those caring for parents, “practical caregiving” was the most frequently coded domain.

Table 4. Information-seeking categories by whom respondent reported caring for

	Caring for Parents	Caring for Self Only	Other Caregiving Situation	Unknown Caregiving Situation	All
Information-Seeking Category	n = 739	n = 249	n = 450	n = 29	n = 1467
	% of n	% of n	% of n	% of n	% of n
Health information	18%	46%	36%	31%	29%
Practical caregiving	32%	6%	13%	14%	21%
Help/information, nonspecific	16%	16%	16%	10%	16%
Legal/financial/insurance	9%	13%	11%	17%	10%
Behavioral	6%	7%	7%	10%	7%
Support	10%	3%	5%	0%	7%
Other	4%	3%	8%	10%	5%
Housing/living situations	3%	4%	2%	0%	3%
Driving	2%	2%	2%	7%	2%

Qualitative Findings

Qualitative findings from the content analysis of four frequently coded categories (health information, practical caregiving, behavioral, and support) are presented below. Although “help/information, non-specific” was relatively frequently coded, the brief responses within this domain were not suitable for further qualitative analysis. Through our qualitative analysis, we also identified two overarching themes that cut across most of the information-seeking categories.

Health Information

A number of respondents requested information about conditions, diseases, and aging. Diseases and conditions mentioned included cancer and cancer treatment side effects, dementias, diabetes, heart disease, and stroke. A few responses specified a need for information regarding geriatric health, or senior health.

Many respondents asked about signs and symptoms of disease, especially as related to dementia and cancer, for example, “signs of Alzheimer’s” and “if low red blood cell tests could be an indicator to cancer.” Other respondents posed narrowly focused questions about symptoms, such as whether there is a “different sound a person makes at the final stage of the disease,” and whether a person can “be sensitive to touch when they have Alzheimer’s?”

There was also interest in the treatment and management of health conditions such as anemia, dementia, and diabetes, suggesting that respondents were engaged in the monitoring and management of either their own health, or that of another. Some responses reflected an urgent need for information (eg, “time limit on an open insulin bottle,” “antidote to overdose of tick medication for my wife,” and “how to care for raw burn from breast radiation.”) Relatively few responses specifically asked about managing pain or other symptoms, and few asked about “cure,” although many responses cited chemotherapy or other therapies that are often delivered with curative intent. In spite of the interest in treatment of disease, there were few responses that mentioned an interest in how to interface with health providers or navigate the medical system.

Questions related to what to expect or anticipate in the future emerged repeatedly within this domain, for example, “How long will chemo stay in the body?” There was a particular interest in the course of dementia, suggesting a need for information to plan for the future or possibly to aid in decision-making, for example, “How long will an Alzheimer’s patient live after being diagnosed?”

Some responses indicated an interest in the prevention of health problems such as heart attacks, diabetes, and dementia. Others asked for tips on staying fit physically or mentally. We also found that some requests indicated a desire for causal explanations and greater understanding of health problems. For instance, respondents asked for explanations of Alzheimer’s, the cause of a parent’s memory loss, and the causes of low blood cell counts.

Practical Caregiving

Many respondents indicated that they were looking for specific advice on the practical aspects of managing the daily living needs of another person, with a majority of these making reference to caring for parents with dementia or other frailty, for example, bathing, giving a pedicure, using a gait belt, hiring care workers, finding affordable services, and getting respite care. Knowing what to expect and how to plan for caregiving emerged as central needs. For example:

> *My parents are at the age that we need to hire in home care. Their health is failing and my family needs more*

> *information about changes in health, what to expect, and how to plan.*
>
> *…some insight as to what my mother is going through and what to expect so I could take care of her better*

A number of the caregiving responses reflected concerns about understanding the needs of the person receiving care and a desire to improve life for this person (eg, “searching for activities for my extremely nearsighted mother”). These questions focused on concern about reducing discomfort and pain, finding enjoyable activities, and respecting the wishes of the person receiving care. Some answers also indicated that respondents were involved from a distance or were trying to help another caregiver:

> *I was hoping to find something that would help me figure out a solution for a distant relative who lives alone*
>
> *…information for my mother who is caring for my grandparents—who are in their 90s, living at home, and impossible*

A number of respondents asked questions about new caregiving situations for which decisions were required, for example, following a discharge from the hospital or sudden increase in caregiving responsibilities with functional decline. Similarly, a number of questions focused on caring for multiple disabled or frail parents or how to provide personal care to a resistant care recipient. Finally, respondents asked about how to balance the challenges of caregiving with other life activities, for example, work and caring for children. Several described being a caregiver while coping with one’s own illness or disability.

Behavioral

Many respondents indicated that they were looking for assistance with behavioral concerns. These responses touched on communication concerns, relationship issues, psychological concerns, as well as management of behavioral symptoms and sleep difficulties.

Responses within this domain often alluded to struggles to understand and cope with relationships challenged by illness and aging. Several respondents indicated a desire to better understand a parent or other person or asked how to raise difficult topics for discussion:

> *Insight on my elderly parents actions*
>
> *Ways to understand what they say without causing an argument*
>
> *Help on talking to my child about my parent's death*
>
> *What issues that could arise between you and your spouse's parents, and how it may positively and negatively affect the marriage*
>
> *Why do adult children turn away from their elderly parents?*

Respondents frequently indicated a need for assistance with the behavior of a loved one in the context of dementia. For instance, several responses indicated a need for information on how to care for a parent who is having difficulty accepting loss of independence with early dementia or how to communicate with someone who has cognitive impairment and emotional instability.

> *Ideas for how to get an intransigent 88-year-old Alzheimers patient (my dad) to accept the help he desperately needs but refuses because he does not want to spend the money and cannot accept our role reversals*
>
> *How to talk with a mother who is probably in the [second] stage of Alzheimer’s and is not always logical, has mood swings, [and is] extremely forgetful*
>
> *Suggestions for communicating with parents in early stages of Alzheimer's*

Other responses indicated an interest in information relating to common neuro-psychiatric syndromes, such as sundowning, hallucinations, and hoarding. For example, respondents asked for “description of sundown dementia” or for “a simple, easy-to-understand definition between a hoarder and a pack rat.” These responses suggested that respondents may be attempting to interpret and explain the behaviors they are observing. One particular response indicated a search for an explanation for “erratic behavior,” suggesting a diagnosis still in question. Several responses requested explanations and tips for addressing sleep difficulties.

Support

Many responses indicated that a primary goal of the respondent was to find sources of emotional support through the website. Most respondents seemed particularly interested in the experiences of others in similar situations, and some specified a desire to know that others were having similar feelings and struggles.

> *…to know I’m not the only one in the world going through this*
>
> *…others caring for terminal parent*
>
> *My mother has Alzheimer’s. My heart breaks. I wanted to see how others are coping.*

Several respondents also expressed a desire to exchange ideas with peers, for example, they asked for a “sounding board” or “ways to ask questions of others going through the same thing.” Furthermore, after expressing a desire for “advice, experience of other people,” one respondent continued by adding, “more importantly I was looking for authentic information, not just ‘Dear Abby’ style answers to broad questions.”

A number of respondents expressed a desire to feel less alone and referred to feeling stressed and overwhelmed. Several noted a need for comfort and relief, and many asked for information on how to better cope. A few respondents did not explicitly seem interested in a community of peers online, but rather asked for broader information on caregiver support resources. One respondent expressed a need for support in being a care recipient rather than a caregiver.

> *…something other than pat answers and harsh judgment…I often feel disappeared by the very people who supposedly care for me. They make decisions about me without including me.*

Many responses indicated that respondents were interested in using the Internet to connect with other caregivers. Through these connections, respondents indicated interests in exchanging ideas, normalizing their experiences, and feeling that they are part of a community.

Overarching Themes Identified Through Qualitative Analysis

Two overarching themes emerged from the qualitative analysis that were pertinent to and spanned all 9 content categories: (1) a desire for assistance with a wide range of practical skills and information and (2) a search for help interpreting symptoms, behaviors, and interpersonal situations, and in knowing what to expect and how to plan.

Practical Skills and Information

Many respondents indicated that they were looking for practical skills and information to address a current situation, especially in the context of providing or facilitating care for another person. In other words, respondents often asked for information on how to do something. For instance, within the “practical caregiving” category, respondents requested information on how to hire a home care worker and how to select a personal medical alarm. A desire for practical skills and solutions was also evident in responses coded into the “health information,” “housing/living situations,” “legal/financial/insurance,” and “driving” categories. For instance, respondents asked for information on how to choose nursing homes and continuing care retirement facilities and how to establish trusts and wills. Another respondent asked “how to take the parents’ car keys when they refuse.”

Respondents also often requested practical skills related to communication and managing relationships, especially in the context of dementia or the discussion of difficult topics.

> *How to deal with a parent with dementia…different strategies to talk to doctor and respond to unusual behavior*
>
> *Advice on how to cope without getting exhausted*
>
> *Help with moving our parents into an assisted living home and making it their idea*

Help Interpreting Situations and Knowing What to Expect

Another theme that emerged across the categories was the need for help in interpreting situations, often so as to know what to expect and, thus, what to do (as opposed to how to do things). Responses illustrating this theme were found within virtually all content categories but were particularly common within “health information,” “behavioral,” “support,” as well as “practical caregiving.”

> *My parents are at the age that we need to hire in home care. Their health is failing and my family needs more information about changes in health, what to expect, and how to plan.*
>
> *…what to expect with the end stage of CHF [congestive heart failure]*
>
> *…to see if what I felt and am doing is of the norm*

Within the “housing/living situations” category, respondents asked for help knowing when it might be time for an older person to be moved from their home. Within “driving,” they requested guidelines to know when driving should be stopped.

Discussion

Principal Results

Through our qualitative analysis of 1467 text responses about what people were looking for at a general caregiving website for aging parents, our study provided a clear view of how some e-caregivers are seeking to meet their needs through the Internet. Among our sample, “health information” and “practical caregiving” were the two most prevalent categories of interest; other frequently mentioned topics encompassed legal/financial/insurance issues, support issues, behavioral issues, and housing/living situations. Many of the needs expressed were not specific to a particular medical condition. There was considerable interest in help with knowing what to expect and in how to plan for the future. There were also many concerns related to understanding behavior and relationships, as well as interest in support and assistance with coping. Many respondents expressed an interest in communicating with other e-caregivers. Furthermore, we noted that several geriatric topics appeared to be prominent concerns for these e-caregivers, including functional decline, cognitive impairment, and challenges with independent living.

Comparison With Prior Work

Our findings are consistent with previous research on caregivers, which has suggested that caregivers’ needs include needs for information on diagnosis and prognosis, for practical information on implementing caregiving, and for support and assistance in coping. While we observed that visitors to a caregiving website spontaneously raised concerns that were similar to those documented in nononline settings [23-26], our qualitative findings highlight the breadth and depth of information needs that might be brought to an eHealth resource focused on aging and caregiving issues. For example, beyond wanting to know about prognosis, respondents expressed a desire to understand how to anticipate and plan for the impacts of another’s declining health across a wide range of domains of living. These results attest to the fact that caring for a dependent adult can generate a dizzying array of questions, which caregivers are now bringing to the Internet.

Our study also provides a unique perspective on what these e-caregivers may be less concerned about finding online. Given the fairly large sample size, we were struck by the relative paucity, or even frank lack, of mention of certain topics that frequently are found in the scientific and professional literature on elders. For instance, although several respondents expressed interest in symptom interpretation, few responses pertained to the treatment of pain or other uncomfortable symptoms, although pain is a common symptom in later life [30]. We also noted that only two responses specifically alluded to depression, although many referred to stress and sadness affecting caregivers and care recipients. Another omission we found conspicuous was a total absence of requests for information on advance care planning. (ie, living wills or advance directives). We furthermore noticed that no respondent explicitly linked concerns about driving to concerns about cognitive impairment. Among health professionals, these topics are widely believed to be relevant to a majority of frail patients. Experts also generally agree that these issues are usually insufficiently addressed in routine clinical encounters. That these issues should also be scarcely mentioned by visitors to a caregiving website raises the possibility that there is low awareness among a group that has been motivated enough to have visited a caregiving website and to have participated in a survey. This is in stark contrast to issues such as what to expect in the future, practical caregiver information, caregiver support needs, and behavioral issues, all represented within these survey results, but which are often inadequately addressed in clinical encounters. However, it is also possible that the omissions we noted do not reflect low awareness, but instead are due to factors such as website traffic or perhaps respondents' experience at the website (ie, the site may have not promoted its advance care planning information as frequently as its driving information).

Limitations

There are some limitations that are important to consider in the interpretation of our results. The first and main one is that our sample was drawn from one particular Internet site. Consequently, our frequency counts cannot be extrapolated to Internet-using caregivers in general. Our sample was also likely influenced by factors related to Caring.com itself, a site which has marketed itself broadly to boomers, and through mainstream Internet health portals (ie, AOL, Yahoo Health, etc). Visitors can arrive at a commercial health information site such as Caring.com in many different ways, such as through a search engine or from a portal if they follow the link to an appealing-sounding article. Hence, although our respondents were visiting a caregiving website, and many identified themselves as caregivers, we cannot assume that all of them came to Caring.com specifically because it was a site with information related to caregivers. It is also possible that for some respondents, their expressed information needs may have been influenced by a perception of Caring.com as a certain kind of commercial site, as opposed to a government site, or site hosted by a medical specialty group. The process by which consumers arrive at websites and evaluate credibility and value is complex [31-36], so it is difficult to know just how these factors may have affected our sample. Furthermore, while the survey was presented at random to users during the data collection period, a nonrandom proportion was willing to complete the survey, and we have no data on those who refused to participate. Still, the number of responses that could be interpreted was large, and our participation rate of 22% is within one standard deviation of the mean Internet survey participation rate of 34% observed in a meta-analysis of 39 Internet surveys [37]. Thus, it is unclear how the information needs of the respondents would be biased beyond an interest in caregiving and senior health plus what would be expected based on what is already known about adults who use the Internet for health information [38,39].

Although our sample was likely influenced by a number of unknowable factors, our qualitative findings still provide an important complement to previous research conducted in settings other than online settings and have substantial value for generating hypotheses about e-caregiver information needs, which can be tested in future research. Some studies have examined caregivers' use of Internet health care resources, yet this work, similar to much of the earlier research on caregivers, has mainly been focused on a single disease or health condition, such as stroke or dementia [20,40]. In contrast, our work identified several domains of caregiver needs that may cut across disease boundaries (eg, driving, housing, and financial issues), and explored caregiving questions related to complex situations involving several health conditions or psychosocial situations. As most elder care occurs within a dynamic context of multi-morbidity and functional impairment, the previous literature's emphasis on specific health conditions poses a challenge for generalist providers of care to elders and their caregivers. In contrast to the prevalent disease-based approach, our findings will be highly relevant to the work of practicing primary care providers, eHealth developers, and others who must serve a diverse group of aging adults and informal caregivers.

An additional consideration important to note is that open health-related Internet sites, such as Caring.com, may attract a mixture of user types, some explicitly targeted by the site and others not targeted for whom some of the site material is relevant. In our study, the interpretable responses included 294 of 1467 (17%) from users who reported caring for themselves only, and not for another person. While Caring.com targets those who are caring for others, self-caring users are clearly a sizable minority of site visitors. Because these individuals seem to have considered themselves to be engaged in a type of caregiving and were interested enough to complete the survey while visiting the site, we reasoned that including these respondents in the qualitative analysis could inform the conceptualization of potential site users and expand the conceptual framework for development of online information materials on caregiving. The qualitative categorization of what these individuals were looking for in contrast to those taking care of others has value in developing hypotheses for future research about the possible differences and similarities in needs across a range of users. Future studies of those using caregiving websites may also benefit from a survey structure designed to distinguish between care recipients, who presumably will have information needs related to many caregiving topics, and individuals who are neither caregivers nor care recipients. Also, it is possible that some users who are neither caregivers nor care recipients may still be in search of information related to caregiving situations, perhaps in anticipation of future care needs. Future research will be needed to better understand how open websites related to caregiving can more effectively serve a range of users.

Conclusions

For clinicians, our qualitative findings clearly emphasize the importance of providing prognostic and other anticipatory information to caregivers to facilitate planning for the future. Our results also confirm that there is a need for decision-making resources designed for those with caregiving concerns and that the Internet might become a very valuable medium through which caregivers can access helpful information to make decisions related to their loved ones. A recent Pew survey underscores the central role of Internet information in health planning and decision making. Of patients seeking health information online, 60% reported that online information affected a decision about how to treat an illness or a condition [1]. Our findings suggest that clinicians should expect that caregivers might be influenced as well by online information.

For eHealth researchers and developers, our study findings highlight the dynamic and complex information needs of caregivers and those visiting a caregiving website and suggest that e-caregivers may have needs that warrant them being considered as a group distinct from e-patients (rather than considered a subset of e-patients). Our findings also shed light on issues that are particularly relevant to applying eHealth to the care of elders. Although our respondents often expressed concerns that transcended the disease-focused categories around which many eHealth resources are organized, we found that much of the information sought by these e-caregivers corresponded to traditional areas of geriatric expertise, such as functional decline, cognitive impairment, and family dynamics stressed by uncertainties and an aging person's increased dependence. To accommodate the complex needs of elders, the practice of geriatrics often focuses on syndromes, that is, clinical conditions in the elderly that usually have multi-factorial origins [41]. Common geriatric syndromes that a caregiver might seek assistance with include falls, dizziness, delirium, incontinence, and frailty; all can have significant impacts on quality of life as well as mortality and morbidity. Because these syndromes span diseases, organ systems, and age-related physical changes, they are often difficult to manage in the disease-based fashion that might work well in a younger person. Instead, geriatrics offers alternative clinical approaches, often interdisciplinary, to managing these very common problems that affect the elderly. Our study findings suggest that such a geriatric approach could be a valuable contribution to eHealth resources designed for elders, and those who care for them.

Given the aging of the population and the broad consensus that family caregivers are an essential component of our nation's care system for the elderly, our results suggest that eHealth resources have great potential to reach and support this important population. To help develop this potential, more data will be needed to better characterize the e-caregiver population. For instance, it would be very useful for eHealth surveys, such as those conducted by the Pew Internet & American Life Project and the National Center for Health Statistics, to begin collecting data on e-caregivers and their behaviors. Future research should focus on developing effective eHealth resources to educate and support e-caregivers, and developers should consider incorporating geriatric principles into the organization of these resources.

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Conflicts of Interest

Dr Kernisan volunteered as one of many medical experts for Caring.com from July 2008 to June 2009 for which she received a small amount of Caring.com stock options. She also has served as a Caring.com senior medical editor (to date, an unpaid position) since July of 2009 and has been providing geriatric content expertise to the site developers. As part of a UC Berkeley master of public health project from October 2009 to May 2010, Dr Kernisan wrote a caregiver education blog on Caring.com; she was not financially compensated for this work. Drs Knight and Sudore have no conflicts of interest to declare.

Multimedia Appendix 1

CHERRIES summary

[PDF file (Adobe PDF File), 282 KB - jmir_v12i3e31_app1.pdf]

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Abbreviations

CHF: congestive heart failure
CHERRIES: checklist for reporting results of Internet e-surveys
IOM: Institute of Medicine
VA: Veteran’s Affairs

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Letter

Review of Online Evidence-based Practice Point-of-Care Information Summary Providers: Response by the Publisher of DynaMed

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Related Articles:

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Abstract

In response to Banzi's et al review of online evidence-based practice point-of-care resources published in the Journal of Medical Internet Research, the publisher of DynaMed clarifies his evidence-based methodology.

(J Med Internet Res 2010;12(3):e39) doi:10.2196/jmir.1622

KEYWORDS

Medical Informatics; Evidence-based medicine; Point-of-care

We congratulate Banzi and colleagues for publishing a review of online evidence-based practice point-of-care resources [1]. It is important that these resources are evaluated and summarized by evidence-based medicine experts who are not involved in the products being reviewed.

The adherence to evidence-based methodology for development and maintenance of these products is important for maintaining trust and validity in the content used by practicing clinicians. Banzi et al evaluated evidence-based methodology for point-of-care resources based on published marketing materials and editorial policies as stated on the websites of the publishers.

We were surprised to see a score for DynaMed (the product I am responsible for as editor-in-chief and medical director of EBSCO Publishing) which was less than 100% for our "evidence-based methodology". In fact, "evidence-based methodology" is the fundamental methodology for how our editors are trained and how we work on a daily basis. A 7-step evidence-based methodology is the core process for updating and maintaining DynaMed [2].

The specific rating difference appears to be for the question "Are systematic reviews preferred over other types of publication?". We should clarify that we absolutely prioritize systematic reviews (preferably Cochrane reviews) in our hierarchical approach to content consideration for inclusion, placement of content, and sources for deriving overall conclusions for evidence synthesis and overview statements. Individual study summaries are often deleted when included in a subsequent systematic review unless the individual studies offer additional information.

However, our editorial policy page referred to the concept without explicitly describing the hierarchy used. We have now updated our editorial policy page to make this more explicit [2].

This is not a change in editorial policy. We have been doing it for years, but in reaction to the Banzi review we have now improved the explicitness and transparency of our method.

Thank you to Banzi et al for bringing this to our attention.

Conflicts of Interest

Dr. Alper is a full-time employee of EBSCO Publishing and Editor-in-Chief of DynaMed.

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Letter

Review of Online Evidence-based Practice Point-of-Care Information Summary Providers: Authors' Reply to the Response by the Publisher of DynaMed

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Abstract

We are pleased that the publisher of DynaMed clarified his evidence-based methodology in response to our review. We stress again how good reporting is a prerequisite for transparency. This lesson comes from the reporting of research findings but its extension to the development of information sources should be considered.

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We thank Dr. Alper for his comment in response to our review [1], which gives us the opportunity to stress again how essential good reporting is for transparency. This lesson comes from the reporting of research findings, but its extension to the development of information sources should be considered.

Methodologic quality is closely intertwined with the quality of reporting [2]. Lack of details on how research (or in this case: editorial processes) is conducted leads users to assume that the quality was inadequate, unless information to the contrary is provided (the "guilty until proven innocent" approach) [3]. This is often justified because faulty reporting generally reflects faulty methods [4, 5].

We appreciate that the editor of DynaMed (which is a "blockbuster" in the point-of-care information service market) shows the willingness to improve the explicitness and transparency of their methodology. A clear reference on the freely accessible website pages helps users and purchasers to better understand the value of the product.

It is reassuring when well-known and leading publishers do not take for granted their value. Reputation itself is no guarantee for quality. We hope that other publishers will be equally transparent and responsive to criticism.

Conflicts of Interest

None declared

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